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Review

School-Based Suicide Risk Assessment Using eHealth for Youth: Systematic Scoping Review

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Abstract

Background: Suicide is a leading cause of death among youth and a prominent concern for school mental health providers. Indeed, schools play a key role in suicide prevention, including participating in risk assessments with students expressing suicidal ideation. In the context of the COVID-19 pandemic, many schools now need to offer mental health services, including suicide risk assessment, via eHealth platforms. Post pandemic, the use of eHealth risk assessments will support more accessible services for youth living in rural and remote areas. However, as the remote environment is a new context for many schools, guidance is needed on best practices for eHealth suicide risk assessment among youth.

Objective: This study aims to conduct a rapid, systematic scoping review to explore promising practices for conducting school-based suicide risk assessment among youth via eHealth (ie, information technologies that allow for remote communication).

Methods: This review included peer-reviewed articles and gray literature published in English between 2000 and 2020. Although we did not find studies that specifically explored promising practices for school-based suicide risk assessment among youth via eHealth platforms, we found 12 peer-reviewed articles and 23 gray literature documents that contained relevant information addressing our broader study purpose; thus, these 35 sources were included in this review.

Results: We identified five key recommendation themes for school-based suicide risk assessment among youth via eHealth platforms in the 12 peer-reviewed studies. These included accessibility, consent procedures, session logistics, safety planning, and internet privacy. Specific recommendation themes from the 23 gray literature documents substantially overlapped with and enhanced three of the themes identified in the peer-reviewed literature—consent procedures, session logistics, and safety planning. In addition, based on findings from the gray literature, we expanded the *accessibility* theme to a broader theme termed *youth engagement,* which included information on accessibility and building rapport, establishing a therapeutic space, and helping youth prepare for remote sessions. Finally, a new theme was identified in the gray literature findings, specifically concerning school mental health professional boundaries. A second key difference between the gray and peer-reviewed literature was the former's focus on issues of equity and access and how technology can reinforce existing inequalities.

Conclusions: For school mental health providers in need of guidance, we believe that these six recommendation themes (ie, youth engagement, school mental health professional boundaries, consent procedures, session logistics, safety planning, and internet privacy) represent the most promising directions for school-based suicide risk assessment among youth using eHealth tools. However, suicide risk assessment among youth via eHealth platforms in school settings represents a critical research gap. On the basis of the findings of this review, we provide specific recommendations for future research, including the need to focus on the needs of diverse youth.

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KEYWORDS

suicide; risk assessment; youth; eHealth; school mental health; mobile phone

Introduction

Background

Suicide is a leading cause of death among youth in the United States and Canada [1-3]. Beyond prematurely ending the life of a young person, suicide has wide-reaching negative impacts on friends, family, and the larger community [4]. Suicide also has substantial economic costs [5]; for example, in 2010, the government of Canada estimated that suicide resulted in CAD $2.96 (US $2.35) billion in direct (eg, health care) and indirect (eg, lost productivity) costs nationally [6].

In the context of the COVID-19 pandemic, suicide risk for some youth may be elevated because of social isolation and the associated mental health impacts of the pandemic [7-9]. In addition, owing to ongoing school closures or remote learning, many youths may not have in-person contact with the school personnel who play a critical role in identifying risk for suicide and supporting students to seek help. However, school mental health providers may find themselves identifying students at risk when they connect with youth remotely, and they may be uncertain how to best support students when they are not face-to-face. Therefore, this rapid, systematic scoping review explores promising practices for conducting school-based suicide risk assessment with youth via eHealth platforms; eHealth refers to the use of information and communication technologies in health care [10]. This can include many remote technologies, such as telephone, text, Zoom, and Google Meet. Findings from this review are applicable in the immediate context of the COVID-19 pandemic and for school mental health providers who will continue to conduct eHealth risk assessments after the pandemic (eg, providers working in rural and remote settings).

Suicide Prevention and the Role of Schools

Schools are a key suicide prevention and intervention site because of their frequent access to many youths. In the usual, non–COVID-19 context, school personnel are in regular contact with most students and thus have multiple opportunities to intervene [11-14]. Furthermore, as many youths at risk for suicide are reluctant to ask for help [15], school personnel play an important role in actively screening and referring at-risk students to appropriate community-based services (eg, mental health clinics and emergency departments). As part of this role, standardized protocols supporting school providers to assess risk effectively, cocreate safety plans with youth, and provide referral pathways to community-based interventions are essential [16,17]. Within these standardized protocols, some commonly used, standardized risk assessments that were created for use with youth in medical settings (eg, Columbia-Suicide Severity Risk Scale [C-SSRS] and Ask-Suicide Screening Questions [ASQ]) [18,19], are often used to assess suicide risk in school settings [16,17]. Conversely, a lack of standardized protocols for holistic suicide risk assessment and intervention can lead to both false positives (ie, overresponse to disclosures that do not indicate an immediate crisis) and false negatives (ie, underresponse for students in need of immediate attention) [20]. Both of these outcomes are detrimental for all stakeholders [21], including youth, families, the health care system, and schools.

Given nationwide school closures that occurred because of the COVID-19 pandemic in March 2020 (and are still ongoing in several areas), schools across the United States and Canada are now providing school mental health services, including suicide risk assessment, through eHealth platforms. In our context, partner school divisions shared that they are still attempting to implement standardized suicide risk assessment protocols remotely but do not know optimal practices for delivery (eg, building rapport and safety in a web-based environment, maintaining connections with vulnerable youth), leading to concerns about the safety and effectiveness of this process for students expressing suicide risk in these challenging times. Given the increased mental health distress some youth may experience during and following situations causing widespread loss or turmoil [22-24]—including the COVID-19 pandemic [7-9]—continued remote use of suicide risk assessment protocols is likely, and thus guidance on e-delivery is critically needed.

Research Question and Objective

This study aims to address the following research question: What are promising practices for providing school-based suicide risk assessment to youth using eHealth? The overall objective of this review is to summarize current evidence on key recommendations for the remote implementation of suicide risk assessment protocols and apply these recommendations to the school context. To address this question and objective, we used a systematic scoping review methodology [25-28], following the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) extension for scoping reviews checklist [29]. We chose this methodology as it is appropriate for rigorous but rapid understanding of key concepts in areas not previously the focus of systematic studies. The goal is to summarize and mobilize existing research to knowledge users and decision-makers. To gather the most up-to-date information, we included both peer-reviewed and gray literature in our review. We included gray literature because we felt that substantial information on eHealth risk assessment would likely be available via professional associations and health or school authorities, and it is often better suited to rapidly respond to emerging concerns because of its closer connection to these issues in practice.

Methods

Peer-reviewed Literature

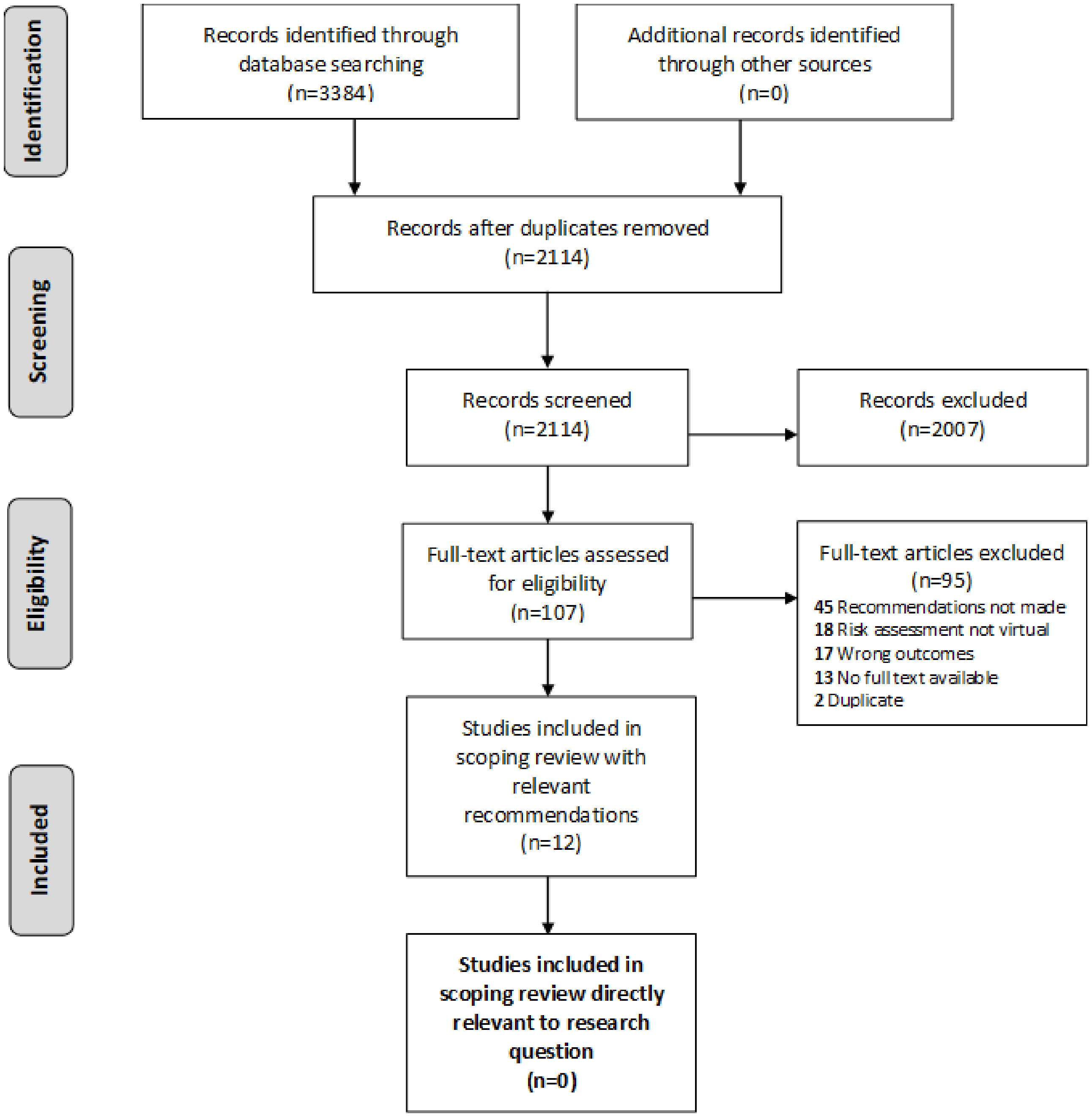
Search Strategy

The search protocol for this study was developed by the research team and reviewed by a medical research librarian and suicide prevention nonprofit organization before searches were conducted. To find relevant peer-reviewed literature for this scoping review, we searched six databases (PsycINFO, MEDLINE, Embase, CINAHL, ERIC, and Education Research Complete) on May 28, 2020. The first author conducted all the searches. The search terms were as follows: (youth OR adolescen* OR teen* OR child*) AND (risk OR suicid* OR safety OR self-harm OR self-injury OR “self-injur* behavio*”) AND (assessment* OR screen*) AND (eHealth OR telepsychology OR telehealth* OR remote* OR virtual OR web-based OR online OR mobile health OR mHealth OR telemedic* OR e-Health OR apps OR computer-based OR digital technolog* OR e-resources OR e-support* OR internet OR iphone* OR smartphone* OR teleconsult* OR tele-consult* OR tele-health* OR tele-medic* OR telemonitor* OR tele-monitor* OR telepsychiatr* OR tele-psychiatr* OR teletherap* OR tele-therap* OR tele-psychology OR virtual care OR website*). We searched the first three search strings (adolescent terms, risk terms, and assessment terms) as individual subject headings and as title or abstract search strings in each database. We searched the final search string (the technology terms) as a title search string only to increase the relevancy of returns.

Inclusion Criteria

Searches were restricted to peer-reviewed articles published in English in the past 20 years (ie, 2000-2020). We made this restriction as we hypothesized that most eHealth articles would be relatively recent. Indeed, a special issue on eHealth ethics was published in 2000 [10], and a Google Scholar search of the term *eHealth* indicated that the first full-text articles on this topic primarily began to appear after the year 2000. Searches were not restricted by geographic region or methodology to be broadly inclusive. To be included, articles needed to provide information relevant to completing suicide risk assessments in an eHealth (ie, remote) environment. Studies were excluded if they did not make relevant recommendations, did not focus on risk assessment, risk assessments were not completed remotely within the study, the full text was not available, or the study was a duplicate (Figure 1 [29,30]).

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) diagram [29,30].



Review Procedures

The screening of the retrieved studies was completed using Covidence by a team of 5 research assistants (3 doctoral students in school and applied child psychology, 1 master of social work graduate, and 1 undergraduate psychology honors student). Research assistants reviewed the titles and abstracts of each of the 2114 potential articles in pairs (Figure 1). Each member of the pair independently reviewed each article. If the pair did not agree on an inclusion decision, they met to reach a consensus. After screening, 107 articles remained for full-text review (Figure 1). Given the expedited nature of this search, all full-text articles were reviewed by the first author. Following full-text review, 95 articles were excluded because they did not meet the inclusion criteria (Figure 1), leaving a final sample of 12 articles that provided recommendations relevant to the objective of this review (Table 1). No study specifically focused on promising practices for providing school-based suicide risk assessment to youth using eHealth. However, the 12 papers included fulfilled the overall purpose of this study (ie, relevant recommendations for remote implementation of suicide risk assessment protocols), and so they were included (Figure 1).

Table 1. Summary of included peer-reviewed studies (n=12).

Authors and year	Study design	Study location	Sample size	Age (years)	White, n (%)	Women, n (%)	LGBTQ-2SIA+, n (%)	Brief study description
Anderson et al [31]	Review of lessons learned	Australia	N/A[a]	12-18[b]	N/A	N/A	N/A	Shares lessons learned in the development and evaluation of a fully automated internet-based cognitive behavioral therapy (iCBT) program for youth experiencing symptoms of OCD
Arjadi et al [32]	Quantitative	Indonesia	313	24.5[c,d]	—[e]	253 (80.8)[c]	—	Presents a randomized controlled trial of the Guided Act and Feel Indonesia (GAF-ID) program, a web-based behavioral activation intervention that includes lay support
Fairchild et al [33]	Quantitative	United States	87	5-17[b]	86 (98.9)[c]	57 (65.5)[c]	—	Evaluates the outcomes of children and youth who received telemental health services within a rural emergency department
Goodday et al [34]	Review of lessons learned	United Kingdom	N/A	N/A	N/A	N/A	N/A	Reports on experiences using the True Colours remote mood monitoring system across a large number of users and settings
Haas et al [35]	Mixed methods	United States	1162	Undergraduate students	—	834 (71.8)[c]	—	Evaluates an interactive, web-based approach to encourage youth at risk of suicide to seek help
King et al [36]	Quantitative	United States	76	22.9 (5.0)[f]	54 (71.1)[c]	45 (59.2)[c]	—	Evaluates the effectiveness of a web-based intervention (*e*Bridge) for college students at risk of suicide
Navarro et al [37]	Qualitative	Australia	9	27-67[b]; 42.6 (14.3) [f]	—	5 (55.6)[c]	—	Explores how eMental health professionals view youths' reasons for accessing text-based counseling on the web and moderators of service delivery effectiveness
Nelson et al [38]	Literature review	N/A	N/A	N/A	N/A	N/A	N/A	Reviews the telepsychology literature (using video to deliver evaluation and/or treatment) and presents telepsychology guidance for current practice environments
Nielssen et al [39]	Quantitative	Australia	9061	18+[d]	—	—	—	Reviews procedures used to manage risk and case summaries for adults who were urgently referred for crisis intervention while using a remote screening assessment or therapy clinic (MindSpot)
Radovic et al [40]	Mixed methods	United States	96	14-26[b]	64 (67)	72 (75)	0 (0) transgender individuals	Evaluates the feasibility, acceptability, and utility of a social media website (SOVA) designed to improve mental health literacy and decrease negative health beliefs about depression or anxiety among youth with a history of depressive or anxiety symptoms

Authors and year	Study design	Study location	Sample size	Age (years)	White, n (%)	Women, n (%)	LGBTQ-2SIA+, n (%)	Brief study description
Sayal et al [41]	Mixed methods	United Kingdom	22	16-30[b]	21 (95)[c]	17 (77)[c]	—	Reviews the feasibility of a randomized controlled trial of a remotely delivered problem-solving cognitive behavior therapy for youth with repeat self-harm and depression called e-DASH[g]
Thomas et al [42]	Quantitative	United States	494	1-19[b]; 13.2 (2.6)[c,f]	360 (72.9)[c]	297 (60.1)[c]	—	Evaluates a telepsychiatry program at a geographically dispersed pediatric emergency department

[a] N/A: not applicable.

[b] Age range.

[c] Hand calculated from the information in the article.

[d] Sample age.

[e] Not available.

[f] Mean age (SD).

[g] e-DASH: Electronic–Depression and Self-Harm.

Data Abstraction

Data from the 12 articles included were extracted using a standardized data charting template created for this study, based on the recommendations of Tricco et al [29] and Levac et al [27]. The standardized data charting template collected information on the study's source of funding, design, sample size, age, demographics, setting or location, data analyses, and relevant information about eHealth suicide risk assessment among youth. Abstractions were completed in pairs by a team of research assistants. Each member of the pair independently reviewed their assigned articles, and the pair then met to reach a consensus on the final abstraction. Abstractions were reviewed by the first and second authors. We did not assess data quality, as this is outside the parameters of scoping reviews [29].

To organize information extracted using the standardized data charting template into overall recommendation themes, the first author inductively applied codes to extract data using Dedoose, a web-based mixed methods data analysis software. Codes were then reviewed and revised by the second author, and the 2 authors met to arrive at a consensus on any discrepancies. From this coding, five recommendation themes emerged from 12 peer-reviewed articles.

Gray Literature

To supplement our peer-reviewed article search, we also included key websites (ie, professional websites focused on school mental health, suicide prevention, or youth mental health) as a gray literature source. We chose to focus on websites in this part of the search as we felt these would have the most up-to-date information on remote suicide risk assessment among youth in the context of the COVID-19 pandemic. Websites for inclusion were identified by the research team and a suicide prevention nonprofit organization. These websites are not geographically restricted. Between May 28 and June 19, 2020, we reviewed 17 websites for information relevant to eHealth suicide risk assessment among youth (Multimedia Appendix 1).

Each website was thoroughly reviewed by a research assistant, and potentially relevant documents or information were saved to a shared folder. These potentially relevant documents or information were then reviewed by a separate pair of research assistants (ie, not including the research assistant that originally pulled documents from the website) to determine if they met the study inclusion criteria. From these 17 websites, we identified 23 gray literature documents that met inclusion criteria. We note that we found three different offerings of similar webinar content about suicide risk assessment via eHealth during this search. In addition to the Suicide Prevention Resource Center webinar titled *Treating Suicidal Patients During COVID-19: Best Practices and Telehealth* [43], this content was also offered as part of the Mental Health Technology Transfer Center Network's Clinical Innovations in Telehealth Learning Series [44] and as part of a School-Based Health Alliance/National Center for School Mental Health webinar [45]. Therefore, only the Suicide Prevention Resource Center [43] webinar was included in the review (Multimedia Appendix 2 [31-43,46-67]).

Once the 23 relevant documents were found, the pair of research assistants then abstracted information using the same procedure employed for peer-reviewed articles. The standardized data charting template for gray literature included the title of the relevant page on the website and a summary of relevant information about remote suicide risk assessment among youth. The abstracted information was then reviewed and themed by the first and second authors using the same procedure as for peer-reviewed articles (see above). Finally, themes from the peer-reviewed literature were compared, contrasted, and integrated with themes from the gray literature by the first and second authors. From this process, we ended up with six total recommendations (four that were supported by information from both the peer-reviewed and gray literature, one supported by information in peer-reviewed literature only, and one supported by information in gray literature only; see the *Results* section for more information).

Results

Peer-reviewed Literature

Description of the Included Articles

We did not find any study that specifically addressed our research question (ie, promising practices for conducting school-based suicide risk assessment with youth via eHealth). However, we found 12 articles that provided information relevant to the overall study purpose and that we felt could inform future research and practice on school-based suicide risk assessment with youth via eHealth within the parameters of a scoping review (Table 1). The included articles used samples from the United States (n=5), Australia (n=3), the United Kingdom (n=2), and Indonesia (n=1; Table 1). All articles were published between 2008 and 2020, with most (10/12, 83%) published since 2015. The most common study design was quantitative (5/12, 42% of the included articles). For nonreview articles, most samples comprised youth aged between 12 and 25 years (Table 1). We also included one qualitative study with a sample consisting of eMental health professionals [36] and one study that described risk assessment outcomes for an eMental health clinic for adults, as the recommendations were highly relevant to our study [38]. The sample size of the included articles ranged from 9 to 9061 participants (Table 1).

Although youth, in general, experience an elevated risk of suicide [68], youth who experience marginalization because of certain aspects of their identity (eg, Indigenous youth, newcomer and refugee youth, immigrant youth, lesbian, gay, bisexual, trans, queer/questioning, two-spirit, intersex, asexual (LGBTQ2SIA+) youth, and youth with disabilities [69-71]) are at disproportionate risk. Owing to stereotypical gender role norms that discourage help-seeking, male youths are also at heightened risk [68,71]. Thus, we specifically explored whether the reviewed studies considered race or ethnicity, gender, and/or LGBTQ2SIA+ identity in their design (Table 1; none of the studies provided information on disability or citizenship status). Of the relevant studies (ie, original empirical studies, n=9), we found that 89% (8/9) reported on participant cisgender, 56% (5/9) reported on participant race or ethnicity, and 11% (1/9) reported on LGBTQ2SIA+ identity (by stating there were 0 transgender individuals in their sample [40]). Where cisgender and race or ethnicity were reported, samples were primarily female (range 55.6%-81%; median 68.9%) and White (range 67%-98.5%; median 72.9%). Thus, relevant recommendation themes should be interpreted with caution, as they may primarily pertain to White, cisgender female and likely heterosexual youth.

Relevant Recommendation Themes

By coding abstracted data, we identified five overall recommendation themes in the 12 peer-reviewed articles: (1) accessibility, (2) consent procedures, (3) session logistics, (4) safety planning, and (5) internet privacy. A summary of recommendation themes is provided in Textbox 1, and full information on themes and underlying recommendations is provided in Multimedia Appendix 2.

Textbox 1. Summary of recommendations from peer-reviewed and gray literature.

Promising practice and relevant recommendations

- Youth engagement: accessibility, building rapport, establishing a therapeutic space, and helping youth prepare for remote sessions (recommendation from peer-reviewed and gray literature)
    - Choose a mode of technology that meets the youth's needs or preferences (eg, consider internet access, if they are comfortable with video, and minutes available on phone plans)
    - Test technology before sessions and ensure devices are fully charged
    - Brainstorm ways to increase youth's sense of privacy (eg, having a codeword if someone is nearby and picking a time of day when the house is quieter)
    - Discuss what virtual sessions will look like and ask youth what they need from the virtual relationship (eg, how can you make them feel safe and secure)
    - Make sure youth can see and hear you clearly the entire time and that they know you are the only one in your room
    - Set up the session to promote comfort and minimize distractions (remove personal items from your room, make sure your room is not distracting, let youth know they can be informal and use a background or emojis, and encourage the youth to be in a quiet part of their house)
    - Use your facial expressions to convey warmth and enthusiasm, and give youth space to speak
    - Keep youth engaged through various methods (eg, using screen sharing or playing a game)
    - Consider providing youth with session transcripts to help them remember information and strategies to use in daily life
- School mental health professional boundaries (recommendation from gray literature only)
    - Make sure youth and caregivers know when you are and are not available and who to contact when you are not available
    - Use an institutional (not personal) device, and have a clear schedule for when you meet with youth
- Consent procedures (recommendation from peer-reviewed and gray literature)
    - Describe what the youth should expect to happen during sessions, what technology will be used (eg, if it is recorded), and the risks and benefits of eHealth
    - Obtain contact information for multiple caregivers (if possible) in case one is not available when you attempt to reach them
    - Provide information on who the youth or caregiver should contact in an emergency
    - Describe what will happen if the youth is determined to be at an immediate safety risk
    - Detail the plan for what happens if the connection is lost during a session (eg, backup phone number)
    - Obtain caregiver consent and youth assent
- Session logistics (recommendation from peer-reviewed and gray literature)
    - Have a plan for what to do if you get disconnected or need to get immediate support to the youth (eg, call a caregiver and have emergency services arrive)
    - Practice using the technology before the call starts, and make sure you are competent with the platform
    - Make sure the technology meets relevant privacy requirements
    - Verify the youth's identity at the start of the session (if you have not met them before or if you cannot see them) and confirm the youth's physical location
    - Monitor how the youth is feeling throughout the session
    - Document when the assessment started and ended, what platform you used, if you had any technical difficulties, specific topics covered, and any other notes
    - End the session by asking what could be improved for next time
    - If a youth misses the session, check in to see how they are and what you can do to make the sessions easier or more comfortable for them to attend
- Safety planning (recommendation from peer-reviewed and gray literature)
    - Follow the same basic steps as in-person risk assessments (eg, completing a safety plan and having information for in-person resources and emergency services ready before the session in case needed)
    - If the risk is not immediate, develop a safety plan and send it to the youth and their caregiver (eg, text it to them, email, or have them take a screenshot) and include contact information for 24-hour resources
    -

    - Consider using ongoing screening data to continually monitor risk (eg, agree to check in every day, week, or biweekly [depending on risk] using web-based assessments), and provide youth with feedback on risk indicators
    - Inform caregivers if suicide risk issues arise and provide clear guidelines on how to manage risk and seek appropriate help
- Internet privacy (recommendation from peer-reviewed literature only)
    - Send virtual session invitations via a secure and encrypted email
    - Give each youth a unique, nonidentifiable username and password
    - Store youth information (eg, email addresses) in an encrypted computer system and use encrypted point-to-point technologies when videoconferencing
    - Ensure the virtual session hosting platform is compliant with relevant health privacy laws in your area (eg, Health Insurance Portability and Accountability Act)

Accessibility

Two articles discussed recommendations relevant to the accessibility of eMental health services, which also seemed potentially relevant for using eHealth for youth suicide risk assessment within school settings. Both articles were original empirical studies. One original study from Indonesia was conducted with youth whose mean age was 24.5 years [32], and the other from Australia was a qualitative study with service providers [37]. The samples were primarily female (median 68.3%). In their study, Arjadi et al [32] discussed that there are important contextual factors concerning accessibility to consider when working in the eHealth environment, such as ensuring that service delivery is accessible for individuals living in poverty, in rural areas, and/or for those with restricted internet access (Multimedia Appendix 2).

Consent Procedures

Two articles discussed recommendations relevant to consent procedures in the eHealth environment. One of these articles was an original empirical study from the United Kingdom conducted with individuals aged between 16 and 30 years (21/22, 95% White and 17/22, 77% female [41]), and the other was a review article [38]. Recommendations included ensuring that the provider had the name and contact information of the primary caregiver (and, given the potential need to contact someone quickly, the names and contact information for several other supportive adults before starting the session, in case an urgent suicide risk emerged; Multimedia Appendix 2). It is also important that the youth or caregiver knows who they should contact in case of a crisis, especially when the school-based provider is not available, and that the consent form describes the risks and benefits of eHealth services (Multimedia Appendix 2).

However, one of our expert reviewers (a school psychologist) noted that the consent procedures described by these studies did not fully apply to the school context (particularly the typical school requirement for caregiver involvement when suicide risk is present, whether or not this is something desired by the youth). In a typical face-to-face school setting, providers are able to conduct a suicide risk assessment without caregiver consent because there are adults in the school who will monitor the youth for safety throughout the process (ie, once a disclosure has been made, youth are never left alone). At the end of the risk assessment process, the school provider then contacts the youth's caregiver so that the caregiver can continue supervision as part of the safety plan [17]. However, in the eHealth environment, school providers generally need to notify the caregiver *before* beginning the risk assessment process to ensure the youth's immediate safety (ie, a caregiver notification is typically sent during the initial assessment in the eHealth environment and not during the safety planning process as in the face-to-face environment). If it is not safe to contact the caregiver, and the need is urgent, emergency services may need to be called to bring the youth to a setting for the assessment where there is supervision. Given these differences in the school (compared with the general community) environment, the existing literature on consent for eHealth suicide risk assessment does not completely align with school-based needs. Thus, research specific to conducting eHealth suicide risk assessment with youth in the school environment is critically needed.

Session Logistics

Five studies discussed recommendations relevant to eHealth session logistics. Four of these papers were original empirical studies from the United States, Indonesia, and Australia [32,35,39,40], and one was a review article [38]. Where information was reported, the original studies were conducted primarily with older, predominately female youth and/or adults. For the studies conducted in the United States and Australia, samples were primarily White. From their experience working with more than 9000 adults in an eMental health setting in Australia, Nielssen et al [39] concluded that (for adults) web-based suicide risk assessments should follow the same basic steps as in-person risk assessments and include specific protocols and procedures. However, given nuances in the eHealth environment (eg, nonverbal clues, how to communicate the safety plan to youth and caregivers), service providers should receive specific training on how to conduct suicide risk assessments via eHealth (Multimedia Appendix 2). Providers should also have a backup plan in case the youth is in crisis and internet and/or technology issues occur, and they should go over this plan with the youth (and caregivers) at the beginning of the session (Multimedia Appendix 2). Finally, it is important that providers understand the relevant professional requirements for providing mental health services remotely to youth at risk of suicide.

Safety Planning

Nine studies discussed recommendations relevant to eHealth safety planning. Six of these papers were original empirical studies from Australia, the United Kingdom, the United States, and Indonesia [32,33,36,39,41,42], and three were review papers [31,34,38]. Where information was reported, the original studies were conducted primarily with older, predominately female youth and/or adults. For the studies conducted in the United States, the United Kingdom, and Australia, samples were primarily White (median 84.2%). A relevant recommendation emerging from these studies is the potential use of screening data and personalized feedback to remotely monitor risk and increase youth engagement, respectively (Multimedia Appendix 2). Specifically, as school mental health providers may not interact with students daily, these screening data can help providers monitor emerging risks in the remote environment. Related to this, Nelson et al [38] suggested that more check-ins may be required when using a web-based format compared with the in-person environment, especially for youth who are more isolated (eg, youth living in rural settings). Finally, it is important to provide clear guidelines to caregivers on how to manage risk and seek appropriate help (Multimedia Appendix 2).

Internet Privacy

Four studies discussed recommendations relevant to internet privacy when providing eMental health services. Three of these papers were original empirical studies from the United States and Indonesia [32,35,42], and one was a review paper that discussed internet privacy issues [38]. Where information was reported, original study samples primarily comprised older, predominately female youth, and samples from the United States were predominately White. Recommendations included using an encrypted email to send session invitations and ensuring that the remote session hosting platform is compliant with relevant health privacy laws (Multimedia Appendix 2). Storage of youth information (eg, email addresses and cell phone numbers) is also an important privacy consideration (Multimedia Appendix 2). Reviewing the telepsychology literature, Nelson et al [38] also recommend asking youth who else is in the room, and whether they are comfortable with those people there or whether those people's presence complies with relevant health privacy laws and institutional requirements. Who is in the room should also be considered by the service provider to ensure that the risk assessment is conducted privately and confidentially.

Gray Literature

Overall, there was more specific and detailed information in the gray literature (ie, documents from relevant websites) on using eMental health with youth, both generally and for conducting suicide risk assessments. From the 17 websites (Multimedia Appendix 1), we extracted relevant information from 23 documents. In general, these 23 resources highlighted that during the COVID-19 pandemic, it is especially important to assess youth at risk of suicide on an ongoing and regular basis, given the stressful changes many youths are experiencing [46]. A summary of recommendation themes from the peer-reviewed and gray literature is provided in Textbox 1, and full information on themes and underlying recommendations is provided in Multimedia Appendix 2.

Specific recommendations from the gray literature substantially overlapped with and enhanced three of the themes identified from the peer-reviewed literature—consent procedures, session logistics, and safety planning; there were no additional recommendations in the gray literature about internet privacy (Multimedia Appendix 2). In addition, per findings from the gray literature, we expanded the aforementioned *accessibility* theme to a broader theme termed *youth engagement*, which included information on accessibility, building rapport, establishing a therapeutic space, and helping youth prepare for remote sessions (Multimedia Appendix 2). Finally, one new theme was identified in the gray literature findings, specifically around school mental health professional boundaries. This theme emphasized the importance of establishing when the school mental health provider would and would not be available in the remote environment and advised arranging coverage periods when possible (Multimedia Appendix 2).

Besides the additional detail provided for specific recommendation themes, a second key difference between the gray and peer-reviewed literature was the former's focus on issues of equity and access and how technology can reinforce existing inequalities [72]. A number of resources specifically detailed that providers must consider youth's ability to use different remote technologies and ensure that care is accessible (eg, considering the internet, data and/or phone minute restrictions; Multimedia Appendix 2). For example, in a webinar from the Mental Health Technology Transfer Network [73], presenters highlighted that each youth should be evaluated based on their individual, communal, and national culture (eg, how different cultures demonstrate pain or distress). This study also highlighted that certain perceived accents might be difficult for some providers or youth to understand, and it is thus key that providers recognize when someone may have difficulties understanding them or when they may have difficulties understanding someone else [73]. Regarding language diversity, efforts should be made to provide services in the language in which the youth are most comfortable [73]. Efforts should also be made to increase accessibility for any resources provided (eg, closed captions and sign language [73]). Overall, it is critical for school mental health providers to explore "intersections of culture, sociodemographics, geography, and technology" when using mental health services—including eHealth suicide risk assessment—with youth [74].

Discussion

Key Findings

In this systematic scoping review, we found six key recommendation themes across the included peer-reviewed and gray literature sources: (1) youth engagement (accessibility, building rapport, establishing a therapeutic space, and helping youth prepare for remote sessions), (2) school mental health professional boundaries, (3) consent procedures, (4) session logistics, (5) safety planning, and (6) internet privacy. We believe these recommendation themes (general summary of recommendations is outlined in Textbox 1; a detailed summary of recommendations is outlined in Multimedia Appendix 2) will be helpful to school mental health providers as they continue to conduct suicide risk assessments with youth via eHealth during the COVID-19 pandemic and beyond. However, as these recommendations are generally from research conducted outside the school setting, they should be applied with caution (eg, recommendations about consent procedures). Research specific to conducting eHealth suicide risk assessment with youth in the school environment is critically needed.

In our comprehensive search of the peer-reviewed literature, we found no peer-reviewed articles that specifically described promising practices for conducting suicide risk assessments (school-based or otherwise) with youth via eHealth. Thus, this represents a major gap in the literature. Although suicide risk assessments have been developed for use with youth in medical settings [18,19], to our knowledge, none of these screeners have been specifically adapted for or tested for use in the school-based context, and, even when they are used within the contexts for which they were designed, suicide risk screeners do not have strong diagnostic accuracy [75,76]. Future studies need to (1) focus on increasing the diagnostic accuracy of suicide risk screeners for youth, (2) adapt and test these screeners within the school-based context, and (3) specifically explore school-based versus community or medical suicide risk assessments for youth delivered via eHealth because of the different requirements in these settings (eg, around confidentiality and liability). The 12 peer-reviewed papers that provided relevant information were also primarily focused on White, cisgender female, and presumably heterosexual youth. As groups at disproportionate risk for suicide include cisgender male youth, Indigenous youth, immigrant, newcomer and refugee youth, LGBTQ2SIA+ youth, and youth with disabilities [71,77], this represents a further gap in the literature. Therefore, new research in this area should focus on expanding the diversity of youth participants. In addition to including diverse groups of youth, it is also critical that future research on this topic centers youth voices and experiences [40].

Although we found very limited peer-reviewed literature, we found many gray literature documents that provided specific information on conducting remote suicide risk assessments with youth. Many of the resulting recommendations overlapped and expanded upon the limited information available in the peer-reviewed literature. Thus, although more research on promising practices for conducting suicide risk assessment with youth via eHealth in the school setting is required, as school mental health providers are in need of immediate guidance in the face of the COVID-19 pandemic, we feel the key recommendation themes extracted from peer-reviewed and gray literature sources in this review represent a set of six promising practices for current implementation. However, research evidence is needed for these recommendations before widespread adoption and to support the development of effective school-based suicide risk assessments for youth.

The lack of peer-reviewed studies in this review reflects the state of the e-suicide prevention literature more broadly. Specifically, in their systematic review of mobile or web-based suicide prevention literature published between 2000 and 2015, Perry et al [78] found only one study that met their inclusion criteria (studies with youth aged 12-25 years; included suicidality as a primary outcome using any study design; and, published in English in a peer-reviewed journal). Given the increased access that e-suicide interventions (including risk assessment) offer youth in the context of COVID-19, and post–COVID-19 for rural and remote youth, it is critical that future research address this gap. Recommendations from gray literature sources provide rich information on which to base this work.

In addition, although we did locate a number of studies that examined eMental health interventions generally for youth, almost none of them described their risk assessment procedures for participants experiencing suicidal ideation; thus, these articles were excluded from this review. As such, we recommend that future eMental health intervention research be explicit about describing procedures for how youth suicide risk can be assessed remotely.

In the context of the COVID-19 pandemic, new research is emerging rapidly, including on the topic of suicide prevention. For example, a recent article by Szlyk, Berk, Peralta, and Miranda [79] (published after we conducted our peer-reviewed literature search at the end of May 2020) explored the implications of COVID-19 for adolescent suicide prevention. In this paper, Szlyk et al [79] recommend several evidence-based strategies to address mental health needs and decrease the risk of suicide among adolescents during the COVID-19 pandemic. First, they recommend restricting access to potential means of suicide (eg, firearms, medication, and knives). Second, for adolescents with a history of suicide attempts, ideation, or self-harm, they recommend that caregivers consider limiting their time spent alone. Third, caregivers and school mental health providers can collaboratively monitor social media use with the youth and help set healthy limits around internet use. They also suggest that school mental health providers have frequent check-ins with adolescents and create a safe space where they can have open discussions about their feelings. Fourth and finally, Szlyk et al [79] recommend taking any discussion of self-harm or suicide seriously; for school mental health providers, this means continuing to conduct risk assessments remotely, and contacting emergency services when indicated per the assessment. These four recommendations align with many of the recommendations of our review.

Furthermore, research is also emerging on advanced methods to improve accurate prediction of suicide attempts, specifically, complex algorithms that can consider a large number of risk factors simultaneously (vs more traditional methods of regression analyses with several predictors). These complex algorithms can be implemented with machine learning, a type of artificial intelligence that learns patterns from data and then applies that knowledge automatically to improve risk prediction. Researchers have recently used this technique to analyze thousands of complex health records to predict which patients are at risk of attempting suicide, leading to a more clinically accurate risk prediction [80,81]. As this technique does not require face-to-face screening, it would be particularly useful in the context of eHealth. Thus, we recommend future research that considers how we can leverage this technology to further enhance suicide risk assessment and intervention efforts with youth.

Limitations

Our study has several limitations. First, many of the specific recommendations made in Multimedia Appendix 2 came from the gray literature, which is generally not independently or peer-reviewed; thus, these recommendations require testing with youth. Second, although we considered any remote approach to fall within our definition of eHealth, most of the recommendations we found were for mediums that included a voice component. As text-based interactions are a different context that likely require a different skill set, the recommendations from our review may not apply to text-based approaches. Finally, and as noted above, almost none of the literature we reviewed (peer-reviewed or gray) was specific to the school setting, and thus recommendations should be applied with caution by school mental health providers.

Conclusions

From this rapid, systematic scoping review, we conclude that promising practices for conducting suicide risk assessments with youth via eHealth in school settings represents a critical research gap. Future research with diverse groups of youth is required to address this gap. However, for school mental health providers searching for immediate guidance, we feel the recommendations in this review represent the most current promising practices for suicide risk assessment with youth via eHealth until additional research is available.

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Authors' Contributions

DEC conceptualized the work, acquired funding for the work, analyzed and interpreted data, and drafted the first version of the manuscript. EB contributed to the project design, data analysis and interpretation, and manuscript drafting. SG, CFC, RRR, MVB, and EV acquired and contributed to the data analysis and manuscript drafting. AA, CP, KDS, and PDA contributed to the project design, data interpretation, and critical review of the manuscript for publication. All authors approved the final version submitted and agreed to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Websites reviewed for relevant gray literature.
[DOCX File , 19 KB - mental_v8i9e29454_app1.docx]

Multimedia Appendix 2
Detailed relevant recommendations from peer-reviewed and gray literature.
[DOCX File , 36 KB - mental_v8i9e29454_app2.docx]

References

1. Raising Canada 2020: Top 10 threats to childhood in Canada and the impact of COVID-19. Children First Canada. 2020. URL: https://static1.squarespace.com/static/5669d2da9cadb69fb2f8d32e/t/5f51503d5ceab254db134729/1599164484483/Raising+Canada+Report_Final_Sept.pdf [accessed 2021-12-01]
2. Ivey-Stephenson AZ, Demissie Z, Crosby AE, Stone DM, Gaylor E, Wilkins N, et al. Suicidal ideation and behaviors among high school students - Youth Risk Behavior Survey, United States, 2019. MMWR Suppl 2020 Aug 21;69(1):47-55 [FREE Full text] [doi: 10.15585/mmwr.su6901a6] [Medline: 32817610]
3. Navaneelan T. Suicide rates: An overview. Statistics Canada Catalogue No. 82-624-X. 2017. URL: https://www150.statcan.gc.ca/n1/pub/82-624-x/2012001/article/11696-eng.htm [accessed 2019-07-02]

4. Robinson J, Cox G, Malone A, Williamson M, Baldwin G, Fletcher K, et al. A systematic review of school-based interventions aimed at preventing, treating, and responding to suicide- related behavior in young people. Crisis 2013 May;34(3):164-182. [doi: 10.1027/0227-5910/a000168] [Medline: 23195455]
5. Bennett K, Rhodes AE, Duda S, Cheung AH, Manassis K, Links P, et al. A youth suicide prevention plan for Canada: a systematic review of reviews. Can J Psychiatry 2015 Jun 01;60(6):245-257 [FREE Full text] [doi: 10.1177/070674371506000603] [Medline: 26175322]
6. The cost of injury in Canada. Public Health Agency of Canada. 2020 Aug 07. URL: https://www.canada.ca/en/public-health/services/injury-prevention/cost-injury-canada.html [accessed 2020-10-14]
7. Schwartz KD, Exner-Cortens D, McMorris CA, Makarenko E, Arnold P, Van Bavel M, et al. COVID-19 and Student Well-Being: Stress and mental health during return-to-school. Can J Sch Psychol 2021 Jun 18;36(2):166-185 [FREE Full text] [doi: 10.1177/08295735211001653] [Medline: 34040284]
8. Liang L, Ren H, Cao R, Hu Y, Qin Z, Li C, et al. The effect of COVID-19 on youth mental health. Psychiatr Q 2020 Sep 21;91(3):841-852 [FREE Full text] [doi: 10.1007/s11126-020-09744-3] [Medline: 32319041]
9. Xie X, Xue Q, Zhou Y, Zhu K, Liu Q, Zhang J, et al. Mental health status among children in home confinement during the coronavirus disease 2019 outbreak in Hubei Province, China. JAMA Pediatr 2020 Sep 01;174(9):898-900 [FREE Full text] [doi: 10.1001/jamapediatrics.2020.1619] [Medline: 32329784]
10. Eysenbach G. Towards ethical guidelines for e-health: JMIR theme issue on eHealth ethics. J Med Internet Res 2000;2(1):E7 [FREE Full text] [doi: 10.2196/jmir.2.1.e7] [Medline: 11720926]
11. De Silva S, Parker A, Purcell R, Callahan P, Liu P, Hetrick S. Mapping the evidence of prevention and intervention studies for suicidal and self-harming behaviors in young people. Crisis 2013 Jan 01;34(4):223-232. [doi: 10.1027/0227-5910/a000190] [Medline: 23502058]
12. Freedenthal S, Breslin L. High school teachers' experiences with suicidal students: a descriptive study. J Loss Trauma 2010 Feb 26;15(2):83-92. [doi: 10.1080/15325020902928625]
13. Gould MS, Marrocco FA, Hoagwood K, Kleinman M, Amakawa L, Altschuler E. Service use by at-risk youths after school-based suicide screening. J Am Acad Child Adol Psychiat 2009 Dec;48(12):1193-1201. [doi: 10.1097/chi.0b013e3181bef6d5]
14. Steele MM, Doey T. Suicidal behaviour in children and adolescents. Part 2: treatment and prevention. Can J Psychiatry 2007 Jun;52(6 Suppl 1):35-45. [Medline: 17824351]
15. Reis C, Cornell D. An evaluation of suicide gatekeeper training for school counselors and teachers. Prof School Counsel 2008 Aug;11(6):386-394. [doi: 10.5330/psc.n.2010-11.386]
16. Substance Abuse and Mental Health Services Administration. Preventing suicide: A toolkit for high schools. HHS Publication No. SMA-12-4669. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration; 2012. URL: https://store.samhsa.gov/product/Preventing-Suicide-A-Toolkit-for-High-Schools/SMA12-4669
17. Lieberman R, Poland S, Kornfeld C. Best practices in suicide prevention and intervention. In: Harrison PL, Thomas A, editors. Best Practices in School Psychology. Bethesda, MD: National Association of School Psychologists; 2014:273-288.
18. Horowitz LM, Bridge JA, Teach SJ, Ballard E, Klima J, Rosenstein DL, et al. Ask Suicide-Screening Questions (ASQ): a brief instrument for the pediatric emergency department. Arch Pediatr Adolesc Med 2012 Dec 01;166(12):1170-1176 [FREE Full text] [doi: 10.1001/archpediatrics.2012.1276] [Medline: 23027429]
19. Gipson PY, Agarwala P, Opperman KJ, Horwitz A, King CA. Columbia-Suicide Severity Rating Scale: Predictive validity with adolescent psychiatric emergency patients. Pediat Emerg Care 2015;31(2):88-94. [doi: 10.1097/pec.0000000000000225]
20. Brief report on suicide prevention in the school setting. Alberta Centre for Injury Control & Research. 2013. URL: https://injurypreventioncentre.ca/downloads/research/Suicide_Prevention_In_School_Settings2012_FINAL.pdf [accessed 2020-05-04]
21. Granello D. The process of suicide risk assessment: Twelve core principles. J Couns Dev 2010;88:363-370. [doi: 10.1002/j.1556-6678.2010.tb00034.x]
22. Becker-Blease K, Turner H, Finkelhor D. Disasters, victimization, and children's mental health. Child Dev 2010;81(4):1040-1052. [doi: 10.1111/j.1467-8624.2010.01453.x] [Medline: 20636681]
23. Goldmann E, Galea S. Mental health consequences of disasters. Annu Rev Public Health 2014 Mar 18;35(1):169-183. [doi: 10.1146/annurev-publhealth-032013-182435] [Medline: 24159920]
24. Overstreet S, Salloum A, Burch B, West J. Challenges associated with childhood exposure to severe natural disasters: research review and clinical implications. J Child Adol Trauma 2014 Jan 16;4(1):52-68. [doi: 10.1080/19361521.2011.545103]
25. Anderson S, Allen P, Peckham S, Goodwin N. Asking the right questions: scoping studies in the commissioning of research on the organisation and delivery of health services. Health Res Policy Syst 2008 Jul 09;6:7 [FREE Full text] [doi: 10.1186/1478-4505-6-7] [Medline: 18613961]
26. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005 Feb;8(1):19-32. [doi: 10.1080/1364557032000119616]
27. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci 2010;5:69 [FREE Full text] [doi: 10.1186/1748-5908-5-69] [Medline: 20854677]

28. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. Int J Evid Based Healthc 2015 Sep;13(3):141-146. [doi: 10.1097/XEB.0000000000000050] [Medline: 26134548]
29. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for Scoping Reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 2018 Oct 02;169(7):467-473 [FREE Full text] [doi: 10.7326/M18-0850] [Medline: 30178033]
30. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 2009 Jul 21;6(7):e1000097 [FREE Full text] [doi: 10.1371/journal.pmed.1000097] [Medline: 19621072]
31. Anderson RA, Rees CS, Finlay-Jones AL. Internet-based cognitive-behavioural therapy for young people with obsessive-compulsive disorder: Lessons learned. J Obsess Compul Rel Disord 2017 Oct;15:7-12. [doi: 10.1016/j.jocrd.2017.08.001]
32. Arjadi R, Nauta MH, Scholte WF, Hollon SD, Chowdhary N, Suryani AO, et al. Internet-based behavioural activation with lay counsellor support versus online minimal psychoeducation without support for treatment of depression: a randomised controlled trial in Indonesia. Lancet Psychiatry 2018 Sep;5(9):707-716. [doi: 10.1016/s2215-0366(18)30223-2]
33. Fairchild RM, Ferng-Kuo S, Rahmouni H, Hardesty D. Telehealth increases access to care for children dealing with suicidality, depression, and anxiety in rural emergency departments. Telemed J E Health 2020 Nov 01;26(11):1353-1362. [doi: 10.1089/tmj.2019.0253] [Medline: 32013779]
34. Goodday SM, Atkinson L, Goodwin G, Saunders K, South M, Mackay C, et al. The true colours remote symptom monitoring system: a decade of evolution. J Med Internet Res 2020 Jan 15;22(1):e15188 [FREE Full text] [doi: 10.2196/15188] [Medline: 31939746]
35. Haas A, Koestner B, Rosenberg J, Moore D, Garlow SJ, Sedway J, et al. An interactive web-based method of outreach to college students at risk for suicide. J Am Coll Health 2008 Jul;57(1):15-22. [doi: 10.3200/jach.57.1.15-22]
36. King CA, Eisenberg D, Zheng K, Czyz E, Kramer A, Horwitz A, et al. Online suicide risk screening and intervention with college students: a pilot randomized controlled trial. J Consult Clin Psychol 2015 Jun;83(3):630-636 [FREE Full text] [doi: 10.1037/a0038805] [Medline: 25688811]
37. Navarro P, Sheffield J, Edirippulige S, Bambling M. Exploring mental health professionals' perspectives of text-based online counseling effectiveness with young people: mixed methods pilot study. JMIR Ment Health 2020 Jan 29;7(1):e15564 [FREE Full text] [doi: 10.2196/15564] [Medline: 32012097]
38. Nelson E, Bui TN, Velasquez SE. Telepsychology: research and practice overview. Child Adolesc Psychiatr Clin N Am 2011 Jan;20(1):67-79. [doi: 10.1016/j.chc.2010.08.005] [Medline: 21092913]
39. Nielssen O, Dear BF, Staples LG, Dear R, Ryan K, Purtell C, et al. Procedures for risk management and a review of crisis referrals from the MindSpot Clinic, a national service for the remote assessment and treatment of anxiety and depression. BMC Psychiatry 2015;15:304 [FREE Full text] [doi: 10.1186/s12888-015-0676-6] [Medline: 26626712]
40. Radovic A, Gmelin T, Hua J, Long C, Stein BD, Miller E. Supporting Our Valued Adolescents (SOVA), a social media website for adolescents with depression and/or anxiety: technological feasibility, usability, and acceptability study. JMIR Ment Health 2018 Feb 26;5(1):e17 [FREE Full text] [doi: 10.2196/mental.9441] [Medline: 29483067]
41. Sayal K, Roe J, Ball H, Atha C, Kaylor-Hughes C, Guo B, et al. Feasibility of a randomised controlled trial of remotely delivered problem-solving cognitive behaviour therapy versus usual care for young people with depression and repeat self-harm: lessons learnt (e-DASH). BMC Psychiatry 2019 Jan 24;19(1):42 [FREE Full text] [doi: 10.1186/s12888-018-2005-3] [Medline: 30678674]
42. Thomas JF, Novins DK, Hosokawa PW, Olson CA, Hunter D, Brent AS, et al. The use of telepsychiatry to provide cost-efficient care during pediatric mental health emergencies. Psychiatr Serv 2018 Feb 01;69(2):161-168. [doi: 10.1176/appi.ps.201700140] [Medline: 29032703]
43. Treating suicidal patients during COVID-19: Best practices and telehealth. Suicide Prevention Resource Center. 2020. URL: https://www.sprc.org/events-trainings/treating-suicidal-patients-during-covid-19-best-practices-telehealth [accessed 2020-04-14]
44. Clinical innovations in telehealth: Telehealth and suicidal care. Mental Health Technology Transfer Center Network Coordinating Office. 2020. URL: https://www.youtube.com/watch?v=vwmSC6BRc4k&feature=youtu.be [accessed 2020-05-19]
45. School-Based Health Alliance and the National Center for School Mental Health. 2020. URL: https://www.youtube.com/watch?v=0Y8ih8i2s_A [accessed 2020-05-15]
46. Zero suicide implementation during COVID-19 response. ZEROSuicide Institute. URL: http://zerosuicide.edc.org/sites/default/files/Zero%20Suicide%20Implementation%20During%20the%20COVID-19%20Response.pdf [accessed 2020-06-19]
47. Abrams Z. Ethical guidance for the COVID-19 era. American Psychological Association. 2020. URL: https://www.apa.org/monitor/2020/06/ce-corner-ethical-guidance [accessed 2021-09-08]
48. TeleMental health via video conferencing checklist. Alvord, Baker & Associates, LLC. URL: https://www.nationalregister.org/wp-content/uploads/2020/03/for-3-18-20-post-Alvord-Telehealth-Checklist.pdf [accessed 2021-09-08]

49. American Psychiatric Association. How to prepare for a video appointment with your mental health clinician. SMI Adviser. 2020. URL: https://smiadviser.org/wp-content/uploads/2020/04/How-to-Prepare-for-a-Video-Appointment.pdf [accessed 2021-09-08]
50. Informed consent checklist for telepsychological services. American Psychological Association. 2020. URL: https://www.apa.org/practice/programs/dmhi/research-information/informed-consent-checklist [accessed 2021-09-08]
51. Office and telepsychology checklist for telepsychological services. American Psychological Association. 2020. URL: https://www.apa.org/practice/programs/dmhi/research-information/telepsychological-services-checklist [accessed 2021-09-08]
52. Planning for virtual/distance school counselling during an emergency shutdown. American School Counselor Association. URL: https://schoolcounselor.org/getmedia/8e31740f-d6af-4f62-a9e3-26563c488443/emergency-shutdown.pdf [accessed 2021-09-08]
53. Cox J. Telemental health 101 [Video]. National Center for School Mental Health. 2020. URL: https://www.youtube.com/watch?v=3A74lXLTABw [accessed 2021-09-08]
54. Kaslow NJ. Speaking of Psychology: Preventing suicide [Episode 14]. American Psychological Association. 2014. URL: https://www.apa.org/research/action/speaking-of-psychology/preventing-suicide [accessed 2021-09-08]
55. Lowenstein L. Creative interventions for online therapy with children: Techniques to build rapport. lianalowenstein.com. URL: http://www.lianalowenstein.com/artcileProfTeleplayLowenstein.pdf [accessed 2021-09-08]
56. Mental Health Technology Transfer Center Network. Engaging with clients over the telephone and using texts. Mental Health Technology Transfer Center [MHTTC] Network, Northeast and Caribbean (HHS Region 2). URL: https://mhttcnetwork.org/sites/default/files/2020-05/Engaging%20with%20Clients%20Over%20the%20Telephone%20and%20Using%20Texts_FINALpdf.pdf [accessed 2021-09-08]
57. Nassar C, Costello JK, Wolf-Prusan L. Telehealth learning and consultation (TLC) Tuesdays, April 28: Telehealth troubleshooting [webinar slides]. Mental Health Technology Transfer Center Network. 2020. URL: https://mhttcnetwork.org/centers/mid-america-mhttc/telehealth-learning-and-consultation-tlc-tuesdays [accessed 2020-09-08]
58. National Association of School Psychologists. Comprehensive suicide prevention in a time of distance learning (handout). NASP Online. 2020. URL: https://www.nasponline.org/resources-and-publications/resources-and-podcasts/covid-19-resource-center/crisis-and-mental-health-resources/comprehensive-school-suicide-prevention-in-a-time-of-distance-learning [accessed 2020-09-08]
59. National Association of School Psychologists. Virtual service delivery in response to COVID-19 disruptions. NASP Online. 2020. URL: https://www.nasponline.org/resources-and-publications/resources-and-podcasts/school-climate-safety-and-crisis/health-crisis-resources/virtual-service-delivery-in-response-to-covid-19-disruptions [accessed 2021-08-09]
60. National Institute of Mental Health. Youth suicide risk screening pathway [Infographic]. NIMH. 2020. URL: https://www.nimh.nih.gov/sites/default/files/documents/research/research-conducted-at-nimh/asq-toolkit-materials/inpatient/pdfs/covid-19_youth_suicide_risk_screening_pathway.pdf [accessed 2021-09-08]
61. Virtual care 101 webinar: Questions and answers. Ontario Centre of Excellence for Child, & Youth Mental Health [CYMH] and School Mental Health Ontario [SMH]. 2020. URL: https://www.cymh.ca/en/projects/resources/virtual/vc_virtual_care_webinar_QandA_wcag.pdf [accessed 2021-09-08]
62. Perlman CM, Neufeld E, Martin L, Goy M, Hirdes JP. Suicide risk assessment inventory: A resource guide for Canadian health care organizations. Patient Safety Institute. 2011. URL: https://www.patientsafetyinstitute.ca/en/toolsResources/SuicideRisk/Documents/Suicide%20Risk%20Assessment%20Guide.pdf [accessed 2021-09-08]
63. Reinert P. Telehealth guidelines for school mental health professionals: Strategies for engaging students and building resilience. School Mental Health. 2020. URL: http://www.schoolmentalhealth.org/media/SOM/Microsites/NCSMH/Documents/COVID-19/Telehealth-for-Mental-Health-DRAFT-7.pdf [accessed 2021-09-08]
64. Telehealth start-up and resource guide. Version 1.1. Telligen Health Information Technology Regional Extension Center [THITREC] and Great Plains Telehealth Resource & Assistance Center [GPTRAC]. 2014. URL: https://www.ruralcenter.org/resource-library/telehealth-start-up-and-resource-guide [accessed 2021-09-08]
65. van Dyk IS, Kroll JL, Martinez RG, Emerson ND, Bursch B. COVID-19 tips: Building rapport with youth via telehealth. ResearchGate. 2020. URL: https://www.williamjames.edu/community/resource-hub/upload/TelehealthTipSheet-COVIDChildVersionFINAL.pdf [accessed 2021-09-08]
66. Telehealth and suicide care during the COVID-19 pandemic. ZEROSuicide Institute. URL: https://zerosuicide.edc.org/sites/default/files/Telehealth%20and%20Suicide%20Care%20During%20the%20COVID-19%20Pandemic.pdf [accessed 2021-09-08]
67. Telehealth tips: Managing suicidal clients during the COVID-19 pandemic. ZEROSuicide Institute. URL: https://zerosuicide.edc.org/sites/default/files/Telehealth%20Tips%20with%20Suicidal%20Clients%20-%20FINAL.pdf [accessed 2021-09-08]
68. Miller AB, Prinstein MJ. Adolescent suicide as a failure of acute stress-response systems. Annu Rev Clin Psychol 2019 May 07;15(1):425-450 [FREE Full text] [doi: 10.1146/annurev-clinpsy-050718-095625] [Medline: 30786243]
69. Cha CB, Franz PJ, M. Guzmán E, Glenn CR, Kleiman EM, Nock MK. Annual Research Review: Suicide among youth - epidemiology, (potential) etiology, and treatment. J Child Psychol Psychiatr 2017 Nov 01;59(4):460-482. [doi: 10.1111/jcpp.12831] [Medline: 29090457]

70. Goldston DB, Molock SD, Whitbeck LB, Murakami JL, Zayas LH, Hall GC. Cultural considerations in adolescent suicide prevention and psychosocial treatment. Am Psychol 2008 Jan;63(1):14-31. [doi: 10.1037/0003-066x.63.1.14]
71. Building Strength, Inspiring Hope: A Provincial Action Plan for Youth Suicide Prevention. Edmonton, AB: Government of Alberta; 2019.
72. App-on-tap: using technology in the prevention of suicide. Mental Health Commission of Canada and Hatcher S. 2014. URL: https://www.mentalhealthcommission.ca/English/media/3410 [accessed 2020-05-27]
73. Evans M. Providing culturally relevant telehealth services during a pandemic. National Hispanic and Latino Mental Health Technology Transfer Center Network. 2020. URL: https://mhttcnetwork.org/centers/national-hispanic-and-latino-mhttc/product/providing-culturally-relevant-telehealth [accessed 2020-06-11]
74. Hilty DM, Ferrer DC, Parish MB, Johnston B, Callahan EJ, Yellowlees PM. The effectiveness of telemental health: a 2013 review. Telemed J E Health 2013 Jun;19(6):444-454 [FREE Full text] [doi: 10.1089/tmj.2013.0075] [Medline: 23697504]
75. Runeson B, Odeberg J, Pettersson A, Edbom T, Adamsson IJ, Waern M. Instruments for the assessment of suicide risk: A systematic review evaluating the certainty of the evidence. PLoS One 2017 Jul 19;12(7):e0180292 [FREE Full text] [doi: 10.1371/journal.pone.0180292] [Medline: 28723978]
76. Giddens J, Sheehan K, Sheehan D. The Columbia-Suicide Severity Rating Scale (C-SSRS): Has the "Gold Standard" become a liability? Innov Clin Neurosci 2014 Sep;11(9-10):66-80 [FREE Full text] [Medline: 25520890]
77. Suicide statistics, Canadian provinces and territories. Centre for Suicide Prevention. URL: https://www.suicideinfo.ca/resource/suicide-stats-canada-provinces/ [accessed 2019-07-02]
78. Perry Y, Werner-Seidler A, Calear AL, Christensen H. Web-based and mobile suicide prevention interventions for young people: a systematic review. J Can Acad Child Adolesc Psychiatry 2016;25(2):73-79 [FREE Full text] [Medline: 27274742]
79. Szlyk HS, Berk M, Peralta AO, Miranda R. COVID-19 takes adolescent suicide prevention to less charted territory. J Adolesc Health 2020 Aug;67(2):161-163 [FREE Full text] [doi: 10.1016/j.jadohealth.2020.05.046] [Medline: 32536511]
80. Walsh CG, Ribeiro JD, Franklin JC. Predicting risk of suicide attempts over time through machine learning. Clin Psychol Sci 2017 Apr 11;5(3):457-469. [doi: 10.1177/2167702617691560]
81. Walsh CG, Ribeiro JD, Franklin JC. Predicting suicide attempts in adolescents with longitudinal clinical data and machine learning. J Child Psychol Psychiatry 2018 Dec 30;59(12):1261-1270. [doi: 10.1111/jcpp.12916] [Medline: 29709069]

Abbreviations

LGBTQ2SIA+: lesbian, gay, bisexual, trans, queer/questioning, two-spirit, intersex, asexual
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses

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Original Paper

Digital Community Inclusion of Individuals With Serious Mental Illness: A National Survey to Map Digital Technology Use and Community Participation Patterns in the Digital Era

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Abstract

Background: Despite the growing interest in developing and using mobile health (mHealth) and digital technologies in mental health, little is known about the scope and nature of virtual community inclusion.

Objective: The overarching goal of this study was to understand and conceptualize virtual community inclusion of individuals with serious mental illness (SMI). Specific objectives of this study were as follows: (1) mapping the prevalence, trends, and experiences related to mHealth and digital technology use among individuals with SMI; (2) comparing patterns of technology use by individuals with and those without SMI; and (3) examining whether use of mHealth and digital technologies predicts recovery among individuals with SMI.

Methods: A web-based survey of technology use and virtual participation was developed and distributed among adults with and those without SMI via social media, national email discussion lists, nonprofit organizations, and advocacy groups.

Results: A total of 381 adults aged 18 years or older participated in the survey, of whom 199 (52%) identified as having a SMI. Participants with SMI reported significantly greater access to technology and significantly fewer days of face-to-face participation in community activities than those without SMI. Among participants with SMI, greater technology use was positively associated with positive emotions and significantly predicted recovery.

Conclusions: This study is the first to explore, map, and conceptualize virtual community inclusion among adults with SMI. Our findings indicate a gap in the literature and research on community inclusion and participation, and emphasize the need for virtual community inclusion, particularly during the COVID-19 pandemic and its future implications.

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KEYWORDS

mobile health; technology; digital community participation; digital community inclusion; serious mental illness; recovery

Introduction

The COVID-19 pandemic has emphasized the necessity of mobile health (mHealth) and the use of digital technology more generally in managing chronic health conditions [1-4]. Recently, the World Health Organization has defined mHealth as the use of mobile and wireless technologies to support the achievement of health objectives [5]. In the field of mental health, digital technologies have been integrated for various purposes, including research, intervention development, diagnosis, and prevention [6-9]. Individuals with serious mental illness (SMI) may benefit from mHealth interventions to learn where to seek help, cope with stigma, access mental health services, and use digital technologies to coordinate among various service providers, especially in peripheral areas [1,10-13].

A pioneering survey conducted in the United States among individuals who self-identified with schizophrenia [14] indicated that 90% owned more than 1 internet-connected device, particularly smartphones, and frequently used digital technologies. A meta-analysis [8] that assessed mobile phone ownership as well as interest in mHealth among individuals with psychosis found that approximately 60% were interested in using novel smartphone apps for monitoring their mental health status. Another systematic review [15] indicated a high rate of adherence to mobile technologies (83%) among people with SMI.

Recently, studies that developed and examined mHealth interventions for individuals with SMI have confirmed the feasibility and acceptability of these emerging interventions [1,15-18]. These studies also provide preliminary support for the notion that individuals with SMI can benefit from mHealth interventions [19-21]. In addition, research has indicated that social use of digital technologies is associated with community participation, which can be valuable for individuals with SMI [22].

Community participation is a multidimensional concept defined as “active involvement in activities that are intrinsically social, and either occur outside of the home or are part of a non-domestic role, such as work, social (outside of the household), and other community roles” [23-25]. Community participation behaviors include involvement in recreational, social, vocational, civic, and other areas of community life, and have been found to contribute to the recovery process and quality of life of individuals with SMI [26-28]. A dynamic approach to recovery was applied in the context of the present study. Recovery (also known as “recovery in”) refers to a subjective process characterized by movement toward conditions of hope, purpose, and wellness. This concept of recovery emphasizes the person’s self-determination and participation in life pursuits as education, employment, friendship, and spirituality, consistent with his/her goals, values, and preferences [29,30]. In this sense, using digital technologies can contribute to greater involvement in physical and web-based activities and consequently to the individual’s recovery.

Use of digital technologies and mHealth interventions may be particularly valuable in the current global pandemic. The COVID-19 crisis has posed significant challenges for the delivery of mental health services [31]. Policies of quarantines and social distancing [32] have forced many practitioners to adjust quickly to using digital technologies [33-36]. This unprecedented crisis presents an imperative for mental health care systems to make mHealth interventions available as a routine part of care. However, there is lack of information about differences in digital participation between individuals with and those without SMI in routine care. Although there is growing literature on face-to-face community participation of individuals with and those without SMI [37], less is known about participation in the digital community among individuals with SMI. In this study, we conceptualize digital participation to describe involvement in social activities and roles within the digital space, such as recreational, social, vocational, civic, and other areas of community life. Knowledge and use of digital technologies are crucial for digital participation; however, to date, this field of research has been limited. In addition, the association between mHealth and the use of digital technologies and recovery of individuals with SMI should be further explored. Comparative data about virtual participation in routine care are valuable in identifying additional pathways for recovery, especially under the current conditions where human communication is so predominantly internet-based.

This study addresses these gaps by exploring patterns of digital participation among individuals with and those without SMI. Our specific objectives were (1) mapping the prevalence, trends, and experiences related to mHealth and digital technology use among individuals with SMI; (2) comparing the usage patterns of individuals with and those without SMI; and (3) examining whether the use of mHealth and digital technologies predicts recovery among individuals with SMI.

Methods

Setting and Survey Development

A web-based survey of technology use and participation was developed for dissemination in Israel on the basis of the National Alliance on Mental Illness (NAMI) mHealth survey [14]. The original survey was translated to Hebrew, adapted to the local context, and supplemented with additional items pertaining to recovery [14] and community participation [37]. The final version of the survey included four sections: (1) technology use, (2) recovery, (3) community participation, and (4) background and demographic characteristics.

Measures

Technology Use

Survey questions focused on access to digital devices (eg, laptop or smartphone), frequency of use, purposes of use (eg, contacting friends, family, and psychiatrists), emotional experience while using digital technologies (negative or positive emotions), and helpfulness of activities using the devices in managing mental health (only for respondents with SMI). Survey questions were translated to Hebrew and adapted from the 2014 NAMI mHealth survey [14].

Recovery

The Recovery Assessment Scale is a valid measure of recovery in mental health research. It was originally developed as a 41-item measure by mental health consumers through an analysis of recovery stories that resulted in the identification of 39 themes of the subjective experience of recovery [38]. In this study, we used the shorter 12-item Recovery Assessment Scale with a 1-5 response scale and Cronbach α values ranging .60-.97 [39,40]. For this study, Cronbach α=.87.

Community Participation

This variable was assessed using the community participation measure [41], a self-report instrument examining the amount, sufficiency, and importance of participation in 26 different areas of community-based activities over the previous 30 days.

Individuals are asked to report the number of days that they participated in each activity without a staff member (amount), whether their level of participation was “enough,” “not enough,” or “too much” (sufficiency), and whether the activities were important to them. We extracted the following to serve as independent variables in our analyses: *amount* of participation, defined as total participation days across all items (range 0-780 [30 days × 26 participation areas]); and *extent* of participation (referred also to as diversity of participation in other research, n=41), defined as the number of unique participation areas (ie, items) with at least 1 day of participation reported. For this analysis, Cronbach α=.93.

Procedure and Analysis

The survey was distributed in Israel between February 2018 and May 2019 among adult individuals (over the age of 18 years) who identified as having SMI (the study group) and those without SMI (a comparison group), based on a screening question. SMI was defined on the basis of the Substance Abuse and Mental Health Services Administration criteria [42], which are acceptable for distribution of block grants to state governments, and the Israel National Insurance Institute criteria in Israel for disability support [43,44]. Accordingly, individuals with chronic conditions, such as schizophrenia, major depression, or another mental health disorder that results in serious disability are considered under the umbrella of SMI [45,46].

Before large-scale dissemination, we conducted a field-test of the final version of the survey with 4 individuals with SMI who commented on the questions and wording and further refinement. Survey participants were recruited via a snowball approach using Facebook groups and national email discussion lists (“Listservs”) of consumers and service providers as well as via nonprofit organizations and advocacy groups of and for people with SMI. We also provided an option of a paper-and-pencil version of the survey for individuals with SMI who were interested in participating via a face-to-face meeting with the research assistant.

The study was approved by both the University of Haifa Institutional Review Board and Israel Ministry of Health. SPSS (version 25, IBM Corp) was used to present descriptive statistics and calculate correlations and means differences. A *P* value of <.05 was set as the significance level.

Results

Participants

The sample includes 381 respondents, of whom 199 (52%) reported having at least 1 SMI, with 16 (8%) having reported more than 1 SMI. The most common condition was schizophrenia (n=58, 29.1%), followed by affective disorders (bipolar disorder, n=16, 8%; depression, n=12, 6%; and anxiety n=5, 2.5%), personality disorders (n=7, 3.5%), and posttraumatic stress disorder (n=6, 3%). Most respondents with SMI (n=157, 78.9%) reported an additional nonmental health chronic condition, mostly diabetes (n=10, 6.4%) or an orthopedic condition (n=10, 6.4%), compared to those without SMI, who reported no such condition.

More women (n=246, 64.6%) than men were included in the survey, although the distribution was more balanced among those with SMI (Table 1). The most frequent age category was 18-34 years (n=146, 38.3%). While most respondents with SMI were single (n=129, 64.8%), the majority of respondents without SMI were married (n=103, 56.6%). While most of the respondents without SMI were employed (n=131, 72.0%), most respondents with SMI were employed only in supported employment programs (n=106, 53.3%). Lastly, while most respondents with SMI had at least a high school diploma (n=80, 40.2%), the majority of respondents without SMI had a higher education degree (n=136, 74.7%).

Table 1. Participant characteristics (N=381).

Variables	Entire sample, n (%)	Respondents with SMI[a] (n=199, 52.2%), n (%)	Respondents without SMI (n=182, 47.8%), n (%)	*P* value
Gender				<.001
Female	246 (64.6)	109 (54.8)	137 (75.3)	
Male	135 (35.4)	90 (45.2)	45 (24.7)	
Age (years)				.06
18-34	146 (38.3)	72 (36.2)	74 (40.7)	
35-46	106 (27.8)	65 (32.7)	41 (38.7)	
47-64	103 (27.0)	53 (26.6)	50 (27.5)	
>65	26 (6.8)	9 (4.5)	17 (9.3)	
Marital status				<.001
Single	185 (48.6)	129 (64.8)	56 (30.8)	
Married	134 (35.2)	31 (15.6)	103 (56.6)	
Separated/Divorced/Widowed	62 (16.3)	39 (19.6)	23 (12.6)	
Religion/ethnicity				.04
Jewish	356 (93.4)	187 (94.0)	169 (92.9)	
Muslim	9 (2.4)	1 (0.5)	8 (4.4)	
Christian	4 (1.0)	2 (1.0)	2 (1.1)	
Other	12 (3.1)	9 (4.5)	3 (1.6)	
Housing status				<.001
Alone	74 (19.5)	55 (27.8)	19 (10.5)	
With a partner	121 (31.9)	33 (16.7)	88 (48.6)	
With family	124 (32.7)	54 (27.3)	70 (38.5)	
Supported housing	60 (15.8)	56 (28.3)	4 (2.2)	
Employment status				<.001
Employed	183 (48.0)	52 (26.1)	131 (72.0)	
Self-employed	24 (6.3)	7 (3.5)	17 (9.3)	
Unemployed	48 (12.6)	31 (15.6)	17 (9.3)	
Retired	19 (5.0)	3 (1.5)	16 (8.8)	
Supported employment	107 (28.1)	106 (53.3)	1 (0.5)	
Education level				<.001
Less than a high school diploma	30 (7.9)	27 (13.6)	3 (1.6)	
High school diploma	105 (27.6)	80 (40.2)	25 (13.7)	
Some college, no degree	37 (9.7)	19 (9.5)	18 (9.9)	
Bachelor's degree or higher	209 (54.9)	73 (36.7)	136 (74.7)	

[a] SMI: Serious mental illness.

Comparing Male and Female Respondents

Overall, men reported having significantly greater access to technology (mean 3.58, SD 1.47) than did women (mean 3.01, SD 1.43; t_{379}=3.62; *P*<.001). Women reported significantly greater negative emotions (mean 2.06, SD 0.86) when using digital technologies compared to men (mean 1.79, SD 0.83; t_{379}=–2.95; *P*<.01). Compared to men, women also reported significantly more total days of community participation in terms of both amount (women: mean 42.02, SD 11.73; men: mean 37.67, SD 12.17; t_{312}=–3.09; *P*<.01) and extent of participation (women: mean 20.02, SD 10.11; men: mean 17.30, SD 10.74; $t_{262.3}$=–2.40; *P*<.05).

Comparing Respondents With and Those Without SMI

Respondents with SMI reported significantly greater access to technology (mean 3.63, SD 1.43) than those without SMI (mean

2.57, SD 1.38; t_{379}=–6.15; $P<.001$). Respondents with SMI also reported significantly greater negative (mean 2.05, SD 0.87) and positive emotions (mean 2.99, SD 0.96) when using digital technologies compared to those without SMI (negative emotions: mean 1.87, SD 0.80; t_{379}=–2.06; $P<.01$; positive: mean 2.59, SD 0.78; $t_{373.8}$=–4.43; $P<.05$). Finally, respondents with SMI reported significantly fewer days of participation in community activities (mean 37.6, SD 11.41) compared to those without SMI (mean 43.9, SD 11.92; t_{312}=4.79; $P<.001$).

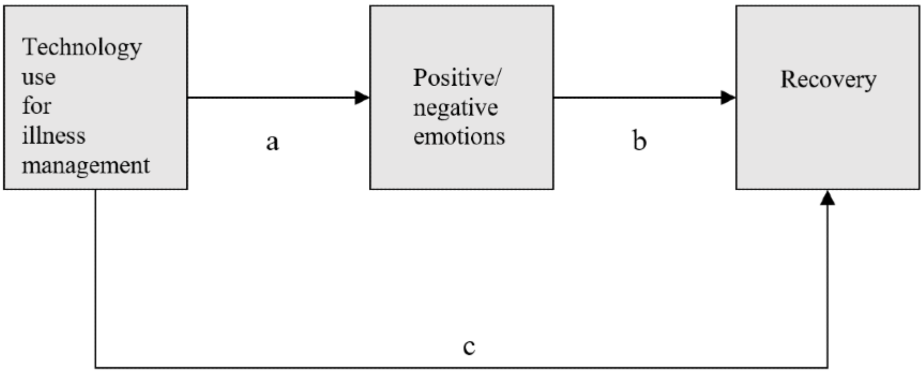
Predicting Recovery Among Respondents With SMI

Multiple linear regression analysis was conducted to predict recovery among the respondents with SMI (n=199) based on their access to digital devices, emotional experience with technology use (negative and positive), and the amount and extent of their community participation. A significant regression model was obtained ($F_{5,163}$=9.39; R^2=0.224; $P<.001$). Greater experience of emotions while using technology, both negative (β=–.290; $P<.001$) and positive (β=.299; $P<.001$), and greater amount of community participation (β=.249; $P<.01$) significantly predicted recovery. Greater positive emotions and more days of community participation were positively related to recovery, while greater negative emotions were negatively related to recovery.

Positive and Negative Emotions as Mediators of Recovery

Regression analyses were conducted to assess the contribution of technology use (for illness management) and emotions experienced while using the technology to recovery among respondents with SMI (n=199). First, we assessed the direct association between technology use for illness management (also referred to "helpfulness of activities when using technological devices" in the NAMI study [14] and recovery; Figure 1, path c). Significant and positive β weights were obtained (β=.19; $P<.01$).

Figure 1. Mediation model.



Second, 2 regression analyses were carried out with technology use for illness management as the independent variable; 1 model included negative emotions and the other included positive emotions as the dependent variables (Figure 1, path a). Significant and positive β weights were obtained for both negative (β=.15; $P<.05$) and positive emotions (β=.50; $P<.001$).

Third, 2 multiple regression analyses were conducted to predict recovery by positive and negative emotions and technology use for illness management, respectively (Figure 1, path b). A negative and significant β weight was obtained between negative emotions and recovery when controlling for technology use (β=–.17; $P<.05$). A positive and significant β weight was obtained between positive emotions and recovery when controlling for technology use (β=.36; $P<.001$). A positive and significant β weight was obtained when predicting recovery with technology use as the predictor and controlling for negative emotions (β=.22; $P<.01$). No such result was obtained when predicting recovery with technology use as the predictor and controlling for positive emotions (β=.01; $P>.05$) (Figure 1, path c). These patterns suggest partial mediation between technology use (for illness management) and recovery when negative emotions serve as a mediator, and complete mediation in the case of positive emotions under the 4 conditions of mediation [39].

Discussion

Principal Findings

This study is the first to explore and conceptualize digital community inclusion among individuals with SMI. Our study focused on digital participation of adults with SMI in Israel. We compared the mHealth and digital technology use (ie, virtual participation) of adults with and those without SMI and explored whether and how participation factors predict recovery among adults with SMI. The main findings included higher rates of digital participation among individuals with SMI compared to those without SMI. In addition, greater positive emotions were noted when digital participation in the community, digital technology use, and more days of face-to-face community participation were positively related to recovery among adults with SMI. Positive emotions during digital community participation mediated the relationship between technology use (for illness management) and recovery. The findings emphasize the important role of digital participation on community inclusion of adults with SMI.

Previous studies that compared digital technology use among individuals with and those without SMI have yielded contradictory findings. On one hand, lower rates of technology access and use were observed among individuals with SMI than among those from the general population [47,48]. On the other hand, some studies found that individuals with SMI used digital technologies at rates similar to those of the general population, and concluded that mental health problems may not be a barrier to technology use [14,49,50]. Although the aforementioned studies found similar or lower rates of technology use among individuals with SMI, our study reported a higher rate of technology use among individuals with SMI than in the general adult population. A plausible explanation for this finding is that the other findings of this study showed that adults with SMI reported significantly fewer days of participation in community activities than those without SMI. Another plausible explanation for this finding is the growing number of mental health and wellness apps available for individuals with SMI [51,52]. Furthermore, using digital technologies for mental health care has created a more accessible environment for people with SMI, thus enabling anonymous participation. In case they decide to disclose personal information, nonverbal and non–face-to-face communication may create a less stigmatic environment for interaction with others [8,53,54].

In addition to exploring mHealth and digital technology use among adults with SMI, this study examined whether digital community participation predicted recovery. The theoretical framework of community participation traditionally refers to face-to-face or actual participation and is defined as the empowered, self-determined choice and action among individuals to be active in valued roles in the communities of their choice [26]. According to this traditional framework, the term “community participation” includes 3 main types of participation: *social* (eg, attending a community event, entertaining family or friends at home, or visiting family or friends), *productive* (going to school to earn a degree or certificate, working for pay, and participating in volunteer activities), and *leisure* (going to a museum, theater or cultural event, going to a park or recreating center, and going to a restaurant) [41]. Engaging with others in the community may also reduce public stigma toward people with SMI, which in turn can contribute to their recovery [55-57].

However, it seems that the life domains of community participation have referred to the physical environment, while participation in the digital environment has been excluded, although the digital environment has become an integral part of our life [58,59] and even more so in the COVID-19 era [4]. Following the concept of recovery as a dynamic process [30], studies have indicated that social support plays a main role in an individual’s recovery [60,61]. Social support can be delivered not only through face-to-face interactions, as demonstrated in the traditional concept of community participation and from a distance through remote communication using digital technologies [62]. While some preliminary studies focused on the impact of social media use on face-to-face community participation among individuals with SMI [22,63,64], they have focused solely on social media and did not include mHealth and digital technologies for illness management.

Moreover, recent studies have not conceptually included digital participation as part of community participation. This study has addressed this concept and theoretical gaps by exploring the predictive factors to recovery while taking into account both digital and face-to-face, in-person participation. As reported by Hendryx et al [65], involvement in a wide range of activities, whether they are more or less social in nature, physically active, or occur inside or outside of home, was related to better recovery. Hence, using digital technologies for greater involvement in physical or digital activities, whether the activities are intended for spending time alone or for contacting others socially, can empower people to manage their recovery [66]. Our findings provide further support to this argument by showing that using technology for illness management predicted recovery.

Furthermore, emotional experience of technology use were found to mediate the relationship between technology use and recovery, while positive emotions completely mediated this relationship. Studies on human-computer interactions emphasize the important role of emotions in technology adoption [67,68]. Emotions, as a central component of attitude toward a referent, are a mental state of readiness for action, which promote behavioral activation [67,69]. Positive emotions are responsible for the user eventually trusting the technology and using it [70].

Limitations

The study has several limitations. First, because the survey was conducted on the internet, sampling may be biased by recruiting adults who are likely to be more technologically savvy. However, we recruited adults with SMI not only through web-based groups but also in face-to-face meetings with individuals with SMI who were interested in participating, and they completed a paper-and-pencil version of the survey. This strategy enabled us to recruit a more heterogeneous sample in terms of access to technology. Second, the majority of survey respondents were young adults with only few over the age of 65 years, which could also explain the relatively high use of technology. Therefore, the results for older adults with SMI must be interpreted with caution, and future studies should target a subgroup of older adults with SMI.

Lastly, although we acknowledge that poverty plays a crucial role in access to technology [71,72], participants in our sample enjoy the social welfare benefits provided by the In Israel Ministry of Health and the Israel National Insurance Institute. This mental health support system provides financial and rehabilitation support, including housing, education, employment, and mental health care. Therefore, although often individuals with SMI experience poverty and lack of access, respondents with SMI in our sample enjoyed social welfare benefits (Table 1), which may explain their greater access to technology. Future studies should focus on evaluating the impact of poverty on digital participation and access to technology.

Conclusions

This study demonstrated the potential of digital community inclusion to recovery and well-being among individuals with SMI. Our findings indicate higher rates of access and use of mHealth and digital technologies among individuals with SMI than among the general population. Furthermore, our findings show that digital participation could promote recovery among adults with SMI. Accordingly, this study emphasizes the need to update and expand the definition and conceptualization of community participation, and include aspects of digital participation needs of individuals with SMI.

Our findings suggest that policy makers, service users, and researchers should use existing digital technologies and design novel mHealth interventions to support the recovery process of adults with SMI. In particular, the current COVID-19 crisis poses an opportunity for mental health care systems to adopt digital technologies for service provision. In this sense, this study, conducted before the current COVID-19 pandemic, contributes to the understating that digital participation of adults with SMI is valuable to their recovery not only in crisis but also in routine. Furthermore, it is important to support the participation of individuals with SMI in the virtual environment in a manner that facilitates a positive emotional experience. Positive emotional experience while using digital technologies is a key factor in their engagement in the web-based environment and consequently in their recovery.

Conflicts of Interest

None declared.

References

1. Naslund JA, Marsch LA, McHugo GJ, Bartels SJ. Emerging mHealth and eHealth interventions for serious mental illness: a review of the literature. J Ment Health 2015;24(5):321-332 [FREE Full text] [doi: 10.3109/09638237.2015.1019054] [Medline: 26017625]
2. Free C, Phillips G, Galli L, Watson L, Felix L, Edwards P, et al. The effectiveness of mobile-health technology-based health behaviour change or disease management interventions for health care consumers: a systematic review. PLoS Med 2013;10(1):e1001362 [FREE Full text] [doi: 10.1371/journal.pmed.1001362] [Medline: 23349621]
3. Aslani N, Lazem M, Mahdavi S, Garavand A. A Review of Mobile Health Applications in Epidemic and Pandemic Outbreaks: Lessons Learned for COVID-19. Arch Clin Infect Dis 2020 Jun 02;15(4):e103649. [doi: 10.5812/archcid.103649]
4. Torous J, Keshavan M. COVID-19, mobile health and serious mental illness. Schizophr Res 2020 Apr;218:36-37 [FREE Full text] [doi: 10.1016/j.schres.2020.04.013] [Medline: 32327314]
5. World Health Organization. MHealth: New Horizons for Health Through Mobile Technologies. Geneva: World Health Organization; 2011.
6. Tal A, Torous J. The digital mental health revolution: Opportunities and risks. Psychiatr Rehabil J 2017 Sep;40(3):263-265. [doi: 10.1037/prj0000285] [Medline: 28891658]
7. Boydell K, Hodgins M, Pignatiello A, Teshima J, Edwards H, Willis D. Using technology to deliver mental health services to children and youth: a scoping review. J Can Acad Child Adolesc Psychiatry 2014 May;23(2):87-99 [FREE Full text] [Medline: 24872824]
8. Firth J, Cotter J, Torous J, Bucci S, Firth JA, Yung AR. Mobile Phone Ownership and Endorsement of "mHealth" Among People With Psychosis: A Meta-analysis of Cross-sectional Studies. Schizophr Bull 2016 Mar;42(2):448-455 [FREE Full text] [doi: 10.1093/schbul/sbv132] [Medline: 26400871]
9. Price M, Yuen EK, Goetter EM, Herbert JD, Forman EM, Acierno R, et al. mHealth: a mechanism to deliver more accessible, more effective mental health care. Clin Psychol Psychother 2014;21(5):427-436 [FREE Full text] [doi: 10.1002/cpp.1855] [Medline: 23918764]
10. Boeh H. The effects of specific mental illness stigma beliefs on treatment seeking attitudes. Diss Abstr Int Sect B Sci Eng 2016;76(11-B(E)):555 [FREE Full text]
11. Brown A, Rice SM, Rickwood DJ, Parker AG. Systematic review of barriers and facilitators to accessing and engaging with mental health care among at-risk young people. Asia Pac Psychiatry 2016 Mar;8(1):3-22. [doi: 10.1111/appy.12199] [Medline: 26238088]
12. Patel V, Belkin GS, Chockalingam A, Cooper J, Saxena S, Unützer J. Grand challenges: integrating mental health services into priority health care platforms. PLoS Med 2013;10(5):e1001448 [FREE Full text] [doi: 10.1371/journal.pmed.1001448] [Medline: 23737736]
13. Corrigan PW, Druss BG, Perlick DA. The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care. Psychol Sci Public Interest 2014 Oct;15(2):37-70. [doi: 10.1177/1529100614531398] [Medline: 26171956]
14. Gay K, Torous J, Joseph A, Pandya A, Duckworth K. Digital Technology Use Among Individuals with Schizophrenia: Results of an Online Survey. JMIR Ment Health 2016 May 04;3(2):e15 [FREE Full text] [doi: 10.2196/mental.5379] [Medline: 27146094]
15. Killikelly C, He Z, Reeder C, Wykes T. Improving Adherence to Web-Based and Mobile Technologies for People With Psychosis: Systematic Review of New Potential Predictors of Adherence. JMIR Mhealth Uhealth 2017 Jul 20;5(7):e94 [FREE Full text] [doi: 10.2196/mhealth.7088] [Medline: 28729235]
16. Biagianti B, Fisher M, Howard L, Rowlands A, Vinogradov S, Woolley J. Feasibility and preliminary efficacy of remotely delivering cognitive training to people with schizophrenia using tablets. Schizophr Res Cogn 2017 Dec;10:7-14 [FREE Full text] [doi: 10.1016/j.scog.2017.07.003] [Medline: 28824850]

17. Fortuna KL, DiMilia PR, Lohman MC, Bruce ML, Zubritsky CD, Halaby MR, et al. Feasibility, Acceptability, and Preliminary Effectiveness of a Peer-Delivered and Technology Supported Self-Management Intervention for Older Adults with Serious Mental Illness. Psychiatr Q 2018 Jun;89(2):293-305 [FREE Full text] [doi: 10.1007/s11126-017-9534-7] [Medline: 28948424]
18. Fortuna K, Barr P, Goldstein C, Walker R, Brewer L, Zagaria A, et al. Application of Community-Engaged Research to Inform the Development and Implementation of a Peer-Delivered Mobile Health Intervention for Adults With Serious Mental Illness. J Particip Med 2019;11(1):e12380 [FREE Full text] [doi: 10.2196/12380] [Medline: 32095314]
19. Aschbrenner KA, Naslund JA, Shevenell M, Kinney E, Bartels SJ. A Pilot Study of a Peer-Group Lifestyle Intervention Enhanced With mHealth Technology and Social Media for Adults With Serious Mental Illness. J Nerv Ment Dis 2016 Jun;204(6):483-486 [FREE Full text] [doi: 10.1097/NMD.0000000000000530] [Medline: 27233056]
20. Ben-Zeev D, Buck B, Hallgren K, Drake RE. Effect of Mobile Health on In-person Service Use Among People With Serious Mental Illness. Psychiatr Serv 2019 Jun 01;70(6):507-510. [doi: 10.1176/appi.ps.201800542] [Medline: 30947636]
21. Jonathan G, Carpenter-Song EA, Brian RM, Ben-Zeev D. Life with FOCUS: A qualitative evaluation of the impact of a smartphone intervention on people with serious mental illness. Psychiatr Rehabil J 2019 Jun;42(2):182-189. [doi: 10.1037/prj0000337] [Medline: 30589278]
22. Brusilovskiy E, Townley G, Snethen G, Salzer M. Social media use, community participation and psychological well-being among individuals with serious mental illnesses. Computers in Human Behavior 2016 Dec;65:232-240 [FREE Full text] [doi: 10.1016/j.chb.2016.08.036]
23. Chang F, Coster WJ. Conceptualizing the construct of participation in adults with disabilities. Arch Phys Med Rehabil 2014 Sep;95(9):1791-1798. [doi: 10.1016/j.apmr.2014.05.008] [Medline: 24879964]
24. Chang F, Coster WJ, Helfrich CA. Community participation measures for people with disabilities: a systematic review of content from an international classification of functioning, disability and health perspective. Arch Phys Med Rehabil 2013 Apr;94(4):771-781. [doi: 10.1016/j.apmr.2012.10.031] [Medline: 23149310]
25. International Classification of Functioning, Disability and Health (ICF). APA PsycTests 2001. [doi: 10.1037/t76403-000]
26. Burns-Lynch B, Brusilovskiy E, Salzer MS. An Empirical Study of the Relationship Between Community Participation, Recovery, and Quality of Life of Individuals with Serious Mental Illnesses. Isr J Psychiatry Relat Sci 2016;53(1):46-54 [FREE Full text] [Medline: 28856880]
27. Mancini MA, Hardiman ER, Lawson HA. Making sense of it all: consumer providers' theories about factors facilitating and impeding recovery from psychiatric disabilities. Psychiatr Rehabil J 2005;29(1):48-55. [doi: 10.2975/29.2005.48.55] [Medline: 16075697]
28. Litwiller F, White C, Gallant KA, Gilbert R, Hutchinson S, Hamilton-Hinch B, et al. The Benefits of Recreation for the Recovery and Social Inclusion of Individuals with Mental Illness: An Integrative Review. Leis Sci 2016 May 04;39(1):1-19. [doi: 10.1080/01490400.2015.1120168]
29. Mezzina R, Davidson L, Borg M, Marin I, Topor A, Sells D. The Social Nature of Recovery: Discussion and Implications for Practice. Am J Psychiatr Rehabil 2006 Jul;9(1):63-80. [doi: 10.1080/15487760500339436]
30. Leonhardt B, Huling K, Hamm J, Roe D, Hasson-Ohayon I, McLeod H, et al. Recovery and serious mental illness: a review of current clinical and research paradigms and future directions. Expert Rev Neurother 2017 Nov;17(11):1117-1130. [doi: 10.1080/14737175.2017.1378099] [Medline: 28885065]
31. Florence AC, Miller R, Bellamy C, Bernard P, Bien C, Atterbury K, et al. When reality breaks from us: lived experience wisdom in the Covid-19 era. Psychosis 2020 Sep 10;12(4):363-367. [doi: 10.1080/17522439.2020.1817138]
32. Piguillem F, Shi L. The Optimal COVID-19 Quarantine and Testing Policies. IDEAS. 2020. URL: https://ideas.repec.org/p/eie/wpaper/2004.html [accessed 2021-08-24]
33. Mann DM, Chen J, Chunara R, Testa PA, Nov O. COVID-19 transforms health care through telemedicine: Evidence from the field. J Am Med Inform Assoc 2020 Jul 01;27(7):1132-1135 [FREE Full text] [doi: 10.1093/jamia/ocaa072] [Medline: 32324855]
34. Taylor CB, Fitzsimmons-Craft EE, Graham AK. Digital technology can revolutionize mental health services delivery: The COVID-19 crisis as a catalyst for change. Int J Eat Disord 2020 Jul;53(7):1155-1157 [FREE Full text] [doi: 10.1002/eat.23300] [Medline: 32449523]
35. Waller G, Pugh M, Mulkens S, Moore E, Mountford VA, Carter J, et al. Cognitive-behavioral therapy in the time of coronavirus: Clinician tips for working with eating disorders via telehealth when face-to-face meetings are not possible. Int J Eat Disord 2020 Jul;53(7):1132-1141 [FREE Full text] [doi: 10.1002/eat.23289] [Medline: 32383530]
36. Portnoy J, Waller M, Elliott T. Telemedicine in the Era of COVID-19. J Allergy Clin Immunol Pract 2020 May;8(5):1489-1491 [FREE Full text] [doi: 10.1016/j.jaip.2020.03.008] [Medline: 32220575]
37. Nagata S, Townley G, Brusilovskiy E, Salzer MS. Community Participation Differences Between Adults With or Without Serious Mental Illness. Psychiatr Serv 2020 Nov 01;71(11):1191-1194. [doi: 10.1176/appi.ps.201900608] [Medline: 32966173]
38. Corrigan PW, Giffort D, Rashid F, Leary M, Okeke I. Recovery as a psychological construct. Community Ment Health J 1999 Jun;35(3):231-239. [doi: 10.1023/a:1018741302682] [Medline: 10401893]

39. Salzer MS, Brusilovskiy E. Advancing recovery science: reliability and validity properties of the Recovery Assessment Scale. Psychiatr Serv 2014 Apr 01;65(4):442-453. [doi: 10.1176/appi.ps.201300089] [Medline: 24487405]
40. Roe D, Mashiach-Eizenberg M, Corrigan P. Confirmatory factor analysis of the brief version of the recovery assessment scale. J Nerv Ment Dis 2012 Oct;200(10):847-851. [doi: 10.1097/NMD.0b013e31826b6d4a] [Medline: 22986276]
41. Chang F, Coster WJ, Salzer MS, Brusilovskiy E, Ni P, Jette AM. A multidimensional measure of participation for adults with serious mental illnesses. Disabil Rehabil 2016;38(7):695-703. [doi: 10.3109/09638288.2015.1056843] [Medline: 26079634]
42. Behind the Term: Serious Mental Illness. Center for Homeland Defense and Security. 2016. URL: https://www.hsdl.org/?abstract&did=801613 [accessed 2021-08-24]
43. Aviram U, Ginath Y, Roe D. Mental health reforms in Europe: Israel's rehabilitation in the community of persons with mental disabilities law: challenges and opportunities. Psychiatr Serv 2012 Feb 01;63(2):110-112. [doi: 10.1176/appi.ps.201100009] [Medline: 22302325]
44. Martínez-Martínez C, Richart-Martínez M, Ramos-Pichardo JD. Operational Definition of Serious Mental Illness: Heterogeneity in a Review of the Research on Quality-of-Life Interventions. J Am Psychiatr Nurses Assoc 2020;26(3):229-244. [doi: 10.1177/1078390320902823] [Medline: 31999207]
45. Drake R, Nordentoft M, Haddock G, Arango C, Fleischhacker WW, Glenthøj B, et al. Modeling determinants of medication attitudes and poor adherence in early nonaffective psychosis: implications for intervention. Schizophr Bull 2015 May;41(3):584-596 [FREE Full text] [doi: 10.1093/schbul/sbv015] [Medline: 25750247]
46. Schizophrenia. World Health Organization. 2019. URL: https://www.who.int/news-room/fact-sheets/detail/schizophrenia [accessed 2021-08-24]
47. Ben-Zeev D, Davis KE, Kaiser S, Krzsos I, Drake RE. Mobile technologies among people with serious mental illness: opportunities for future services. Adm Policy Ment Health 2013 Jul;40(4):340-343 [FREE Full text] [doi: 10.1007/s10488-012-0424-x] [Medline: 22648635]
48. Abu Rahal Z, Vadas L, Manor I, Bloch B, Avital A. Use of information and communication technologies among individuals with and without serious mental illness. Psychiatry Res 2018 Aug;266:160-167. [doi: 10.1016/j.psychres.2018.05.026] [Medline: 29864616]
49. Trefflich F, Kalckreuth S, Mergl R, Rummel-Kluge C. Psychiatric patients' internet use corresponds to the internet use of the general public. Psychiatry Res 2015 Mar 30;226(1):136-141. [doi: 10.1016/j.psychres.2014.12.037] [Medline: 25623020]
50. Bauer R, Conell J, Glenn T, Alda M, Ardau R, Baune BT, et al. Internet use by patients with bipolar disorder: Results from an international multisite survey. Psychiatry Res 2016 Aug 30;242:388-394. [doi: 10.1016/j.psychres.2016.05.055] [Medline: 27391371]
51. Radovic A, Vona PL, Santostefano AM, Ciaravino S, Miller E, Stein BD. Smartphone Applications for Mental Health. Cyberpsychol Behav Soc Netw 2016 Jul;19(7):465-470 [FREE Full text] [doi: 10.1089/cyber.2015.0619] [Medline: 27428034]
52. Hind J, Sibbald S. Smartphone Applications for Mental Health—A Rapid Review. WURJ:HNS 2014 Nov 03;5(1):1-9. [doi: 10.5206/wurjhns.2014-15.16]
53. Highton-Williamson E, Priebe S, Giacco D. Online social networking in people with psychosis: A systematic review. Int J Soc Psychiatry 2015 Feb;61(1):92-101. [doi: 10.1177/0020764014556392] [Medline: 25381145]
54. Naslund JA, Grande SW, Aschbrenner KA, Elwyn G. Naturally occurring peer support through social media: the experiences of individuals with severe mental illness using YouTube. PLoS One 2014;9(10):e110171 [FREE Full text] [doi: 10.1371/journal.pone.0110171] [Medline: 25333470]
55. Corrigan PW, Morris SB, Michaels PJ, Rafacz JD, Rüsch N. Challenging the public stigma of mental illness: a meta-analysis of outcome studies. Psychiatr Serv 2012 Oct;63(10):963-973. [doi: 10.1176/appi.ps.201100529] [Medline: 23032675]
56. Zisman-Ilani Y, Lysaker PH, Hasson-Ohayon I. Shared Risk Taking: Shared Decision Making in Serious Mental Illness. Psychiatr Serv 2021 Apr 01;72(4):461-463. [doi: 10.1176/appi.ps.202000156] [Medline: 33557595]
57. Zisman-Ilani Y, Roth RM, Mistler LA. Time to Support Extensive Implementation of Shared Decision Making in Psychiatry. JAMA Psychiatry 2021 Aug 18. [doi: 10.1001/jamapsychiatry.2021.2247] [Medline: 34406346]
58. Bargh JA, McKenna KYA. The internet and social life. Annu Rev Psychol 2004;55:573-590. [doi: 10.1146/annurev.psych.55.090902.141922] [Medline: 14744227]
59. Gil H, Jung N. Social Media Use for News and Individuals' Social Capital, Civic Engagement and Political Participation. J Comput-Mediat Comm 2012;17(3):336. [doi: 10.1111/j.1083-6101.2012.01574.x]
60. Onken SJ, Craig CM, Ridgway P, Ralph RO, Cook JA. An analysis of the definitions and elements of recovery: a review of the literature. Psychiatr Rehabil J 2007;31(1):9-22. [doi: 10.2975/31.1.2007.9.22] [Medline: 17694711]
61. Corrigan PW, Phelan SM. Social support and recovery in people with serious mental illnesses. Community Ment Health J 2004 Dec;40(6):513-523. [doi: 10.1007/s10597-004-6125-5] [Medline: 15672690]
62. Utz S, Breuer J. The Relationship Between Use of Social Network Sites, Online Social Support, and Well-Being: Results From a Six-Wave Longitudinal Study. J Media Psychol 2017;29(3):115-125 [FREE Full text] [doi: 10.1027/1864-1105/a000222] [Medline: 29147141]

63. Snethen G, Zook P. Utilizing social media to support community integration. Am J Psychiatr Rehabil 2016 Jun 10;19(2):160-174. [doi: 10.1080/15487768.2016.1171176]
64. Veretilo P, Billick SB. Psychiatric illness and facebook: a case report. Psychiatr Q 2012 Sep;83(3):385-389. [doi: 10.1007/s11126-012-9207-5] [Medline: 22274630]
65. Hendryx M, Green CA, Perrin NA. Social support, activities, and recovery from serious mental illness: STARS study findings. J Behav Health Serv Res 2009 Jul;36(3):320-329 [FREE Full text] [doi: 10.1007/s11414-008-9151-1] [Medline: 19011972]
66. Noel VA, Acquilano SC, Carpenter-Song E, Drake RE. Use of Mobile and Computer Devices to Support Recovery in People With Serious Mental Illness: Survey Study. JMIR Ment Health 2019 Feb 20;6(2):e12255 [FREE Full text] [doi: 10.2196/12255] [Medline: 30785401]
67. Wan NW, Nazlan M. The impact of Persuasive Technology on User Emotional Experience and User Experience Over Time. J Chem Inf Model 2019;53(9):1689-1699. [doi: 10.32890/jict2018.17.4.8273]
68. Partala T, Kallinen A. Understanding the most satisfying and unsatisfying user experiences: Emotions, psychological needs, and context. Interact Comput 2012 Jan;24(1):25-34. [doi: 10.1016/j.intcom.2011.10.001]
69. Bohner G, Dickel N. Attitudes and attitude change. Annu Rev Psychol 2011;62:391-417. [doi: 10.1146/annurev.psych.121208.131609] [Medline: 20809791]
70. Hassenzahl M, Tractinsky N. User experience - a research agenda. Behav Inf Technol 2006 Mar;25(2):91-97. [doi: 10.1080/01449290500330331]
71. Zisman-Ilani Y, Gorbenko KO, Shern D, Elwyn G. Comparing Digital vs Paper Decision Aids about the Use of Antipsychotic Medication: Client, Clinician, Caregiver and Administrator Perspectives. IJPCM 2017 Jul 13;7(1):21-30. [doi: 10.5750/ijpcm.v7i1.618]
72. Greer B, Robotham D, Simblett S, Curtis H, Griffiths H, Wykes T. Digital Exclusion Among Mental Health Service Users: Qualitative Investigation. J Med Internet Res 2019 Jan 09;21(1):e11696 [FREE Full text] [doi: 10.2196/11696] [Medline: 30626564]

Abbreviations

mHealth: mobile health
NAMI: National Alliance on Mental Illness
SMI: serious mental illness

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Review

Effectiveness of Using Mobile Technology to Improve Cognitive and Social Skills Among Individuals With Autism Spectrum Disorder: Systematic Literature Review

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Abstract

Background: Mobile technology has become a necessity in the lives of people in many countries. Its characteristics and advantages also make it a potential medium of intervention for people with autism spectrum disorder (ASD).

Objective: The objective of this review was to evaluate previous evidence, obtained in randomized controlled trials (RCTs), on the effectiveness of using mobile devices as the medium of intervention targeting social and cognitive skills among individuals with ASD.

Methods: Literature search was conducted on electronic databases including Medline, PsycInfo, PsycArticles, Education Resources Information Centre, and Social Science Citation Index. Only RCTs published in English and after year 2000 were included for this review. Data extraction was carried out by 2 independent reviewers using constant comparative methods.

Results: Totally 10 RCTs were identified. Most of the findings indicated that mobile devices could be an effective medium of intervention for people with ASD, among which 6 indicated significant intervention effects and 2 showed mixed findings. Effective intervention was more likely to be achieved in the studies that recruited older participants (aged over 9 years), targeting practical skills that could be readily applied in real life, or using pictures or materials that were highly relevant in daily life in the apps or mobile devices. Furthermore, the use of mobile devices was also reported to promote participation in the intervention among individuals with ASD.

Conclusions: The results suggested that mobile devices could be a promising means for the delivery of interventions targeting people with ASD. Although including a small number of studies was a limitation of this review, the results provided useful implications for designing effective mobile technology–assisted interventions for the ASD population in future studies.

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KEYWORDS

autism spectrum disorder; mobile devices; systematic review; randomized controlled trial; social skills; cognitive skills

Introduction

Individuals with autism spectrum disorder (ASD) face difficulties in the social and cognitive domains of their lives. According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders [1], the 2 core symptoms of ASD include limitations in social interaction and communication, together with stereotypic interests and behaviors. These limitations create significant problems when functioning in social situations including friendship building and daily interaction with others, in vocational or school settings that require effective problem-solving skills and persistence, and in daily life situations where flexibility and the ability to accept changes are necessary. Furthermore, difficulties in mood regulation create extra difficulties for carers and professionals to provide effective training and treatments, which could further perpetuate the aforementioned problems.

In recent years, the rapidly increasing popularity of mobile technology has provided a new possibility for providing interventions. Mobile technology refers to any handheld digital devices including different brands of mobile phones or smartphones, such as iPod touch, personal digital assistants (PDAs), or tablet computers. The World Health Organization statistics suggest that the number of mobile phone subscriptions reached 6.9 billion in 2014 [2], which is believed to continue increasing. High accessibility, together with the versatility owing to the wide variety of apps available on the market [3], makes mobile technology an effective medium of intervention. Mobile devices also offer additional advantages such as greater flexibility, lower costs, and overcoming geographical limitations when compared with traditional face-to-face treatment. Several characteristics of mobile technology such as the highly attractive screen and stimulating visual display, high portability [4], entertaining music and game functions [5], ease of use even for people with disabilities [4,6], and potential usage in augmentative and alternative communication, regarded as “a general term for communication support encompassing low-tech and high-tech systems,” [5] appear to be particularly suitable for use among people with ASD.

There are 3 main approaches in using mobile technology as the medium of intervention for individuals with ASD in previous research. First, tailored apps serve as the main tools of intervention. For example, King and her colleagues developed the Proloquo2Go app to train individuals in requesting skills [3]. Another app called iTake Turns was designed to train for turn-taking behaviors [7], whereas the MyTalk mobile software installed in iPod Touch was used to train for functional communication [5]. All these studies showed positive training results. Second, mobile devices are used as speech-generating devices (SGDs) [8-10]. In short, the SGDs facilitate communication by transferring what the users have selected (ie, touching objects on the screen) to an audible output from the devices. Previous research has successfully employed SGDs to improve various communication skills among people with ASD, such as requesting continuation of toy play [8], 3-step communication sequences (ie, general request for toys, specific request for a selected toy, followed by a thank you response) [9], and training for mand repertoire [10]. Finally, some interventions use video modeling or video prompting strategies to deliver training through mobile devices, which have been shown to successfully train for transitional behaviors in schools [11], vocational and daily living skills [12], multiple-step job performance [13], and handwashing skills [14].

According to the weak central coherence hypothesis [15], people with ASD tend to focus on details but fail to capture the meaning of a global picture during information processing. They are unable to see the link between situations or environments, so this tendency makes it difficult for them to generalize their newly learned skills across different settings. Despite these difficulties, previous systematic reviews have shown that mobile technology–based interventions targeting people with ASD could produce significant improvements in the acquisition of mand or functional communication repertoire [16] and academic skills [17]. Hong and colleagues reported similar positive results in their systematic review of single case studies on the effectiveness of tablet-mediated interventions for people with ASD [18]. Recently, Moon and his colleagues conducted a systematic review with meta-analysis to evaluate the effectiveness of mobile device intervention in randomized controlled trials (RCTs) [19]. The meta-analysis showed positive results, suggesting that mobile interventions could significantly improve performance in the fine motor and visual areas. Collectively, the findings showed that mobile technology could be an effective and attractive means of intervention for people with ASD.

Although previous systematic reviews on various interventional case studies reported promising results, one limitation was that most of these reviewed studies employed single case designs or a multiple probe design or were based on a small sample (fewer than 10 subjects). RCTs in this area have increased in recent years. Even though the review conducted by Moon and his colleagues [19] provided positive evidence concerning the effectiveness of mobile intervention in people with ASD, a more detailed investigation where the characteristics of these trials are particularly useful would be crucial, as the findings could provide useful practical implications for designing future RCTs in this area. As a result, this systematic review focuses on currently available RCT studies with the following specific research question: What are the crucial characteristics that contribute to effective mobile intervention to promote social and cognitive skills among people with ASD?

Methods

Sources of Data

Literature search was conducted on electronic databases of multiple disciplines, including Medline, PsycInfo, PsycArticles, Education Resources Information Centre, and Social Science Citation Index. This selection covered the widely used databases in the education, psychology, medicine, and social science fields. Additional internet searches were carried out to identify relevant articles that could answer the above research question. The search terms used during these searches were “Autis* or Asperger* or pervasive development* disorder* (Title)” and “mobile* or apps* or tablet* or iPad* or iPod* or handheld*(Title);” the 2 first authors conducted initial screening of the titles and abstracts of the identified studies.

Eligibility and Exclusion Criteria

Inclusion criteria for this systematic review were interventional studies targeting people with ASD using touch-screen mobile devices published in English. To include studies with higher levels of evidence (Level 1b as described by the Centre for Evidence-Based Medicine [20]), this review only focused on studies with RCT designs and excluded those with case studies or other noninterventional studies such as cross-sectional surveys, cohorts, reviews, or discussion papers. Given that the popularity of mobile phones and tablets has only been increasing in recent years, only articles published from January 1, 2000, to March 31, 2019, were selected [17,21].

Procedures

The preparation of this systematic review was in accordance with the PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analysis) guidelines [22]. The first authors (LPWS and WWCW) conducted the literature search using the keywords listed above. After removing all the duplicated articles, initial screening of the titles and abstracts was carried out to ensure the identified studies met the inclusion and exclusion criteria. Finally, 2 independent researchers (LPWS and BLLC) conducted a more thorough examination of the full texts of the eligible studies to investigate the final eligibility.

Risk of Bias Assessment

The Cochrane risk of bias tool [23] is the most frequently used tool to evaluate the quality of RCTs [24] and has the advantage of measuring possible biases in the selected studies including selection, performance, detection, attribution, reporting, and other types of biases. RevMan 5 (Cochrane Training) [25] was used to summarize and generate statistics of the assessment results.

Data Extraction and Analysis

From the selected studies, the following categories of data were extracted: basic information of the articles (author, title, year of publication, journal, and country); participants’ details (eg, age, gender, and intelligence level); treatment content and treatment format employed (eg, mobile phone, apps, and tablets); characteristics of intervention delivery (eg, frequency, duration, and group size); description of intervention in the control group; outcome measures; and effectiveness of the treatment (defined by any significant improvements in primary outcomes). Two independent reviewers carried out the extraction of data and reached consensus after discussion on the discrepancies. Using constant comparative methods, a third independent reviewer’s opinion would be sought for any disagreement between the 2 reviewers.

In this review, the selected studies had a variety of treatment goals and employed different assessment methods, such as using game scores in apps, observing actual performances, or calculating scores using validated scales. Therefore, meta-analysis might not a feasible way of data analysis as the small number may be prone to providing misleading conclusions. Instead, the findings of the current study were based on the analysis of the descriptive summaries of the selected studies.

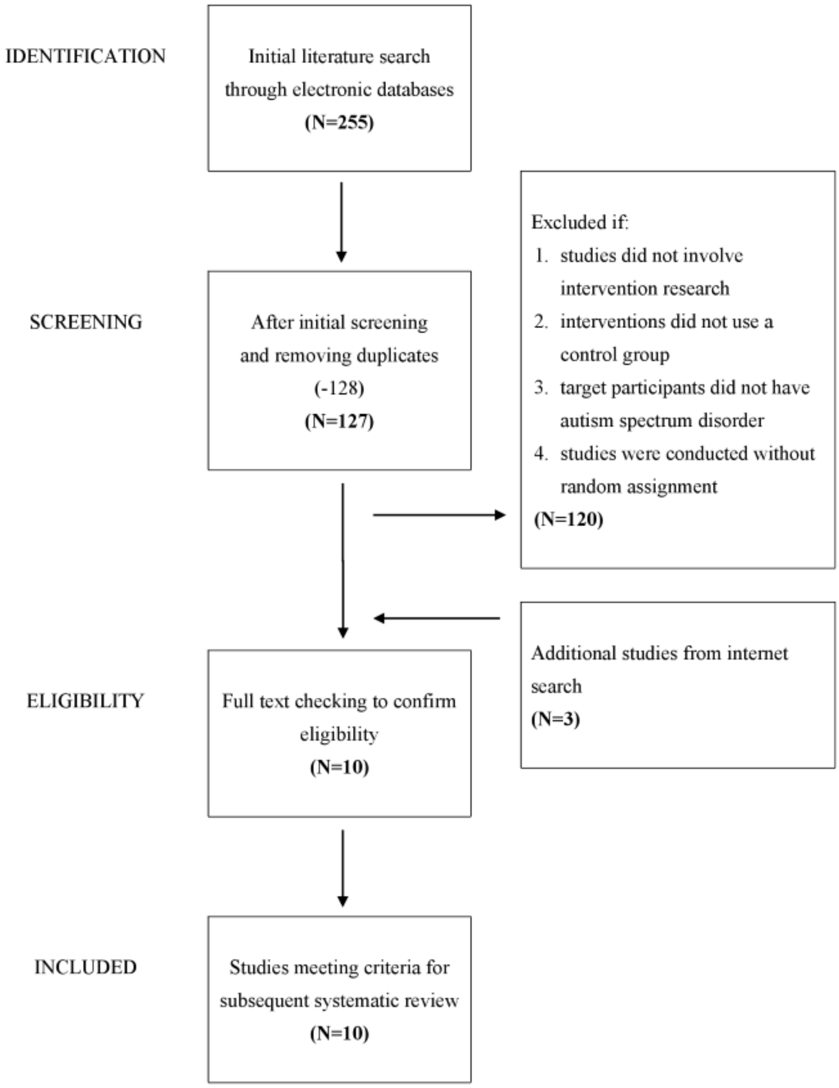
Specifically, interventions would be classified as either “effective,” “partially effective,” or “ineffective” based on the outcome evaluations. Similar to the data extraction procedures, 2 reviewers conducted the classification independently, together with a third reviewer when there was any disagreement. More specifically, effective interventions meant that the main targeted outcomes were found to improve significantly after the intervention; “partially effective” denoted interventions in which some (but fewer than half) indicators of the primary outcome showed significant improvement, whereas “ineffective” interventions meant the data of the targeted outcomes could not justify the intervention as effective. Satisfactory reliability of this classification system was achieved, as the level of agreement between reviewers reached 100%.

Results

Article Inclusion and Exclusion

The initial search identified a total of 255 articles, among which 128 articles were excluded owing to duplication, and a further 120 articles were excluded as they did not meet the inclusion criteria (ie, not interventional studies, not recruiting participants with ASD, or intervention studies that did not employ an RCT design). A further Google search identified 3 more articles that met the inclusion criteria. Finally, this systematic review included a total of 10 articles [26-35]. Figure 1 shows the flowchart of this process.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analysis) checklist for systematic review.



Risk of Bias Assessment

Figures 2 and 3 show the risk of bias assessment results. Figure 2 gives an overall description of the biases among the 10 included studies, whereas Figure 3 provides a more detailed explanation of the bias assessment results in individual studies.

Although all the studies adopted random assignment for group allocation, 3 studies failed to give sufficient details on how the randomization was conducted [26-28] and 5 did not describe the procedure of allocation concealment [26,28-31]. In addition, given the different interventions in experimental and control groups, it was impossible to blind the participants and personnel in these studies. Only 4 studies were able to blind the assessors to minimize assessment bias [27,31-33]. Finally, all the included studies had low risk of bias for incomplete data, selective reporting, and other biases.

Figure 2. Overall risk of bias assessment results among the 10 included studies.

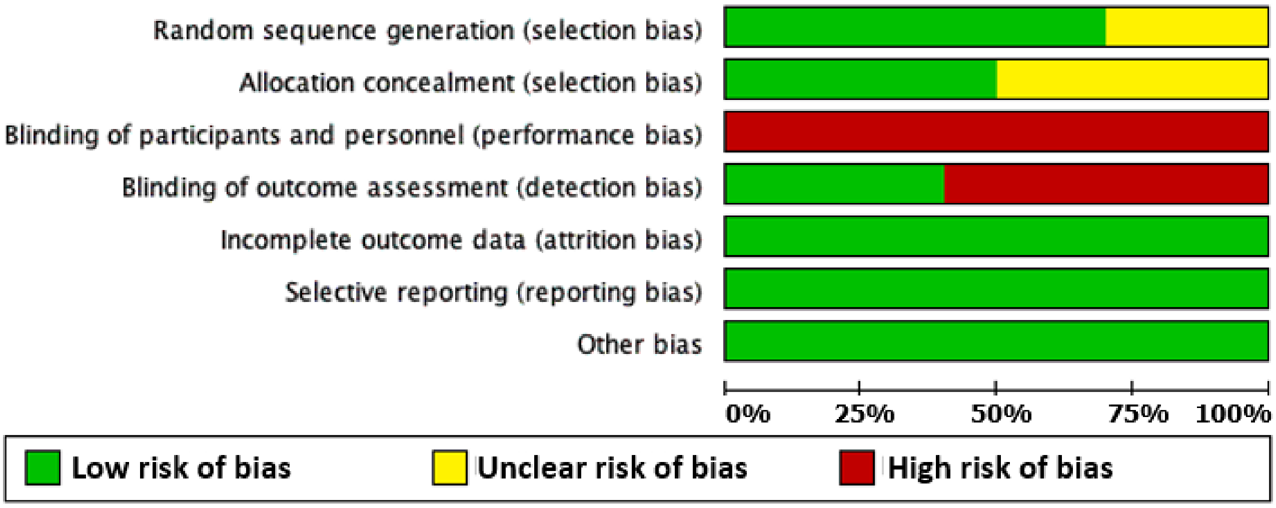
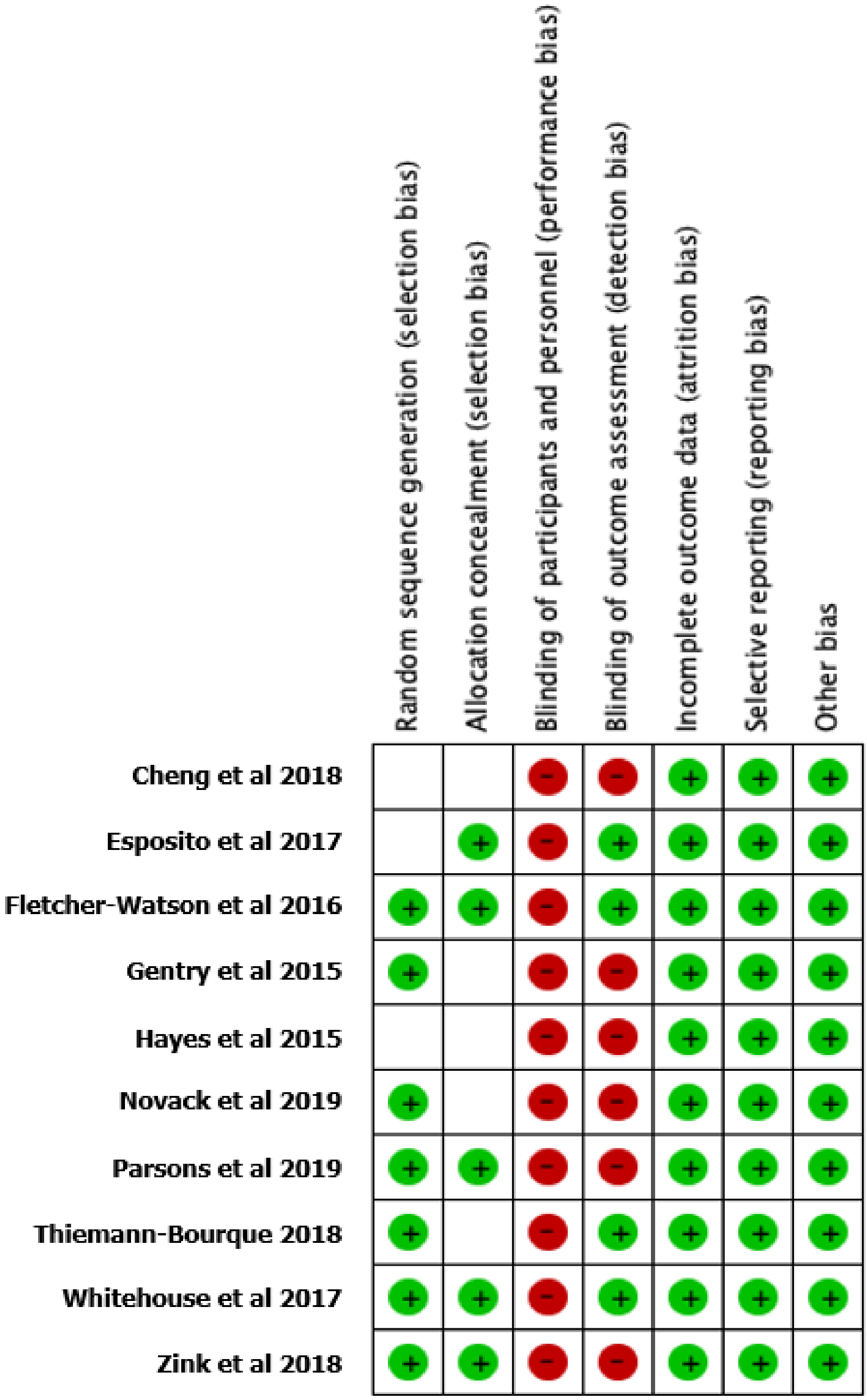


Figure 3. Detailed risk of bias assessment results in individual studies.



	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Cheng et al 2018			−	−	+	+	+
Esposito et al 2017		+	−	+	+	+	+
Fletcher-Watson et al 2016	+	+	−	+	+	+	+
Gentry et al 2015	+		−	−	+	+	+
Hayes et al 2015			−	−	+	+	+
Novack et al 2019	+		−	−	+	+	+
Parsons et al 2019	+	+	−	−	+	+	+
Thiemann-Bourque 2018	+		−	+	+	+	+
Whitehouse et al 2017	+	+	−	+	+	+	+
Zink et al 2018	+	+	−	−	+	+	+

Overview of Included Studies

Table 1 provides a summary of the research designs used in the 10 selected studies.

Social skills were selected as the main treatment outcomes in half of these studies [26,27,31,33,34]. Among these, 2 studies targeted improving the cognitive skills of people with ASD using mobile technology [29,30]. In the remaining 3 studies, the intervention targeted cognitive and social skills among children with ASD [27,32,35].

Table 1. Characteristics of the research design in the studies included in this review (N=10).

Characteristic	n (%)
Age of participants	
Below 6 years (toddlers to young children)	6 (60)
Between 9 and 18 years (children to adolescents)	3 (30)
Above 18 years	1 (10)
Total number of participants with ASD[a]	
30 participants or fewer	4 (40)
31 to 60 participants	5 (50)
61 to 100 participants	1 (10)
Duration of intervention	
1 month or shorter	4 (40)
2 to 3 months	3 (30)
Longer than 3 months	2 (20)
Not specified	1 (10)
Format of intervention	
In-session training	3 (30)
Used in their own time (whenever convenient or necessary)	7 (70)
Experimental group content	
Self-constructed app	8 (80)
PDA[b]-based app	1 (10)
Speech-generating device	1 (10)
Control group content	
Treatment as usual (including delayed treatment)	6 (60)
Picture exchange communication system	1 (10)
Behavioral therapy	1 (10)
Paper-based emotion card training	1 (10)
Use of untrained peers	1 (10)
Outcome variables	
Social skills	5 (50)
Cognitive skills	2 (20)
Cognitive and social skills	3 (30)

[a] ASD: autism spectrum disorder

[b] PDA: personal digital assistant

Most of the interventions targeted young children or adolescents, 6 of which recruited children under the age of 6 years [27,30-33,35]; 3 of them targeted those aged 9 to 18 years [26,28,34], and only 1 study recruited adults with ASD [29]. Findings suggested that interventions targeting those aged 9 years or above were all found effective (all the 4 studies considered), but the effectiveness was less robust among younger children, as shown in Table 2 (2 effective, 2 partially effective, and 2 ineffective).

Table 2. Effectiveness across different characteristics selected in the trials (N=10).

Characteristic	Effectiveness[a]		
	Effective, n (%)	Partially effective[b], n (%)	Ineffective, n (%)
Age of participants			
Below 6 years (n=6)	2 (33)	2 (33)	2 (33)
Between 9 to 18 years (n=3)	3 (100)	0 (0)	0 (0)
Above 18 years (n=1)	1 (100)	0 (0)	0 (0)
Duration of intervention			
1 month or shorter (n=4)	3 (75)	0 (0)	1 (25)
2 to 3 months (n=3)	2 (67)	0 (0)	1 (33)
Longer than 3 months (n=2)	1 (50)	1 (50)	0 (0)
Format of intervention			
In-session training (n=3)	3 (100)	0 (0)	0 (0)
Used in their own time (n=7)	3 (43)	2 (29)	2 (29)
Control group content			
Treatment as usual (including delayed treatment) (n=6)	3 (50)	2 (33)	1 (17)
Picture exchange communication system (n=1)	1 (100)	0 (0)	0 (0)
Behavioral therapy (n=1)	0 (0)	0 (0)	1 (100)
Paper-based emotion card training (n=1)	1 (100)	0 (0)	0 (0)
Use of untrained peers (n=1)	1 (100)	0 (0)	0 (0)
Outcome variables			
Social skills (n=5)	4 (80)	0 (0)	1 (20)
Cognitive skills (n=2)	2 (100)	0 (0)	0 (0)
Social and cognitive skills (n=3)	0 (0)	2 (67)	1 (33)

[a] Effectiveness is defined by the extent of significant improvements in the selected primary outcomes of the studies.

[b] Partially effective means that fewer than half of the indicators of the main outcomes showed significant improvement.

The sample sizes in these studies were generally small, with 4 studies recruiting 30 or fewer participants [26-28,30], and the sample size in the other 5 studies ranged between 31 and 60 participants [29,31,33-35]. The duration of the interventions ranged from 3 weeks to 6 months, and there were studies with long and short durations that reported insignificant intervention effects.

Given the advantage of high accessibility to mobile technology devices, over half of the studies (7/10) provided the training devices to participants who could use them at any time convenient to them [26-29,32,33,35], whereas in the other 3 studies, only in-session trainings were delivered through mobile devices at a fixed duration and frequency [30,31,34]. Nevertheless, all the studies using in-session training were found to be effective (3 out of 3 studies, Table 2).

In terms of interventional content, the authors of 8 studies developed their own apps as the training content was tailored to their training objectives [26-28,30,32-35]. In the remaining 2 studies [29,31], the authors used the built-in functions of the mobile devices to design their training, namely the speech-generating functions to facilitate communication [31], and the built-in PDA-based apps to provide vocational support [29]. As for the content of the control groups, more than half of them employed treatment as usual or delayed treatment design [28-30,32,33,35].

Elements of Effective Interventions

Table 3 summarizes each of the 10 selected studies.

Table 3. Summary of the 10 selected trials.

Authors	Mean age of participants	Duration	Intervention content	Format	Control	Main outcomes (operational definitions and tools)	Effectiveness
Esposito et al [27]	47 months	4 weeks	App games: a game play app to train for vocabulary, attention, and imitation skills	Self-use	Behavioral therapy	Cognitive and social skills: vocabulary, attention, and imitation skills (1) Target improvement (2) Game scores	Ineffective: (1) Attention: *P*=.06 Imitation of actions with objects: *P*=.84. Receptive identification of objects: *P*=.21 (2) Attention: *P*=.47 Imitation of actions with objects: *P*=.02 Receptive identification of objects: *P*=.32
Thiemann-Bourque et al [31]	Exptl gp[a]: 48 months Ctl gp[b]: 46 months Peers: 40 to 61 months	9 to 19 weeks	SGD[c] with trained peers: promoting communication through SGD and trained peers, guided by trained school staff	In-session training	Untrained peers	Social skills: communication behaviors (1) Rate of communication (2) Balanced initiation and response during interactions	Effective: (1) Rate of communication: *P*<.001 (2) Balanced initiation and response; *P*=.047
Fletcher-Watson et al [33]	Exptl gp: 49.30 months Ctl gp: 49.96 months	2 months	FindMe app: a game play app to train for attending to people (touching the single person on the screen) and following social cues (touch the item being pointed and looked at)	Self-use	TAU[d]	Social skills: social communication skills (1) BOSCC[e] (2) ADOS-2[f] (3) MCDI[g] (4) CSBS-DP[h]	Ineffective: (1) Overall: *P*=.29 Social communication: *P*=.56 (2) Communication: *P*=.93 Reciprocal social interaction: *P*=.40 Social effect: *P*=.52 Restricted repetitive behavior: *P*=.81 (3) Words understood: *P*=.12 Words produced: *P*=.09 Gestures: *P*=.07 (4) Social communication: *P*=.31 Gestures: *P*=.93
Parsons et al [35]	Exptl gp: 64.4 months Ctl gp: 60.8 months	3 months	TOBY[i] app: a game play app to train for visual motor (perception and discrimination of sensory information), imitation (copy an action), language (recognize and reproduce object and action names), and social skills (eye gaze, gestures, etc)	Self-use	Delayed treatment	Cognitive and social skills: visual motor, imitation, language, and social skills 1. MSEL[j] 2. CSBSMSEL[k] 3. ToPMSEL[l] 4. POMMSEL[m] 5. SPTMSEL[n]	Partially effective: (1) Visual reception: *P*=.39 Fine motor: *P*=.15 Receptive language: *P*=.04 Expressive language: *P*=.30 (2) Social domain: *P*<.001 Speech domain: *P*=.07 Symbolic domain: *P*<.001 (3) ToP: *P*=.12 (4) POM: *P*=.02 (5) SPT: *P*=.95
Novack et al [30]	69.29 months	4 weeks	Camp Discovery app: identifying the correct words based on the instructions they heard	In-session training	Delayed treatment	Cognitive skills: receptive language skills (1) Number of new target words learned	Effective (1) Number of words learned: *P*<.001

Authors	Mean age of participants	Duration	Intervention content	Format	Control	Main outcomes (operational definitions and tools)	Effectiveness
Whitehouse et al [32]	3.38 years	6 months	TOBY app: a game play app to train for visual motor (perception and discrimination of sensory information), imitation (copy an action), language (recognize and reproduce object and action names), and social skills (eye gaze, gestures, etc)	Self-use	TAU	Cognitive and social skills: early behavioral intervention (1) ATEC[o] (2) MSEL (3) VABS-II[p]	Partially effective: (1) Total: *P*=.14 Communication: *P*=.08 Sociability: *P*=.50 Sensory: *P*=.20 Physical: *P*=.28 (2) Receptive language: *P*=.32 Expressive language: *P*=.89 Visual reception: *P*=.03 Fine motor: *P*=.07 (3) Total composite: *P*=.08 Communication: *P*=.10 Socialization: *P*=.35 Daily living skills: *P*=.03 Motor skills: *P*=.08
Cheng et al [26]	Exptl gp: 11.3 years Ctl gp: 10.9 years	3 weeks	3DFER[q] app: identifying facial expressions and the associations between situations and emotions	Self-use	Paper-based	Social skills: emotional facial recognition skills (1) Achievement scores in the app game	Effective (1) Posttest between group score difference: *P*<.001
Zink et al [34]	Exptl gp: 12.5 years Ctl gp: 12.0 years	Not described	App with self-constructed pictures: showing dental procedures with images and audio comments	In-session training	PECS[r]	Social skills: patient-dentist communication (1) Number of attempts required for skill acquisition (2) Number of dental appointments required to complete dental cleaning	Effective (1) Number of attempts required for skills acquisition: *P*<.001 (2) Number of dental appointments required: *P*<.001
Hayes et al [28]	All aged 18 years (except one aged 17)	1 month	VidCoach app: use of video modeling and video prompting strategies to learn interview skills	Self-use	TAU	Social skills: job interview skills (1) Scores in interview performance assessed by employers	Effective (1) Scores improved in intervention group: *P*<.001

Authors	Mean age of participants	Duration	Intervention content	Format	Control	Main outcomes (operational definitions and tools)	Effectiveness
Gentry et al [29]	24 years	3 months	PDA[s] in iPod: Training on iPod Touch–based apps and strategies to support their job	Self-use	Delayed treatment	Cognitive skills: job coaching support (1) Cumulative job coaching hours (2) Monthly job coaching hours	Effective (1) Difference in cumulative coaching hours: *P*<.001 (2) Difference in monthly coaching hours: *P*<.001

[a] Exptl gp: experimental group.
[b] Ctl gp: control group.
[c] SGD: speech-generating device
[d] TAU: treatment as usual.
[e] BOSCC: Brief Observation of Social Communication Change.
[f] ADOS-2: Autism Diagnostic Observation Schedule second edition.
[g] MCDI: MacArthur Communicative Development Inventory.
[h] CSBS-DP: Communication and Symbolic Behavior Scale – Developmental Profile.
[i] TOBY: Therapy Outcomes By You.
[j] MSEL: Mullen Scales of Early Learning.
[k] CSBS: Communication and Symbolic Behavior Scale.
[l] ToP: Test of Playfulness.
[m] POM: Pragmatic Observation Measure.
[n] SPT: Symbolic Play Test.
[o] ATEC: Autism Treatment Evaluation Checklist.
[p] VABS-II: Vineland Adaptive Behavior Scale second edition.
[q] 3DFER: 3D complex facial expression recognition.
[r] PECS: picture exchange communication system.
[s] PDA: personal digital assistant.

In the 2 studies that used real-life pictures or 3D animations in the apps [26,34], the intervention was effective. These materials highly resembled what the participants could encounter in daily life. For example, Cheng and colleagues designed a new 3D complex facial expression recognition system to train children for emotional facial recognition with high-functioning ASD (aged approximately 9 to 12 years) [26]. A ViewPad showed 3D animated humanoids, and participants were required to identify certain facial expressions and then associate the corresponding emotions with appropriate situations. Participants in the intervention group demonstrated significant positive training effects when compared to the control group (*P*<.001) after 3 weeks of training.

In another study, Zink and her colleagues designed a mobile intervention to train a group of children aged 9 to 15 years with ASD for patient-doctor communication during their first dental visit [34]. The app used real-life pictures showing different treatment procedures. Positive results among the intervention group were reported (fewer sessions required to complete dental prophylaxis, *P*<.001) when compared to those receiving picture exchange communication system training in the control group.

Besides developing their own training apps, there were 2 studies in which the interventions used the built-in functions of mobile devices and achieved positive intervention effects. Gentry and his colleagues evaluated the use of PDA functions in Apple iPod Touch as a cognitive behavioral aid in supporting work among adults with ASD [29]. After being trained by occupational therapists, participants learned how to use the built-in functions of the device to obtain timely on-the-job assistance, including task reminders, task lists, maps, and videos as prompts for task completion. Those in the intervention group required significantly fewer cumulative job coaching hours than those in the control group during their first 12 months in their jobs (*P*=.01). Thiemann-Bourgue and her colleagues used iPads as SGDs to train preschoolers with ASD in communication behaviors [31]. Instead of directly evaluating the effectiveness of the intervention, that study employed trained peers for delivering the intervention as compared with the control group using untrained peers. The results demonstrated that those in the intervention group showed improved communication behaviors, manifested by more intentional communication (*P*<.001) and a more balanced proportion of responses and initiations during communication (*P*<.001).

Although the content design of mobile interventions was an important factor influencing the overall training effectiveness, mobile interventions targeting practical skills directly applied in daily lives, such as verbal communication, job coaching, and interview performance, were also effective for people with ASD. Hayes and colleagues used the video play function of mobile devices as the intervention tool to improve interview performance [28]. They developed a new app called VidCoach to train adolescents with ASD for interview skills using two training strategies, video modeling and video prompting. The intervention brought positive results, and those in the intervention group showed significantly greater improvement in interview performance than those in the control group (difference between the pretest and posttest scores: 0.561 vs 0.194, *P*<.001). In another study [30], Novack et al developed a new mobile app called Camp Discovery to improve the receptive language skills among children with ASD. This app aimed to enhance receptive language skills among younger children aged 1 to 8 years. Participants were required to correctly touch the pictures described in the voice output of an iPad. After training for a month, those in the intervention group demonstrated a significant improvement in receptive language skills than those in the delayed treatment group (*P*<.001; effect size d=2.33).

On the other hand, 4 studies reported insignificant training effects using mobile interventions targeting people with ASD. These studies used "in-app" mini games to train people for certain microskills such as visual motor, social communication, attention, and imitation skills required in social situations or performing cognitive tasks. For example, Esposito and his colleagues developed an app with interactive games to improve vocabulary, attention, and imitation skills among children with ASD [27]. Participants in the intervention group demonstrated no statistically significant improvements (*P* values ranged from.06 to.84) after the 4 weeks of training.

More importantly, a common characteristic of these 3 "insignificant" studies was the use of validated scales as the tools for effectiveness assessments. These authors administered relevant scales at baseline and postintervention and calculated the score changes to determine the intervention effectiveness. The Therapy Outcomes By You app was evaluated in 2 studies that aimed to improve language and social abilities among children with ASD [32,35]. Although the duration of the 2 interventions (3 months vs 6 months) and the level of support (support over telephone every 2 weeks vs only technical support when necessary) were varied, both studies did not achieve any significant improvements in their primary outcomes after the interventions (Whitehouse et al: *P*s=.03 to.89; Parsons et al: *P*s=.03 to.84).

In another study, Fletcher-Watsons and her colleagues developed an app called FindMe for developing social communication skills among autistic children aged under 6 years [33]. The intervention consisted of interactive games to train these children in attending to persons and following social cues. After 2 months of training with the app through an iPad, there was no significant improvement observed in the main social communication outcomes when compared with the outcomes in the control group (*P*=.29 to.74). These results suggested that after delivering the intervention to the participants through the apps, their learning might not be fully reflected in the assessment conducted using validated rating scales, when compared to measuring outcomes via actual observation or based on game performances in the apps.

Discussion

Principal Findings

This review identified 10 RCT studies that employed mobile technology for delivering interventions to improve the social and cognitive skills of people with ASD. Among these, 5 RCTs focused on social skills, 2 on cognitive skills, and the remaining 3 on both. Overall, most of the studies showed that mobile technology interventions could provide positive and significant training effects to improve the social and cognitive skills for people with ASD. The present review also suggests that beneficial effects are more likely to be achieved when interventions focus more on training for practical skills, such as interview skills [28], receptive language skills [30], and those providing on-the-job support [29]. The current findings provide some potential useful directions for future intervention studies.

In addition, we found that the age of the target population could potentially affect the intervention outcomes. All 4 studies recruiting adolescent or adult participants reported positive training effects, compared with the insignificant findings reported in 4 out of the 6 studies conducted with younger children aged under 6 years. This difference can be related to the fact that older participants have more "hands-on experience" and are more competent in using mobile devices, which in turn make them more receptive to mobile interventions. Therefore, mobile technology interventions are more likely to be effective among those with ASD at or beyond early adolescence.

In contrast to using mini games, training this group of people to develop more explicit and practical skills for application in real life could be easier. Similarly, the use of real pictures and 3D animation in apps might further enhance their learning. These findings suggest that the training context within the mobile intervention is crucial to the overall effectiveness of the intervention. Within a familiar context, people with ASD can perform better. In addition, practice can have a major impact on their task performance as well, and they are able to perform better in tasks with fewer modifications or unexpected changes.

It should be noted that effective interventions through mobile devices were not limited to the use of tailor-made training apps. Using the PDA [29] or speech-generating functions [31] of mobile devices, these interventions could produce significant effects among their participants, including adults and young children. One advantage of using mobile phones is the possible delivery of multisensory outputs including visual, auditory, and even vibrating stimuli, which effectively strengthen the learning process among people with ASD. In addition, some PDA functions, such as reminder alarms, are also useful solutions to improve their executive functioning and planning abilities. Therefore, these results provide further supportive evidence that mobile devices could be a favorable intervention tool for people with ASD [4-6].

Nonetheless, different assessment methods could cause substantial differences in the results. Among the studies with "ineffective" training effects [32,33,35], the assessments of the interventions (delivered through interactive games or activities in their self-designed apps) were conducted using validated scales measuring the improvements in the targeted microskills in the participants' own lives, such as visual motor, attention, or social communication skills. Therefore, performance outcomes depended on how well participants could generalize what they had learned in the apps to their daily lives. According to the weak central coherence hypothesis [15], this skill generalization process is particularly challenging among people with ASD. Some insignificant results might not be attributed directly to ineffective training, but rather to the difficulty in applying the skills learned by the people with ASD in their daily life [33]. Given these findings, to measure the effectiveness of the intervention comprehensively, multiple assessment approaches are recommended in future studies, which should include the measures of "in-app" task performances and those used to assess how well the participants can apply these skills in real-life scenarios.

In previous systematic reviews on mobile interventions targeting people with ASD that reported significant effects [16-18], most of the included studies employed a small sample size and did not include a control group. The current findings were able to provide further positive support to the effectiveness of using mobile interventions targeting people with ASD. As a result, the robustness of these findings suggested that mobile phones could be an effective medium of intervention. In addition to other interventions shown to be effective in the past reviews, such as peer-mediated [36] or psychosocial interventions [37], mobile interventions could be another potentially viable treatment option for people with ASD.

In addition to these intervention effects, several reviewed studies further reported positive feedback from participants with ASD and their parents regarding the use of mobile devices as the means of intervention. For example, most of the participants reported higher motivation to participate in the intervention [26,27,32]. This additional benefit may not be readily achieved during interventions delivered by "real persons" in which more time and effort would be required to build a rapport and trustful relationships with participants having ASD. Therefore, even in the traditional face-to-face intervention, adding some components of mobile technology might potentially benefit the intervention effects.

According to a recent World Health Organization guideline on the use of technology to assist the delivery of health care services, "health content," "digital health interventions," and "digital applications" are the 3 components for effective digital health implementation [38]. The current findings state that mobile devices could serve as an effective "digital medium" for people with ASD. The guideline recommended that providing training in an internet-based setting should "complement rather than replace" [38] traditional face-to-face format, and mobile phones could be used as an additional medium of instruction, termed "mobile learning" [38]. Therefore, the overall positive findings from this review emphasize the usefulness of mobile learning for people with ASD.

Limitations

There are several limitations that should be considered when interpreting the results of this study. First, given that mobile technology intervention is still a new research area, there were only 10 eligible RCT studies included for this review. More RCT studies with rigorous research designs would be needed to understand the actual effectiveness of these interventions. Second, as aforementioned, the previous interventions focused on different treatment outcomes and used assessment strategies. Only 2 studies used the same measurement tool; therefore, meta-analysis was not performed, which might otherwise provide a biased conclusion given the small number of studies.

Implications for Future Studies

People with ASD have their own cognitive styles and ways of learning. The results of the present review provided several useful implications for designing future interventional studies targeting this unique population. First, mobile technology could be a promising means of providing interventions for people with ASD. Second, older participants (eg, aged above 9 years) are more likely to benefit from using mobile technology as the medium of intervention. Third, in-session training regarding the use of these apps may be the preferred mode of intervention delivery. Fourth, training materials should resemble what the participants might encounter in daily life, such as the use of real-life pictures shown on mobile devices or 3D animations created based on real faces or objects. Fifth, given the weakness of people with ASD for developing new skills, the targeted skills should be practical and related to their daily life. Finally, effectiveness assessment should be composed of different levels, such as in-app task performances and the improvement demonstrated in daily life based on self-reports or caregivers' observations.

Conflicts of Interest

None declared.

References

1. Diagnostic Statistical Manual of Mental Disorders. 5th Edition. Washington DC: American Psychiatric Association; 2013.
2. Electromagnetic fields and public health: mobile phones. World Health Organization. URL: https://www.who.int/en/news-room/fact-sheets/detail/electromagnetic-fields-and-public-health-mobile-phones [accessed 2019-09-16]
3. King ML, Takeguchi K, Barry SE, Rehfeldt RA, Boyer VE, Mathews TL. Evaluation of the iPad in the acquisition of requesting skills for children with autism spectrum disorder. Res Autism Spectr Disord 2014 Sep;8(9):1107-1120. [doi: 10.1016/j.rasd.2014.05.011]

4. Johnson JW, Blood E, Freeman A, Simmons K. Evaluating the effectiveness of teacher-implemented video prompting on an iPod Touch to teach food-preparation skills to high school students with autism spectrum disorders. Focus Autism Other Dev Disabl 2013 Mar;28(3):147-158. [doi: 10.1177/1088357613476344]
5. Nepo K, Tincani M, Axelrod S, Meszaros L. iPod Touch® to increase functional communication of adults with autism spectrum disorder and significant intellectual disability. Focus Autism Other Dev Disabl 2015 Oct;32(3):209-217. [doi: 10.1177/1088357615612752]
6. Kagohara DM, Sigafoos J, Achmadi D, van der Meer L, O'Reilly MF, Lancioni GE. Teaching students with developmental disabilities to operate an iPod Touch® to listen to music. Res Dev Disabil 2011 Nov;32(6):2987-2992. [doi: 10.1016/j.ridd.2011.04.010]
7. Kim S, Clarke E. Case study: an iPad-based intervention on turn-taking behaviors in preschoolers with autism. Behav Dev Bull 2015 Oct;20(2):253-264. [doi: 10.1037/h0101314]
8. Sigafoos J, Lancioni GE, O'Reilly MF, Achmadi D, Stevens M, Roche L, et al. Teaching two boys with autism spectrum disorders to request the continuation of toy play using an iPad®-based speech-generating device. Res Autism Spectr Disord 2013 Aug;7(8):923-930. [doi: 10.1016/j.rasd.2013.04.002]
9. Waddington H, Sigafoos J, Lancioni GE, O'Reilly MF, Meer L, Carnett A, et al. Three children with autism spectrum disorder learn to perform a three-step communication sequence using an iPad-based speech-generating device. Int J Dev Neurosci 2014 May;39(1):59-67. [doi: 10.1016/j.ijdevneu.2014.05.001]
10. Lorah ER. Evaluating the iPad Mini® as a speech-generating device in the acquisition of a discriminative mand repertoire for young children with autism. Focus Autism Other Dev Disabl 2016 Oct;33(1):47-54. [doi: 10.1177/1088357616673624]
11. Cihak D, Fahrenkrog C, Ayres KM, Smith C. The use of video modeling via a video iPod and a system of least prompts to improve transitional behaviors for students with autism spectrum disorders in the general education classroom. J Posit Behav Interv 2009 Feb;12(2):103-115. [doi: 10.1177/1098300709332346]
12. Bereznak S, Ayres KM, Mechling LC, Alexander JL. Video self-prompting and mobile technology to increase daily living and vocational independence for students with autism spectrum disorders. J Dev Phys Disabil 2012 Feb;24(3):269-285. [doi: 10.1007/s10882-012-9270-8]
13. Burke R, Allen K, Howard M, Downey D, Matz M, Bowen S. Tablet-based video modeling and prompting in the workplace for individuals with autism. J Vocat Rehabil 2013;38:1-14. [doi: 10.3233/jvr-120616]
14. Campbell JE, Morgan M, Barnett V, Spreat S. Handheld devices and video modeling to enhance the learning of self-help skills in adolescents with autism spectrum disorder. OTJR (Thorofare N J) 2015 Apr;35(2):95-100. [doi: 10.1177/1539449215570040] [Medline: 26460472]
15. Frith U. Autism: Explaining the Enigma. Oxford: Blackwell Publishers; 1989.
16. Lorah ER, Parnell A, Whitby PS, Hantula D. A systematic review of tablet computers and portable media players as speech generating devices for individuals with autism spectrum disorder. J Autism Dev Disord 2015 Dec;45(12):3792-3804. [doi: 10.1007/s10803-014-2314-4] [Medline: 25413144]
17. Ledbetter-Cho K, O'Reilly M, Lang R, Watkins L, Lim N. Meta-analysis of tablet-mediated interventions for teaching academic skills to individuals with autism. J Autism Dev Disord 2018 Apr;48(9):3021-3036. [doi: 10.1007/s10803-018-3573-2]
18. Hong ER, Gong L, Ninci J, Morin K, Davis JL, Kawaminami S, et al. A meta-analysis of single-case research on the use of tablet-mediated interventions for persons with ASD. Res Dev Disabil 2017 Nov;70:198-214. [doi: 10.1016/j.ridd.2017.09.013]
19. Moon SJ, Hwang J, Hill HS, Kervin R, Birtwell KB, Torous J, et al. Mobile device applications and treatment of autism spectrum disorder: a systematic review and meta-analysis of effectiveness. Arch Dis Child 2020 May;105(5):458-462. [doi: 10.1136/archdischild-2019-318258] [Medline: 31848147]
20. Oxford Centre for Evidence-based Medicine – Levels of Evidence (March 2009).: Centre for Evidence-Based Medicine; 2009. URL: https://www.cebm.net/2009/06/oxford-centre-evidence-based-medicine-levels-evidence-march-2009/ [accessed 2020-05-14]
21. Mechling LC. Review of twenty-first century portable electronic devices for persons with moderate intellectual disabilities and autism spectrum disorders. Educ Train Autism Dev Disabil 2011;46:479-498.
22. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 2009 Jul;6(7):e1000097 [FREE Full text] [doi: 10.1371/journal.pmed.1000097] [Medline: 19621072]
23. Higgins JPT, Altman DG, Gøtzsche PC, Jüni P, Moher D, Oxman AD, Cochrane Bias Methods Group, Cochrane Statistical Methods Group. The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. BMJ 2011 Oct;343:d5928 [FREE Full text] [doi: 10.1136/bmj.d5928] [Medline: 22008217]
24. Farrah K, Young K, Tunis MC, Zhao L. Risk of bias tools in systematic reviews of health interventions: an analysis of PROSPERO-registered protocols. Syst Rev 2019 Nov;8(1):280-288 [FREE Full text] [doi: 10.1186/s13643-019-1172-8] [Medline: 31730014]
25. The Cochrane RevMan. Cochrane Training. Copenhagen: The Cochrane Collaboration; 2014. URL: https://training.cochrane.org/online-learning/core-software-cochrane-reviews/revman [accessed 2020-10-24]

26. Cheng Y, Luo S, Lin H, Yang C. Investigating mobile emotional learning for children with autistic spectrum disorders. Int J Dev Disabil 2016 Aug;64(1):25-34 [FREE Full text] [doi: 10.1080/20473869.2016.1206729] [Medline: 34141288]
27. Esposito M, Sloan J, Tancredi A, Gerardi G, Postiglione P, Fotia F, et al. Using Tablet Applications for Children With Autism to Increase Their Cognitive and Social Skills. J Spec Educ Technol 2017 Jul 18;32(4):199-209. [doi: 10.1177/0162643417719751]
28. Hayes GR, Custodio VE, Haimson OL, Nguyen K, Ringland KE, Ulgado RR, et al. Mobile video modeling for employment interviews for individuals with autism. J Vocat Rehabil 2015 Oct;43(3):275-287. [doi: 10.3233/jvr-150775]
29. Gentry T, Kriner R, Sima A, McDonough J, Wehman P. Reducing the need for personal supports among workers with autism using an iPod Touch as an assistive technology: delayed randomized control trial. J Autism Dev Disord 2015 Mar;45(3):669-684. [doi: 10.1007/s10803-014-2221-8] [Medline: 25212414]
30. Novack MN, Hong E, Dixon DR, Granpeesheh D. An evaluation of a mobile application designed to teach receptive language skills to children with autism spectrum disorder. Behav Anal Pract 2019 Mar;12(1):66-77 [FREE Full text] [doi: 10.1007/s40617-018-00312-7] [Medline: 30918771]
31. Thiemann-Bourque K, Feldmiller S, Hoffman L, Johner S. Incorporating a peer-mediated approach into speech-generating device intervention: effects on communication of preschoolers with autism spectrum disorder. J Speech Lang Hear Res 2018 Aug;61(8):2045-2061. [doi: 10.1044/2018_jslhr-l-17-0424]
32. Whitehouse AJ, Granich J, Alvares G, Busacca M, Cooper MN, Dass A, et al. A randomised controlled trial of an iPad-based application to complement early behavioural intervention in autism spectrum disorder. J Child Psychol Psychiatry 2017 Sep;58(9):1042-1052. [doi: 10.1111/jcpp.12752] [Medline: 28543302]
33. Fletcher-Watson S, Petrou A, Scott-Barrett J, Dicks P, Graham C, O'Hare A, et al. A trial of an iPad™ intervention targeting social communication skills in children with autism. Autism 2016 Oct;20(7):771-782 [FREE Full text] [doi: 10.1177/1362361315605624] [Medline: 26503990]
34. Zink AG, Molina EC, Diniz MB, Santos MTBR, Guaré RO. Communication application for use during the first dental visit for children and adolescents with autism spectrum disorders. Pediatr Dent 2018 Jan;40(1):18-22. [Medline: 29482677]
35. Parsons D, Cordier R, Lee H, Falkmer T, Vaz S. A randomised controlled trial of an information communication technology delivered intervention for children with autism spectrum disorder living in regional Australia. J Autism Dev Disord 2019 Feb;49(2):569-581. [doi: 10.1007/s10803-018-3734-3] [Medline: 30209645]
36. Aldabas R. Effectiveness of peer-mediated interventions (PMIs) on children with autism spectrum disorder (ASD): a systematic review. Early Child Dev Care 2019 Feb;190(10):1586-1603. [doi: 10.1080/03004430.2019.1580275]
37. Bishop-Fitzpatrick L, Minshew NJ, Eack SM. A systematic review of psychosocial interventions for adults with autism spectrum disorders. J Autism Dev Disord 2013 Mar;43(3):687-694 [FREE Full text] [doi: 10.1007/s10803-012-1615-8] [Medline: 22825929]
38. WHO Guideline: Recommendations on Digital Interventions for Health System Strengthening. Geneva: World Health Organization; 2019.

Abbreviations

ASD: autism spectrum disorder
PDA: personal digital assistant
RCTs: randomized controlled trials
SGDs: speech-generating devices

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Original Paper

Implementing Home Office Work at a Large Psychiatric University Hospital in Switzerland During the COVID-19 Pandemic: Field Report

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Abstract

Background: During the COVID-19 pandemic in 2020, psychiatric hospitals all over the world had to adapt their services to the prevailing governmental regulations. As a consequence, home office use and telepsychiatry boomed.

Objective: The purpose of this study was to evaluate the potential of home office use, its adoption, and the association of home office use with employees' mental health in a large psychiatric university hospital in Switzerland.

Methods: We obtained and analyzed home office implementation and use data from the psychiatric university hospital's information technology services. We also conducted a cross-sectional web-based survey to assess the employees' attitudes toward the clinic's crisis management during the COVID-19 pandemic in early 2020. Part of this web-based survey consisted of questions about home office use between March and June 2020, attitudes toward home office implementation, and mental health. Three mental health measures assessed depressive symptoms (Patient Health Questionnaire [PHQ]–2), anxiety (General Anxiety Disorder [GAD]–2), and stress factors (stress module of the PHQ-D); a cut-off score ≥3 was used for the PHQ-2 and GAD-2.

Results: Of the 200 participating employees, 69 reported that they had worked from home at least partially (34.5%). Home office use differed significantly across professional groups (χ_{16}^2=72.72, *P*≤.001, n=200). Employees experienced neither depressive symptoms (mean 0.76, SD 1.14) nor anxiety (mean 0.70, SD 1.03). The employees reported minor psychosocial stressors (mean 2.83, SD 2.92). The number of reported stress factors varied significantly across groups with different levels of home office use (χ_4^2=9.72, *P*=.04).

Conclusions: In general, home office implementation appears to be feasible for large psychiatric hospitals, however, it is not equally feasible for all professional groups. Professional groups that require personal contact with patients and technical or manual tasks must work onsite. Further evaluation of home office use in psychiatric hospitals up to the development of clinics that function merely online will follow in future research. The situation created by the COVID-19 pandemic served as a stepping stone to promote home office use and should be used to improve employees' work–life balance, to save employers costs and foster other benefits.

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KEYWORDS

home office; psychiatry; employees; mental health; depression; anxiety; stress factors; Patient Health Questionnaire; PHQ-2; General Anxiety Disorder; GAD-2; PHQ-D; COVID-19; pandemic

Introduction

Looking back on 2020, COVID-19 had the world firmly in its grip, with over 80 million confirmed cases and more than 1.8 million associated deaths [1]. After its first detection in China at the end of 2019, it spread rapidly around the globe. As a consequence, governments all over the world imposed major restrictions on the general population such as face masks requirements, social distancing requirements, and general lockdowns. In Switzerland, a national lockdown was declared shortly after the first confirmed cases in the country [2]; the general population was obliged to stay at home, shops were closed, and employees were urged to work from home, with only a few exceptions.

Researchers have reported numerous psychological effects of the pandemic [3-13]. Fear of transmission, isolation, unemployment, and economic recession were associated with increased distress [9,10], anxiety [9,10], and depression [4,9,10]. In particular, women [4,5,8,10], young people [7,8,10], individuals who lost their job [7,8,10], and individuals with a history of mental illness [10] seemed to suffer from negative consequences. Moreover, health professionals and mental health professionals reported increased distress during the pandemic, especially when facing COVID-19 infections at their workplace [3,5,6,14]. Accordingly, mental health services also face a rather high demand for psychiatric treatment during the ongoing pandemic [15,16]. However, it was difficult to offer treatment within the scope of the prevailing governmental measures (such as social distancing). This problem had to be solved, practically overnight, in psychiatric hospitals around the world. Traditional operating processes were adapted—new and especially safe approaches to offer psychiatric treatment while also preventing COVID-19 infections among patients and professionals.

Home office and telepsychiatry, the process of providing health care from a distance through technology [17], therefore, found their way into the daily routines of doctors, psychologists, and nurses in large psychiatric hospitals. Home office implementation has been associated with several benefits during the pandemic (ie, reduced COVID-19 infection risk due to reduced personal contact with co-workers and patients and less commuting) and beyond this extraordinary situation (ie, increased perceived autonomy in employees, higher job satisfaction, and less work–family conflicts [18-20]). Fadinger and Schymik [21] showed that home office use during the COVID-19 pandemic was associated with a lower infection risk and was less costly than confinement. However, home office use also exerts potentially detrimental effects on social relationships [18]. Moreover, home office work may not be feasible for all professional groups (eg, construction workers, nurses). Rutzer and Niggli [22] calculated a home office index that indicates the probability of being able to work from home (where 0 indicates that home office work is not possible, and 1 indicates that all work can be done from home). They found that the home office index differed between economic sectors as well as between professional groups. For the public health sector, the authors reported a home office index of 0.19 because there are many positions for which home office is not or minimally feasible. Because there are situations in which in-person treatments may be necessary, the implementation of home offices may be challenging for psychiatric hospitals.

However, numerous studies [23-27] since the 1990s have shown that telepsychiatry is comparable to in-person psychiatry (onsite psychiatric assessments and treatments) with respect to feasibility, validity, reliability of diagnoses, therapeutic alliance, and patient satisfaction, and doctor satisfaction. In addition, telepsychiatry increases accessibility for people living in rural areas, saves commuting time, and reduces costs [28]. However, there are also some challenges. First, certain technical prerequisites (ie, suitable devices for patients and health care professionals, and a stable internet connection) are required. Second, data security has to be ensured. Third, telepsychiatry may not be appropriate for certain populations (eg, suicidal or involuntarily treated patients and patients who struggle with navigating web-based platforms) [28].

Regarding these challenges, the implementation of telepsychiatry is an extremely complex and challenging process for mental health professionals, in general, and for large psychiatric hospitals, in particular. Before the COVID-19 pandemic, web-based treatment was not widely used in psychiatric hospitals in Switzerland; onsite treatment was the standard. However, the pandemic “has served as a catalyst for the rapid implementation and acceptance of telemental health” [28] as an effective option to deliver mental health services. Telepsychiatry (and home offices) suddenly became an integral part of work in psychiatric hospitals. However, the question arises—how will large psychiatric hospitals successfully implement home offices during the COVID-19 pandemic? We explored this issue by investigating the following research questions: How did home office use change over the course of the year 2020? Which employees were able to work in home office? How did the implementation of home office work from the employees’ viewpoint? Is home office use associated with the mental health of employees?

Methods

Background

The first case of COVID-19 in Switzerland was confirmed on February 25, 2020, and the first case in Basel was confirmed on February 27, 2020. Shortly afterward, on March 16, the Federal Council simultaneously declared extraordinary circumstances and a national lockdown [2,29]. Subsequently, the management board of the Psychiatric University Clinics Basel (UPK) requested that all employees for whom it was possible work from home. On June 19, 2020, the Federal Council eased the restrictions and ended the national status of extraordinary circumstances [2]. In autumn, the number of COVID-19 cases in Switzerland rose again, which led to renewed restrictions. On October 19, 2020, the Federal Council, therefore, recommended that employees work from home whenever possible [30]. These restrictions remained in place for the rest of the year and beyond. In 2020, a total of 8 patients with COVID-19 were treated at UPK.

Research Design

We aimed to evaluate the potential of home office use, actual home office use, and the association of home office use with employees' mental health for the staff from a large psychiatric university hospital (>1200 employees) in Switzerland. Background information about home office implementation and use were gathered by the hospital's chief information officer (CM), and web-based survey data were collected as part of a retrospective analysis to assess the employees' attitudes toward the clinic's crisis management during the COVID-19 pandemic in early 2020. The cross-sectional web-based survey was mandated by the management board of UPK as a consequence of the far-reaching policies and extensive home office implementation in March 2020.

Participants and Procedures

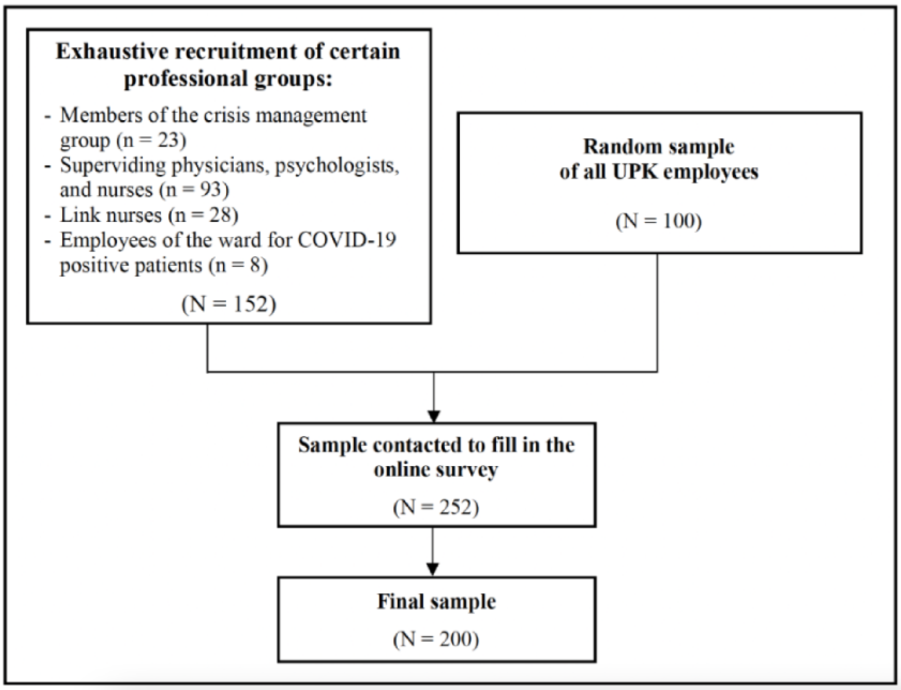
Home office users had access to the hospital's home office environment (ie, their desktop and preinstalled apps) through Citrix Workspace (Citrix Systems Inc, 2020), with access from a large range of end devices with a broad selection of supported operating systems. This infrastructure had already been put into place before the pandemic but had only been used by a very limited number of employees. The email service was provided by internal Office Outlook servers (Windows 10; Microsoft Inc). In addition, a webmail service offered flexible email checking. Zoom (Zoom Video Communications Inc) was used for videoconferences. It was introduced at UPK in March 2020 to ensure efficient exchange between teams and individual employees and to provide a platform for telepsychiatry.

For the web-based survey, we estimated the required sample size using G*Power (version 3.1). We assumed medium effect sizes (f=0.25 [31]), α=.05, and power 0.8 [32]; the required sample size was 196. Based on expected attrition, we included 252 persons in the web-based survey. Because data were collected as part of a retrospective survey to assess crisis management, professional groups with a direct and significant effect on crisis management were included in the study: members of the crisis management group (n=23), supervising physicians, psychologists and nurses (n=93), link nurses (n=28), and employees of the ward established for COVID-19–positive patients (n=8). Link nurses are responsible for hospital hygiene on their division; they connect their division to the authorized representative for hospital hygiene of the canton Basel-City. In addition, a representative sample (with respect to profession, organizational unit, and years of professional experience) was randomly selected (n=100) from all other employees of UPK Basel. Exclusion criteria were employees with a small workload (<50%) and employees such as interns, medical student assistants, or without clinical or administrative duties. We assumed that these employees had not sufficiently been affected by the hospital's clinical crisis management.

Employees (n=252) were asked by email on June 10, 2020 to fill in the web-based survey. They received a reminder 7 days later and on June 26, 2020, which was 3 days before the assessment phase ended. A total of 200 employees (79.4% of the 252 initially approached employees) completed the web-based survey (Figure 1). Employees did not receive any compensation for their participation in the study. Data were anonymized and stored on a local server of the department of Quality and Processes at UPK Basel. Participants agreed to the publication of anonymized data.

No ethics committee approval was necessary; at the request of the authors, the Ethics Committee of Northwestern and Central Switzerland confirmed that these analyses do not fall within the scope of the Human Research Act (article 2 paragraph 1 [33]) as they are not defined as research concerning human diseases or concerning the structure and function of the human body.

Figure 1. Sample composition of the web-based survey. UPK: Psychiatric University Clinics Basel.



Measurements

Home Office Use

Frequency and distribution of videoconferences on Zoom were retrieved from the administrator account of the hospital's chief information officer (CM). Data were downloaded on January 15, 2021. The frequencies of videoconferences over the course of the year 2020 were included as a proxy for home office use. Due to data protection regulations, detailed information about access to the home office environment are deleted after 30 days at UPK; therefore, these data were not available.

The web-based survey (Multimedia Appendix 1) asked "”Do you work from home?" Response options were "Yes, always"; "Yes, partially"; "No, it is not possible for my position"; "No, I did not want to"; or "No, I was rejected to work from home." Employees' rated several statements that assessed their attitudes toward the home office implementation (eg, "I have the necessary IT infrastructure available at home.") on a 5-point Likert scale from "strongly disagree" to "strongly agree."

Depression

The Patient Health Questionnaire (PHQ)-2 [34] assesses main criteria of depressive disorders with 2 items: "little interest or pleasure in doing things" and "feeling down, depressed, or hopeless." Participants were asked to rate the frequency of these symptoms over the previous 2 weeks on a 4-point Likert scale from 0 (not at all) to 3 (nearly every day). The sum ranges between 0 and 6, and scores ≥3 have been shown to reliably screen for a current depressive episode [34]. This brief version of the PHQ-8 shows comparable reliability and validity for screening [34-36].

Anxiety

The General Anxiety Disorder (GAD)–2 scale [34] contains the first 2 items of the GAD-7 to assess core criteria of general anxiety disorder; a score ≥ 3 has been identified as the optimal cut-off for screening purposes. The GAD-2 has been shown to be a similarly valid and reliable screening instrument for all anxiety disorders (such as panic, social anxiety, and posttraumatic stress disorder) compared to the GAD-7 [34,36,37].

Stress

The stress scale of the PHQ–D [38] consists of 10 items to assess common psychosocial stressors (eg, financial status, family relationships, work). Each item is rated on a scale from 0 to 2 (not bothered, bothered a little, bothered a lot) [39]. The sum score (between 0 and 20) represents level of experienced stress. A score of 0 represents no stress factors, whereas a score of 20 stands for heavily experienced stress factors. No valid cut-off score is currently available for this stress scale [40]. In this sample, the stress scale of the PHQ-D showed acceptable to good internal consistency (Cronbach =0.78) [41]. The German version has been found to be a valid, reliable, and well-accepted screening instrument [38].

Demographic Information

Sociodemographic data, including gender, professional group, and workload, were collected.

Statistical Analysis

Descriptive statistics are presented. Frequencies and percentages are given for nominal data, and for interval data (ie, the questionnaires about mental health), mean and standard deviation were calculated. We divided the sample, first, on the basis on professional groups (ie, doctors, psychologists, nurses, employees working in administration, and others). The category *others* consisted of employees who did not belong to any of the other groups (ie, trainees, housekeeping, social services, etc). Second, we categorized the sample by home office use responses (ie, "Yes, always"; "Yes, partially"; "No, it is not possible for my position"; "No, I did not want to"; and "No, I was rejected to work from home"). The distribution of participants among the 5 home office groups were compared across the 5 professional groups using the Fisher exact test because group sizes were small. Cramer *V* was calculated to estimate the effect size.

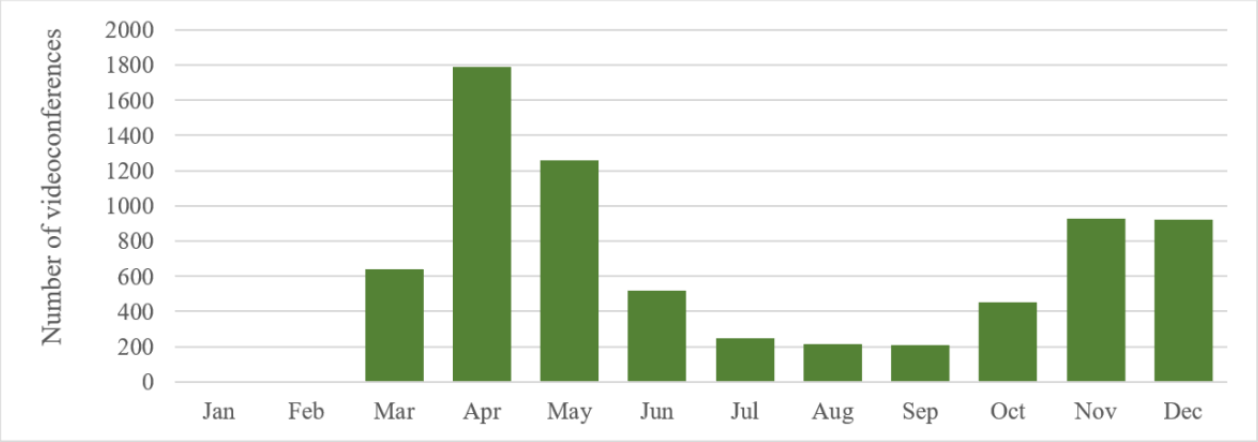
Due to the nature of sample structure (ie, small group sizes), nonparametric tests (namely, the Kruskal-Wallis test) were used for comparisons regarding psychological well-being across home office groups and across professional groups. Exact calculation of the Monte-Carlo significance was chosen because of the small group sizes. For the final analysis, because some groups were too small to reliably conduct posthoc analyses; therefore, we used the Mann-Whitney U test to compare the 2 groups only—affirmative ("Yes, always" and "Yes, partially") and negative ("No, it is not possible for my position"; "No, I did not want to"; and "No, I was rejected to work from home").

Statistical analyses were performed using SPSS Statistics for Mac OS (version 27.0; IBM Corp), and graphical analyses were conducted in Excel for Mac (version 16.45; Microsoft Inc). Given the exploratory nature of this study, outliers were included in all analyses and no correction for multiple testing was applied. For all analyses, 2-tailed tests were used, and a significance level at 5% was chosen. Missing values were excluded pairwise.

Results

In total, 7173 videoconferences took place in 2020. More videoconferences were held in April 2020 (n=1788) than in any other month that year (Figure 2). In the month of April, the daily maximum was 125 videoconferences (on Tuesday April 20, 2020). Since then (over the months), the number of videoconferences has gradually decreased. For example, the daily maximum in June was 39 videoconferences (on Tuesday June 1 and Thursday June 3, 2020). In August, the daily maximum was 17 videoconferences (on Thursday August 12, 2020). The number of videoconferences again increased, to over 900 videoconferences per month in November and December. More detailed information (eg, videoconference participants or purpose) was not available due to data protection regulations.

Figure 2. Distribution of videoconferences in 2020.



Of the 200 web-based survey respondents, 115 (57.5%) were female. More than half of the sample (117/200, 58.5%) worked full-time (ie, level of employment between 90% and 100%), whereas the rest (n=83, 41.5%) worked between 50 and 89% (employees with a workload below 50% were excluded in advance).

The majority of employees continued to work at their original workspace (131/200, 65.5%) rather than working from home (69/200, 34.5%). For the majority of employees who were still working in person at the hospital, it was not possible for them to work from home because of their position (104/131, 79.4%). This seemed to be true for nurses in particular; 84.9% (62/73) reported that home office was not possible. In other professional groups, home office work seemed to be more feasible. Only 20% of employees in administration (6 out of 30) stated that home office was not possible. Most employees who worked from home worked part-time in person at their original working environment (61/69, 88%). Few employees worked full-time from home (8/69, 12%). Of 200 employees, 3 were denied the possibility of working from home (1.5%). The distribution across the 5 home office groups (Table 1) varied between the professional groups (χ_{16}^2=72.72, $P\leq.001$, n=200). The effect size (Cramer V=.31) indicated a medium effect [42].

Table 1. Home office status (Did you work from home?) in the 5 professional groups during the COVID-19 pandemic in early 2020.

Responses	Doctors (N=42), n (%)	Psychologists (N=23), n (%)	Nurses (N=73), n (%)	Administration (N=30), n (%)	Others[a] (N=32), n (%)	All (N=200), n (%)
Yes, always	1 (2.4)	1 (4.3)	0 (0.0)	3 (10.0)	3 (9.4)	8 (4.0)
Yes, partially	19 (45.2)	14 (60.9)	7 (9.6)	11 (36.7)	10 (31.3)	61 (30.5)
No, it was not possible for my position	17 (40.5)	6 (26.1)	62 (84.9)	6 (20.0)	13 (40.6)	104 (52.0)
No, I did not want to	4 (9.5)	1 (4.3)	4 (5.5)	10 (33.3)	5 (15.6)	24 (12.0)
No, I was rejected to work from home	1 (2.4)	1 (4.3)	0 (0.0)	0 (0.0)	1 (3.1)	3 (1.5)

[a] Employees who do not belong to any of the other categories (ie, trainees, housekeeping, social services, etc).

Employees who worked at least partially in home office (n=69) rated their work from home as a mainly positive experience. The majority of this subgroup had the necessary information technology infrastructure available at home (50/65, 76.9%) and promptly received a home office account from the information technology department (46/49, 93.9%). Most employees (55/66, 83.3%) had a quiet working space at home. Videoconferences via Zoom connected those working from home and those in the hospital. Zoom was seen as suitable for videoconferences or web-based therapy by 73.1% (106/145). Whereas the program was provided in time for 81.4% of the employees (131/161), many did not have sufficient equipment (eg, headset, webcam) for videoconferences (75/148, 50.7%). Almost half of the sample (83/170, 48.8%) reported that the help desk service of the information technology department was not available as usual.

Table 2 shows descriptive statistics of the 3 mental health measures (depression, anxiety, and psychosocial stressors). This sample seemed to experience only mild psychological distress, if at all. On average, employees reported minor psychosocial stressors (mean 2.83, SD 2.92). The only 2 exceptions were employees who had to work at home full-time and those who were rejected to work from home. Both groups reported a rather high number of psychosocial stressors (mean 5.13, SD 4.19 and mean 7.00, SD 5.20, respectively).

Table 2. Depression, anxiety, and psychosocial stressors for the whole sample and for the 5 home office groups separately.

	Depression[a], mean (SD)	Anxiety[b], mean (SD)	Stress factors[c], mean (SD)
All	0.76 (1.14)	0.70 (1.03)	2.83 (2.92)
Did you work from home?			
Yes, always	1.75 (1.91)	1.38 (1.77)	5.13 (4.19)
Yes, partially	0.69 (1.01)	0.53 (0.73)	2.12 (2.24)
No, it was not possible for my position	0.73 (1.11)	0.73 (1.14)	3.09 (3.08)
No, I did not want to	0.57 (0.99)	0.57 (0.73)	2.18 (1.94)
No, I was rejected to work from home	1.67 (2.08)	2.00 (0.00)	7.00 (5.20)

[a] Assessed using Patient Health Questionnaire–2.

[b] Assessed using General Anxiety Disorder–2.

[c] Stress scale of Patient Health Questionnaire–D.

A Kruskal-Wallis H test revealed that the 5 home office groups differed concerning their reported number of stress factors (χ_4^2=9.72, *P*=.04). No significant differences were found for anxiety (χ_4^2=8.56, *P*=.07) or depression scores (χ_4^2=3.62, *P*=.47). A Mann-Whitney U test showed that the 2 groups (affirmative and negative) did not differ regarding reported stress factors (χ_4^2=3344.50, *P*=.17). The 5 professional groups also did not differ on any of the psychological scales (depression: χ_4^2=8.06, *P*=.08; anxiety: χ_4^2=3.17, *P*=.54; stress factors: χ_4^2=7.01, *P*=.13).

Discussion

The aim of this field report was to describe the implementation of home office work for UPK staff in Basel, Switzerland during the COVID-19 pandemic. The national lockdown declared by the Swiss government in March 2020 boosted home office use, but home office use was not equally frequent in the different professional groups. UPK employees experienced no or only mild psychological distress during the current COVID-19 pandemic. Thus, the implementation of home office use for UPK staff can be seen as relatively successful; however, the broad implementation of home office in large psychiatric hospitals has to be viewed as a process that has just started [18].

COVID-19 and consequently declared governmental restrictions have provided a major impetus to telepsychiatry and home office implementation in Switzerland and all over the world [28]. At UPK, the use of the videoconferencing fluctuated along with governmental restrictions. In March 2020, the number of videoconferences increased sharply with the declaration of the national lockdown. Within days, the necessary technical requirements to offer videoconferences were set up by the hospital’s information technology department. Home office users grew from less than 100 to almost 400 employees, as every person had to work from home as long as the extraordinary circumstances [2,30] prevailed. The dramatically increasing capacity utilization, and lack of apps in the hospital’s home office environment were 2 major challenges in this time according to the hospital’s chief information officer. In June 2020, the Federal Council eased the restrictions [2], which led to a lower number of videoconferences—less than 250 per month—between July and September 2020. With the renewed rise of coronavirus infections in October 2020, the Federal Council again recommended that employees should work from home if possible [2,30]. The number of videoconferences, therefore, increased again at the end of this year, to almost 1000 videoconferences per month in the UPK Basel.

Interestingly, only one-third (69/200, 34.5%) of the UPK employees who responded to the web-based survey worked at least partially from home. The rest—approximately two-thirds—did not work from home at all. This ratio is in line with the home office index of 0.19 reported by Rutzer and Niggli [22] for the public health sector, where 19% of the positions or tasks can potentially be performed from home. Moreover, these findings also support the large differences between professional groups that have been reported [22]. Almost two-thirds of the psychologists (65.2%) answered that they work at least partially from home whereas only every tenth nurse did (9.6%). These percentages are in line with the home office indices reported by Rutzer and Niggli [22].

These large differences across professional groups correspond to work-related factors. According to Rutzer and Niggli [22], for employees in positions that require personal contact with clients or patients as well as mainly technical or manual tasks (eg, administering injections) must work in person (therefore, make home office impossible). Strategic, administrative, or creative tasks, on the other hand, can easily be completed from home (or any other place), which includes psychotherapeutic treatment [22]. As web-based assessments and treatment has been shown to be comparable to in-person appointments [23-25], home office use seems to be feasible even for large psychiatric university hospitals; however, as mentioned above, feasibility strongly differs between professional groups and may also depend on other factors (eg, inpatient vs outpatient services).

At UPK Basel, many of the employees in our sample did not want to work from home (24/200, 12.0%), especially those in administration (10/30, 33.3%). This choice belonged to the employees as the Federal Council only recommended—not required—that employees to work from home in March 2020. The attractiveness of home office use may therefore also depend on other factors (such as the employee’s personal living conditions). In spring 2020, more than 1200 employees of the

UPK were challenged to adapt to novel working circumstances within a very short time. Nonetheless, employees rated home office implementation as mainly positive. They reported having the technical requirements as well as the necessary environmental conditions (such as a quiet working space). However, employees may have faced multiple (ie, not only work-related) challenges during these times. Suddenly, whole families were confined in their apartments; parents worked from home, and children had to be home-schooled. Several studies conducted before the COVID-19 pandemic reported the benefits of working from home (such as higher perceived autonomy, increased job satisfaction, and less work-family conflicts [18-20]), which might, however, have been reduced during these chaotic and insecure times.

Employees might have experienced heightened psychological distress as their daily routines suddenly dissolved and they had to take on new responsibilities (eg, home-schooling of their children). However, employees of the UPK reported no or only mild psychological distress in the web-based survey. In a meta-analysis, Batra et al [3] reported several risk factors for experiencing higher levels of depression and anxiety in health care workers (eg, being a nurse and being at risk of contact with COVID-19 patients). We found no differences between professional groups' mental health measures; nurses did not experience heightened psychosocial stress in comparison to other professional groups in our findings. At UPK, only 8 patients with COVID-19 were treated. Employees might, therefore, have experience only mild anxiety and stress about possible COVID-19 infections.

The number of psychosocial stress factors differed across the home office groups but not between employees who worked from home and those who did not. Employees working full-time from home (n=8) as well as employees who were denied permission to work from home (n=3) seemed to experience substantially more stress factors than those experienced by other groups. These are 2 groups who reported some form of constraint (not being allowed to home office vs having to work in home office). This constraint may be seen in the framework of the locus of control theory [43]. An external locus of control means that a person believes that his or her life is controlled by factors outside his or her person (eg, by other people or fate) [43]. In previous studies [44-46], an external locus of control has been associated with mental health problems. These findings are in line with the results of our study that employees who did not have the choice of where to work seemed to experience more stress factors. Moreover, data analysis revealed a small group of employees who seemed to excessively suffer during the pandemic (n=8). Most of these employees perceived more psychological stress across several measures; however, there was no trend with respect to professional group, workload, or home office status. Although underlying reasons remain unknown, it is particularly important that employers maintain supportive relationships with their employees during exceptional times such as these. Detrimental work relationships, especially between employees, have been reported as negative consequences of home office use [18]. This risk has to be addressed during implementations of home office use. Nevertheless, most UPK employees reported no psychological distress during the insecure and challenging times of the COVID-19 pandemic.

The study had several limitations. First, a cross-sectional design might be neither appropriate for investigating the effects of the ongoing COVID-19 pandemic nor appropriate for investigating the time-consuming implementation of home office use. However, as exploratory analyses, the aim was to gain first impressions of how home office use was implemented in a large psychiatric hospital. Without question, further research is needed (eg, about maximizing the effectiveness of home office in psychiatric hospitals). Second, only a subgroup of the workforce at UPK participated in the web-based survey; however, all key employees were included (such as the crisis management group, link nurses, and employees of the newly established ward for COVID-19 positive patients), and with the random sample, it is assumed that the UPK workforce was well represented. Third, some videoconferences were possibly held onsite (instead of in home office) as meetings of more than 5 employees were prohibited for certain time periods. Videoconferences may, therefore, not reliably represent home office use. This limitation should be considered in future studies. Fourth, other variables that may have affected employees' mental health (such as school-age children in the household, financial problems, etc) were not assessed. This limits generalizability. However, the focus of our findings was on home office implementation. Moreover, employees appeared to experience generally no or little psychological distress. It, therefore, can be assumed that the assessment of these variables would not have added substantial value to our findings. Fifth, the web-based survey was mandated by the management board of the UPK. This might have affected employees willingness to openly answer some questions (eg, questions about their mental health). As absolute anonymity was guaranteed, the bias is assumed to be negligible.

The situation created by the COVID-19 pandemic served as a stepping stone for home office use and telepsychiatry implementation in psychiatric hospitals all over the world. In large psychiatric hospitals, home office implementation is clearly feasible, and it will probably remain an inherent component of the working world. This shift offers numerous benefits for all involved, as long as the pitfalls of home office use are considered. However, the broad implementation of home office in psychiatry has just started. It is an ongoing process that requires further observation and research (eg, about the efficient use of home office in large psychiatric hospitals). Thus, the pandemic, in spite of its sudden appearance, will probably have long-term effects on our daily lives and on mental health care.

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Authors' Contributions

CGH designed the study, and JSK and CGH wrote the initial draft of the paper. JSK, RG, and CM collected the data. JSK, JM, and CGH analyzed and interpreted the data. All authors have contributed to, read, and approved the final version of the manuscript. JSK has full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Web-based survey items: home office and information technology services.
[DOCX File , 30 KB - mental_v8i9e28849_app1.docx]

References

1. WHO coronavirus disease (COVID-19) dashboard. World Health Organization (WHO). 2020. URL: https://web.archive.org/web/20210101095149/https://covid19.who.int/ [accessed 2020-12-31]
2. Coronavirus: Massnahmen und Verordnungen. Bundesamt für Gesundheit (BAG). URL: https://web.archive.org/web/20210129053026/https://www.bag.admin.ch/bag/de/home/krankheiten/ausbrueche-epidemien-pandemien/aktuelle-ausbrueche-epidemien/novel-cov/massnahmen-des-bundes.html [accessed 2020-12-31]
3. Batra K, Singh TP, Sharma M, Batra R, Schvaneveldt N. Investigating the psychological impact of COVID-19 among healthcare workers: a meta-analysis. Int J Environ Res Public Health 2020 Dec 05;17(23):9096-10029 [FREE Full text] [doi: 10.3390/ijerph17239096] [Medline: 33291511]
4. Debowska A, Horeczy B, Boduszek D, Dolinski D. A repeated cross-sectional survey assessing university students' stress, depression, anxiety, and suicidality in the early stages of the COVID-19 pandemic in Poland. Psychol Med 2020 Oct 02:1-4 [FREE Full text] [doi: 10.1017/S003329172000392X] [Medline: 33004087]
5. Barzilay R, Moore TM, Greenberg DM, DiDomenico GE, Brown LA, White LK, et al. Resilience, COVID-19-related stress, anxiety and depression during the pandemic in a large population enriched for healthcare providers. Transl Psychiatry 2020 Aug 20;10(1):291-298 [FREE Full text] [doi: 10.1038/s41398-020-00982-4] [Medline: 32820171]
6. Zhang W, Wang K, Yin L, Zhao W, Xue Q, Peng M, et al. Mental health and psychosocial problems of medical health workers during the COVID-19 epidemic in China. Psychother Psychosom 2020 Apr 9;89(4):242-250 [FREE Full text] [doi: 10.1159/000507639] [Medline: 32272480]
7. Every-Palmer S, Jenkins M, Gendall P, Hoek J, Beaglehole B, Bell C, et al. Psychological distress, anxiety, family violence, suicidality, and wellbeing in New Zealand during the COVID-19 lockdown: a cross-sectional study. PLoS One 2020 Nov 4;15(11):e0241658-e0241619 [FREE Full text] [doi: 10.1371/journal.pone.0241658] [Medline: 33147259]
8. Rodríguez-Rey R, Garrido-Hernansaiz H, Collado S. Psychological impact and associated factors during the initial stage of the coronavirus (COVID-19) pandemic among the general population in Spain. Front Psychol 2020;11:1540 [FREE Full text] [doi: 10.3389/fpsyg.2020.01540] [Medline: 32655463]
9. Salari N, Hosseinian-Far A, Jalali R, Vaisi-Raygani A, Rasoulpoor S, Mohammadi M, et al. Prevalence of stress, anxiety, depression among the general population during the COVID-19 pandemic: a systematic review and meta-analysis. Global Health 2020 Jul 06;16(1):57-11 [FREE Full text] [doi: 10.1186/s12992-020-00589-w] [Medline: 32631403]
10. Xiong J, Lipsitz O, Nasri F, Lui LM, Gill H, Phan L, et al. Impact of COVID-19 pandemic on mental health in the general population: a systematic review. J Affect Disord 2020 Dec 01;277:55-64 [FREE Full text] [doi: 10.1016/j.jad.2020.08.001] [Medline: 32799105]
11. McIntyre RS, Lee Y. Preventing suicide in the context of the COVID-19 pandemic. World Psychiatry 2020 Jun 11;19(2):250-251 [FREE Full text] [doi: 10.1002/wps.20767] [Medline: 32394579]
12. Mamun MA, Ullah I. COVID-19 suicides in Pakistan, dying off not COVID-19 fear but poverty? - the forthcoming economic challenges for a developing country. Brain Behav Immun 2020 Jul 11;87:163-166 [FREE Full text] [doi: 10.1016/j.bbi.2020.05.028] [Medline: 32407859]
13. Thakur V, Jain A. COVID 2019-suicides: a global psychological pandemic. Brain Behav Immun 2020 Aug;88:952-953 [FREE Full text] [doi: 10.1016/j.bbi.2020.04.062] [Medline: 32335196]
14. Lai J, Ma S, Wang Y, Cai Z, Hu J, Wei N, et al. Factors associated with mental health outcomes among health care workers exposed to coronavirus disease 2019. JAMA Netw Open 2020 Mar 02;3(3):e203976-e203912 [FREE Full text] [doi: 10.1001/jamanetworkopen.2020.3976] [Medline: 32202646]
15. Titov N, Staples L, Kayrouz R, Cross S, Karin E, Ryan K, et al. Rapid report: Early demand, profiles and concerns of mental health users during the coronavirus (COVID-19) pandemic. Internet Interv 2020 Sep;21:100327-100325 [FREE Full text] [doi: 10.1016/j.invent.2020.100327] [Medline: 32537424]

16. Thome J, Deloyer J, Coogan AN, Bailey-Rodriguez D, da Cruz E Silva OAB, Faltraco F, et al. The impact of the early phase of the COVID-19 pandemic on mental-health services in Europe. World J Biol Psychiatry 2020 Dec 23:1-10. [doi: 10.1080/15622975.2020.1844290] [Medline: 33143529]
17. What is Telepsychiatry? American Psychiatric Association. URL: https://web.archive.org/web/20210113145702/https://www.psychiatry.org/patients-families/what-is-telepsychiatry [accessed 2020-12-31]
18. Gajendran RS, Harrison DA. The good, the bad, and the unknown about telecommuting: meta-analysis of psychological mediators and individual consequences. J Appl Psychol 2007 Nov;92(6):1524-1541. [doi: 10.1037/0021-9010.92.6.1524] [Medline: 18020794]
19. Hill E, Ferris M, Märtinson V. Does it matter where you work? a comparison of how three work venues (traditional office, virtual office, and home office) influence aspects of work and personal/family life. J Vocat Behav 2003 Oct;63(2):220-241. [doi: 10.1016/s0001-8791(03)00042-3]
20. Baruch Y. Teleworking: benefits and pitfalls as perceived by professionals and managers. New Technol Work Employ 2002 Dec 17;15(1):34-49. [doi: 10.1111/1468-005x.00063]
21. Fadinger H, Schymik J. The costs and benefits of home office during the COVID-19 pandemic: evidence from infections and an input-output model for Germany. COVID Economics 2020 Apr 17:107-134. [doi: 10.3886/E124902V2]
22. Rutzer C, Niggli M. Corona-Lockdown und Homeoffice in der Schweiz. Universität Basel Center for International Economics and Business. URL: https://web.archive.org/web/20201101125739/https://cieb.shinyapps.io/HomeOffice_CH/ [accessed 2020-12-31]
23. Hyler SE, Gangure DP, Batchelder ST. Can telepsychiatry replace in-person psychiatric assessments? a review and meta-analysis of comparison studies. CNS Spectr 2005 May 07;10(5):403-413. [doi: 10.1017/s109285290002277x] [Medline: 15858458]
24. García-Lizana F, Muñoz-Mayorga I. What about telepsychiatry? a systematic review. Prim Care Companion J Clin Psychiatry 2010;12(2):1-15 [FREE Full text] [doi: 10.4088/PCC.09m00831whi] [Medline: 20694116]
25. Hilty DM, Ferrer DC, Parish MB, Johnston B, Callahan EJ, Yellowlees PM. The effectiveness of telemental health: a 2013 review. Telemed J E Health 2013 Jun;19(6):444-454 [FREE Full text] [doi: 10.1089/tmj.2013.0075] [Medline: 23697504]
26. Berryhill MB, Culmer N, Williams N, Halli-Tierney A, Betancourt A, Roberts H, et al. Videoconferencing psychotherapy and depression: a systematic review. Telemed J E Health 2019 Jun;25(6):435-446. [doi: 10.1089/tmj.2018.0058] [Medline: 30048211]
27. Berger T. The therapeutic alliance in internet interventions: a narrative review and suggestions for future research. Psychother Res 2017 Sep;27(5):511-524. [doi: 10.1080/10503307.2015.1119908] [Medline: 26732852]
28. Madigan S, Racine N, Cooke JE, Korczak DJ. COVID-19 and telemental health: benefits, challenges, and future directions. Canadian Psychology 2021 Feb 26;62(1):5-11. [doi: 10.1037/cap0000259]
29. Coronavirus: Bundesrat erklärt die «ausserordentliche Lage» und verschärft die Massnahmen. Bundesamt für Gesundheit (BAG). 2020 Mar 7. URL: https://www.admin.ch/gov/de/start/dokumentation/medienmitteilungen.msg-id-78454.html [accessed 2020-12-31]
30. Lockerungen und Verschärfungen der nationalen Massnahmen. Bundesamt für Gesundheit (BAG). Bern URL: https://www.bag.admin.ch/bag/de/home/krankheiten/ausbrueche-epidemien-pandemien/aktuelle-ausbrueche-epidemien/novel-cov/massnahmen-des-bundes.html [accessed 2020-12-31]
31. Cohen J. Statistical Power Analysis for the Behavioral Sciences 2nd ed. Hillsdale: NJ Lawrence Erlbaum Associates; 1988:273-406.
32. Bühner M, Ziegler M. Statistik für Psychologen und Sozialwissenschaftler. München: Pearson Deutschland GmbH; 2009:199-208.
33. Federal act on research involving human beings. Fedlex. URL: https://www.fedlex.admin.ch/eli/cc/2013/617/en [accessed 2021-08-11]
34. Kroenke K, Spitzer RL, Williams JB, Löwe B. An ultra-brief screening scale for anxiety and depression: the PHQ-4. Psychosomatics 2009;50(6):613-621. [doi: 10.1176/appi.psy.50.6.613] [Medline: 19996233]
35. Löwe B, Kroenke K, Gräfe K. Detecting and monitoring depression with a two-item questionnaire (PHQ-2). J Psychosom Res 2005 Feb;58(2):163-171. [doi: 10.1016/j.jpsychores.2004.09.006] [Medline: 15820844]
36. Kroenke K, Spitzer RL, Williams JBW, Löwe B. The patient health questionnaire somatic, anxiety, and depressive symptom scales: a systematic review. Gen Hosp Psychiatry 2010;32(4):345-359. [doi: 10.1016/j.genhosppsych.2010.03.006] [Medline: 20633738]
37. Kroenke K, Spitzer RL, Williams JB, Monahan PO, Löwe B. Anxiety disorders in primary care: prevalence, impairment, comorbidity, and detection. Ann Intern Med 2007 Mar 06;146(5):317-325. [doi: 10.7326/0003-4819-146-5-200703060-00004] [Medline: 17339617]
38. Gräfe K, Zipfel S, Herzog W, Löwe B. Screening psychischer Störungen mit dem “Gesundheitsfragebogen für Patienten (PHQ-D)“. Diagnostica 2004 Oct;50(4):171-181. [doi: 10.1026/0012-1924.50.4.171]
39. Klapow J, Kroenke K, Horton T, Schmidt S, Spitzer R, Williams JBW. Psychological disorders and distress in older primary care patients: a comparison of older and younger samples. Psychosom Med 2002;64(4):635-643. [doi: 10.1097/00006842-200207000-00014]

40. Beutel TF, Zwerenz R, Michal M. Psychosocial stress impairs health behavior in patients with mental disorders. BMC Psychiatry 2018 Dec 04;18(1):375-313 [FREE Full text] [doi: 10.1186/s12888-018-1956-8] [Medline: 30509234]
41. Blanz M. Forschungsmethoden und Statistik für die Soziale Arbeit: Grundlagen und Anwendungen. Stuttgart: Kohlhammer Verlag; 2021.
42. Ellis P. The Essential Guide to Effect Sizes: Statistical Power, Meta-analysis, and the Interpretation of Research Results. Cambridge: Cambridge University Press; 2010.
43. Rotter JB. Generalized expectancies for internal versus external control of reinforcement. Psychol Monogr 1966;80(1):1-28. [doi: 10.1037/h0092976] [Medline: 5340840]
44. Hovenkamp-Hermelink JH, Jeronimus BF, van der Veen DC, Spinhoven P, Penninx BW, Schoevers RA, et al. Differential associations of locus of control with anxiety, depression and life-events: a five-wave, nine-year study to test stability and change. J Affect Disord 2019 Jun 15;253:26-34. [doi: 10.1016/j.jad.2019.04.005] [Medline: 31009845]
45. Wiersma JE, van Oppen P, van Schaik DJF, van der Does AJW, Beekman ATF, Penninx BWJH. Psychological characteristics of chronic depression: a longitudinal cohort study. J Clin Psychiatry 2011 Mar;72(3):288-294. [doi: 10.4088/JCP.09m05735blu] [Medline: 21450151]
46. Struijs SY, Groenewold NA, Oude Voshaar RC, de Jonge P. Cognitive vulnerability differentially predicts symptom dimensions of depression. J Affect Disord 2013 Oct;151(1):92-99. [doi: 10.1016/j.jad.2013.05.057] [Medline: 23787407]

Abbreviations

GAD: General Anxiety Disorder
PHQ: Patient Health Questionnaire
UPK: Psychiatric University Clinics Basel

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Review

Implementation of Electronic Medical Records in Mental Health Settings: Scoping Review

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Abstract

Background: The success of electronic medical records (EMRs) is dependent on implementation features, such as usability and fit with clinical processes. The use of EMRs in mental health settings brings additional and specific challenges owing to the personal, detailed, narrative, and exploratory nature of the assessment, diagnosis, and treatment in this field. Understanding the determinants of successful EMR implementation is imperative to guide the future design, implementation, and investment of EMRs in the mental health field.

Objective: We intended to explore evidence on effective EMR implementation for mental health settings and provide recommendations to support the design, adoption, usability, and outcomes.

Methods: The scoping review combined two search strategies that focused on clinician-facing EMRs, one for primary studies in mental health settings and one for reviews of peer-reviewed literature in any health setting. Three databases (Medline, EMBASE, and PsycINFO) were searched from January 2010 to June 2020 using keywords to describe EMRs, settings, and impacts. The Proctor framework for implementation outcomes was used to guide data extraction and synthesis. Constructs in this framework include adoption, acceptability, appropriateness, feasibility, fidelity, cost, penetration, and sustainability. Quality assessment was conducted using a modified Hawker appraisal tool and the Joanna Briggs Institute Critical Appraisal Checklist for Systematic Reviews and Research Syntheses.

Results: This review included 23 studies, namely 12 primary studies in mental health settings and 11 reviews. Overall, the results suggested that adoption of EMRs was impacted by financial, technical, and organizational factors, as well as clinician perceptions of appropriateness and acceptability. EMRs were perceived as acceptable and appropriate by clinicians if the system did not interrupt workflow and improved documentation completeness and accuracy. Clinicians were more likely to value EMRs if they supported quality of care, were fit for purpose, did not interfere with the clinician-patient relationship, and were operated with readily available technical support. Evidence on the feasibility of the implemented EMRs was mixed; the primary studies and reviews found mixed impacts on documentation quality and time; one primary study found downward trends in adverse events, whereas a review found improvements in care quality. Five papers provided information on implementation outcomes such as cost and fidelity, and none reported on the penetration and sustainability of EMRs.

Conclusions: The body of evidence relating to EMR implementation in mental health settings is limited. Implementation of EMRs could benefit from methods used in general health settings such as co-designing the software and tailoring EMRs to clinical needs and workflows to improve usability and acceptance. Studies in mental health and general health settings rarely focused on long-term implementation outcomes such as penetration and sustainability. Future evaluations of EMRs in all settings should consider long-term impacts to address current knowledge gaps.

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KEYWORDS

electronic medical records; health information technology; implementation; mental health

Introduction

Information and information transfer are critical to the delivery of health care services, including in mental health settings [1]. Modern health care increasingly relies on new information technology (IT) systems to store, retrieve, and transfer information to support decision-making for care and administrative processes [2]. Among the health-related IT systems currently in use, electronic medical records (EMRs) are the most widely implemented across many settings [3]. In their simplest form, EMRs are digital versions of case histories containing patient health–related information, but they can also support artificial intelligence capabilities, clinical decision-support systems, natural language processing, and so on [4]. EMRs have the potential to improve adherence to clinical guidelines across all settings [5], thereby reducing resource wastage, increasing care quality, and reducing patient harm. Examples include improved prescribing practices and medication safety through integrated electronic ordering systems [6] and reductions in inappropriate laboratory testing because of integrated decision-support tools [7]. Ultimately, EMRs are expected to contribute to creating safer and more effective health systems [5].

Although several studies identifying the potential of EMRs have been published, evidence on their benefit to organizational, clinical, and patient outcomes after implementation continues to be mixed, with success appearing to be largely dependent on the design and fit with the local health care settings and workflows. For example, implementation of the same EMR system in two different university hospitals revealed that the time spent on documentation increased in one site but decreased in the other [8]. Furthermore, high-profile, unintended consequences because of EMR implementation by-products have been reported in recent times. A notable example includes the implementation of a £200 million EMR system in a major UK teaching hospital, leading to reduced performance and demoralized staff [9]. Poor usability of EMRs can impact quality of care and patient safety, as poor fit and design may cause fatigue, delayed case note entry, and adjacency errors [10]. As research on the implementation of EMRs continues to emerge, there is a strong need to understand the processes, systems, contexts, and human factors that influence successful implementation [11].

Although the adoption of EMRs has grown significantly in recent years, research that is specific to mental health settings or mental health clinicians has been minimal. Documentation in mental health settings brings unique challenges for the implementation of EMRs. Effective mental health documentation requires the recording of individualized, detailed, and narrative information, which is not easily reduced to checklists [12]. Care is often long term and multidisciplinary, requiring staff of different disciplines to record and retrieve information over long periods or in different settings (eg, hospital and community). Hence, the implementation of EMRs in mental health settings may have specific negative impacts, either real or perceived, on patient-centered care, the ability to develop the patient-clinician rapport, and on clinician time. Understanding the available evidence on implementation determinants and outcomes of EMRs in mental health settings, as well as the implementation features that contribute to its success or failure, could aid the future investment, design, and implementation of EMRs in this field.

The aim of this scoping review of the peer-reviewed literature was to provide a synthesis of implementation studies relevant to EMRs in mental health settings and inform EMR mental health policy recommendations in New South Wales, Australia. To provide in-depth recommendations, the review also considered broader evidence from general health settings to reflect on EMR implementation lessons. The specific objectives of this scoping review were to (1) identify published studies pertaining to the implementation of EMRs in mental health settings and literature reviews in general health settings, (2) synthesize the specific implementation determinants and outcomes examined in these studies according to the Proctor framework for implementation outcomes [13], and (3) provide local policy recommendations for future design and implementation of EMRs in mental health settings based on the findings.

Methods

Review Protocol

Our scoping review followed a predetermined (but unregistered) protocol that was developed in accordance with the PRISMA-ScR (Preferred Reporting Items of Systematic Review and Meta-Analyses Extension for Scoping Reviews) [14,15] and followed methods used in published peer-reviewed scoping reviews [16]. An exploratory search of 1 database over a 2-year period, conducted in consultation with a medical librarian and mental health experts on our team (GS and CT), confirmed that the studies on EMRs implemented in mental health settings were limited. Therefore, in our scoping review, we also conducted a review of reviews to capture implementation literature across EMRs in all health settings and not just mental health, given that the broad issues around the usability of EMRs in general health settings are potentially relevant. The results of both search strategies were analyzed; for synthesis, we used a combination of results from primary studies and review papers.

In our scoping review, we defined mental health professionals as psychiatrists, psychologists, nurses, and any other health professional involved in treating people with mental health disorders in health service settings, including allied health professionals. These settings could be mental health clinics, or general inpatient or outpatient clinics but needed to be in high-income countries. High-income countries were classified as category 1 countries by the Organisation for Economic Co-operation and Development (OECD) [17]. This criterion was used to maintain relevance to the local policy setting context. Implementation determinants were defined as barriers and enablers that may prevent or facilitate improvements in practice [18], as reported in the included studies. The Proctor framework provides a systematic taxonomy of implementation outcomes (ie, acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability), distinguishing these from service and patient outcomes [13].

Search Strategy

Our scoping review combined two systematic searches; the first captured published studies reporting primary data on the use and implementation of clinician-facing EMRs specifically in mental health settings (henceforth termed “primary studies”). The second search captured published reviews on the use of clinician-facing EMRs as implemented in all health settings irrespective of their relationship to mental health (henceforth termed “reviews”). The searches were conducted in three academic databases (MEDLINE via the PubMed Interface, EMBASE, and PsycINFO) and used the terms outlined in Table 1. Additionally, we manually searched the reference lists of the included studies (primary studies and reviews) for other relevant publications. All searches were limited to studies and reviews published between January 2010 and June 2020. The search strategies were devised by the review team with the assistance of an experienced medical librarian.

Table 1. Database search strategy used in MEDLINE.

Construct	Search terms for primary studies	Search terms for reviews
EMR[a]-related terms	“Electronic Health Records”[MeSH] OR Medical Records Systems, Computerized [MeSH] OR ((health record*[b] OR medical record* OR healthcare record* OR health care record* OR clinical record*) AND (digital OR electronic OR computerized OR computerized OR ambulatory)) [Title/Abstract]	“Electronic Health Records”[MeSH] OR Medical Records Systems, Computerized [MeSH] OR ((health record* OR medical record* OR healthcare record* OR health care record* OR clinical record*) AND (digital OR electronic OR computerized OR computerized OR ambulatory)) [Title/Abstract]
Health professional–related terms	“Psychiatry”[MeSH] OR “Psychiatric Nursing”[MeSH] OR (mental health OR psychiatric nurs* OR psychiatry OR psychiatrist OR psychology OR psychologist) [Title/Abstract]	“Psychiatry”[MeSH] OR “Psychiatric Nursing”[MeSH] OR “Physicians”[MeSH] OR “Nurses”[MeSH] OR “Health Personnel”[MeSH] OR (Physician OR nurse OR doctor OR psychiatrist OR psychologist OR health professional OR health personnel OR psychiatric nursing) [Title/Abstract]
Impact-related terms	(uptake OR adoption OR usability OR utility OR utilization OR utilization OR evaluate OR evaluation OR implementation OR acceptance OR acceptability) [Title/Abstract]	(uptake OR adoption OR usability OR utility OR utilization OR utilization OR evaluate OR evaluation OR implementation OR acceptance OR acceptability) [Title/Abstract]
Additional limiters	Published in English AND published between January 2010 and June 2020	(Systematic review or meta-analysis) AND published in English AND published between January 2010 and June 2020

[a] EMR: electronic medical record.

[b] Asterisk indicates truncation.

Inclusion and Exclusion Criteria

In both searches, articles were included if they met the following inclusion criteria: investigated implemented clinician-facing EMRs; conducted in high-income countries (countries classified as category 1 by the OECD [17]); assessed and reported implementation outcomes and contextual determinants of implementation (ie, barriers and facilitators); and published between January 1, 2010, and June 30, 2020. The population and study type inclusion criteria differed between the searches. The review of primary studies included studies related to mental health clinicians, whereas the review of reviews included literature reviews of studies about any health professionals in any health setting.

In both searches, articles were excluded if the implemented EMRs were exclusively patient-facing ones, they did not report on implementation processes or outcomes, or they were not published in English. The complete list of the inclusion and exclusion criteria is available in Multimedia Appendix 1.

Screening, Data Extraction, and Synthesis Procedures

Reference details, including abstracts, were downloaded into the reference management software EndNote X8 (Clarivate) [19]; duplicates were removed and the deduplicated list was exported to Rayyan QCRI [20], a systematic reviews web app, for title and abstract screening. Five investigators (HLT, LT, LAE, AG, and IM) independently conducted the two-phase screening process: (1) title and abstract screening and (2) full-text screening. Two investigators (HLT and IM) cross-checked 50% of the records to ensure that article screening was consistent in accordance with accepted practices [21]. Interrater reliability (Cohen kappa coefficient) in this cross-checking indicated strong agreement (>0.8) [22]. A custom data extraction workbook in Excel (Microsoft Corporation) was developed and tested. Data were systematically extracted by six investigators (HLT, LL, LT, AG, LAE, and IM). Four investigators (LT, LAE, YZ, and IM) examined the data for consistency and cross-checked the extracted data against original articles.

Key information extracted included the study publication details (authors, date of publication, country of study, and number of studies in reviews), health settings, study methods (quantitative, qualitative, and mixed methods), design features of EMRs, and implementation barriers, enablers, and outcomes. To ensure consistency in our review, the Proctor framework of implementation outcomes presented in Table 2 was used as the guiding structure, with definitions tailored to suit the EMR implementation context [13].

Table 2. Proctor implementation outcomes as applied in this study.

Domain	Definition
Adoption	Uptake of the EMR[a] from the professionals, organizations, and settings
Acceptability	Clinician satisfaction with various aspects of the innovation (eg, content, complexity, comfort, delivery, and credibility)
Appropriateness	Perceived fit, relevance, compatibility, suitability, usefulness, and practicability defined by clinicians
Feasibility	Actual fit or usefulness, suitability for everyday use, and practicability assessed at the level of the health service provider/organization/setting
Fidelity	Program delivered as intended, adherence by clinicians, integrity, and quality of program delivery
Cost	Financial impact of technology implementation on the health provider or organization
Penetration	Spread or reach of the technology assessed at the organization or setting level
Sustainability	Maintenance or integration of a technology within a health service

[a] EMR: electronic medical record.

Assessment of Evidence Quality

Primary studies were appraised for quality using a modified Hawker appraisal tool and scoring system [23,24]. This tool was selected as it is designed to review evidence from a variety of methods [23]. The Critical Appraisal Checklist for Systematic Reviews and Research Syntheses developed by the Joanna Briggs Institute was used to appraise the systematic review studies [25]. Two investigators (HLT and IM) appraised 10% of the articles independently to ensure consistency. Quality assessment results were reported to reflect the quality of the studies and reviews included in our scoping review. We did not exclude studies based on quality assessment.

Data Analysis and Synthesis

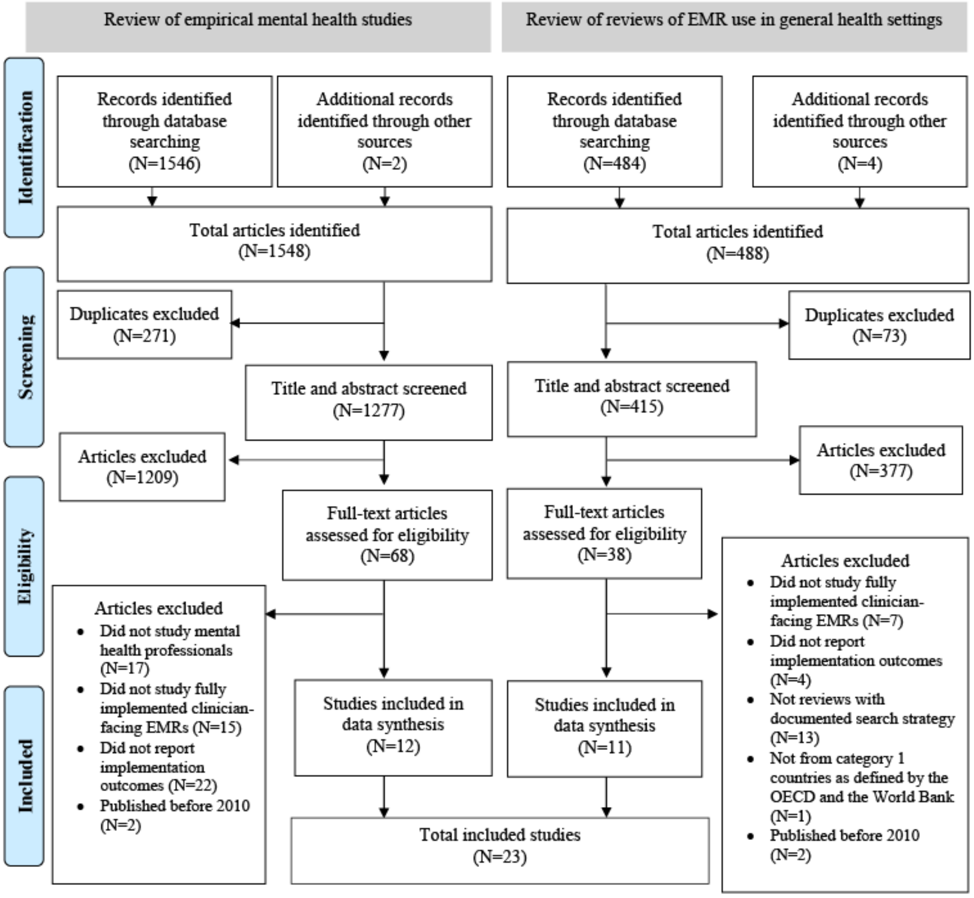
The extracted data were analyzed for common features and summarized into tables. Implementation outcomes were grouped by outcomes (eg, satisfaction), and barriers and enablers were grouped by themes (eg, technical factors). Barriers, enablers, and implementation outcomes were also categorized using the Proctor framework (Table 2), while recognizing some degree of overlap among constructs as suggested by other publications [13,26]. Assignments to the constructs were based on the definitions applied by the review team (Table 2) rather than the assignment made by the authors of the included articles owing to inconsistencies in the manner of defining, measuring, and reporting implementation outcomes [13]. Three investigators (YZ, LAE, and IM) reviewed the assignment of all the results, and any discrepancies were discussed among the three authors until a consensus was reached. Summary statistics (frequencies and proportions) were calculated for the final assignment.

Results

Search Results and Study Selection

The search for primary studies yielded 1546 results relevant to mental health professionals or settings (Medline: 606; EMBASE: 620; PsycINFO: 320). Manually searching the article reference lists yielded 2 more papers. Among these, 271 duplicates were removed; after title/abstract screening, 1209 papers were excluded because they did not meet the inclusion and exclusion criteria. Furthermore, 68 studies underwent full-text review, and another 56 papers were excluded. We included 12 primary studies for data extraction and synthesis, as shown in Figure 1.

Figure 1. Selection of primary studies and reviews. EMR: electronic medical record; OECD: Organisation for Economic Co-operation and Development.



The search for reviews yielded 484 results (Medline: 175; EMBASE: 297; PsycINFO: 12). We identified 4 additional papers by manually searching article reference lists. Then, 73 duplicates were removed, and after title and abstract screening, 377 papers were excluded. Another 27 were excluded after full-text review, and 11 were included for data extraction and synthesis (Figure 1). A total of 23 studies were included for data extraction and synthesis from the 2 searches.

Half of the primary studies (6/12, 50%) were from the United States of America. The remaining primary studies were from Canada (2/12, 16.7%), the United Kingdom (2/12, 16.7%), France (1/12, 8.3%), and Sweden (1/12, 8.3%), as shown in Table 3. Most primary studies were conducted using quantitative methodologies (5/12, 42%), and fewer studies were conducted using qualitative (3/12, 25%) or mixed (4/12, 33%) methodologies. Each of the review studies included publications from several countries; however, in each review, at least more than 50% of the countries were OECD nations, as observed in Table 4. Among these 11 review studies, 1 (9%) focused on mental health settings [27], and the remaining 10 (91%) involved general health settings.

Table 3. Summary of the included primary studies.

Study	Country	Setting	EMR[a] implemented	Participants
Boyer et al [28]	France	Psychiatric hospital	Hospital EMR including coded data, unstructured text, and scanned paper documents	115 health professionals
Bruns et al [29]	United States	Mental health facilities	EMR with standardization of information, assessments, and diagnosis; facilitated a coordinated care plan, team communication, and routine reporting	34 wraparound care coordinators
Erlingsdóttir et al [30]	Sweden	Psychiatry services	Patient-accessible EMR	871 mental health professionals preimplementation; 699 postimplementation
Golberstein et al [31]	United States	Primary care clinics	EMR prompting specific mental health questions and enabling e-consult ordering with psychiatry	Primary care providers (457 in the first wave; 499 in the second) from 45 clinics
Jetelina et al [32]	United States	Primary care	EMR with referral pathways, screening tools (point-and-click tools, drop-down menus, auto calculators, and auto population of some fields), and tracking and documentation of clinical and social information and goal setting	6 community care clinics with a mix of primary care, and psychology and social work
Madden et al [33]	United States	Medical practice	Not specified	Health insurance plan members with depression (5140), bipolar disorder (462), and a control group (43,582)
Martin et al [34]	Canada	Psychiatric hospital	Not specified	24 nurses
Reyes-Portillo et al [35]	United States	Child and youth psychiatry clinic	Alert in existing EMR that triggered a safety plan when a suicidal ideation, a plan, or an attempt was recorded	40 mental health clinicians
Riahi et al [36]	Canada	Mental health facility	EMR containing closed-loop medication administration, assessment and screening tools, care plan, details of restraint and seclusion, clinical practice guidelines, and infection control details	1300 facility staff
Ser et al [37]	United Kingdom	Mental health hospitals	Interoperable EMR	33 hospital staff
Skelton et al [38]	United Kingdom	Older adult psychiatric inpatient ward	Out-of-hours handover built into existing EMR	10 doctors
Stanhope et al [39]	United States	Community mental health clinics	Delivering person-centered care in the context of different EMRs	31 clinical supervisors and 52 direct care staff

[a] EMR: electronic medical record.

Table 4. Summary of the included reviews.

Study	Country (number of studies)	Setting	EMR[a] implemented	Included studies, n
Baumann et al [40]	United States (12), Australia (5), Germany (5), United Kingdom (1), Canada (1), Austria (1), Denmark (1), Greece (1), and France (1)	Academic, private, and community hospitals	Not specified	28
Boonstra et al [41]	United States (17), Canada (2), Norway (1), and Ireland (1)	General health settings	Not specified	22
Castillo et al [42]	United States (52), Canada (4), Australia (3), Germany (2), International group (1), Denmark (1), France (1), Sweden (1), Hong Kong (1), United Kingdom (1), and Norway (1)	General health settings	Not specified	68
Delardes et al [43]	United Kingdom (4), United States (3), Ireland (1), and Taiwan (1)	General health settings	Not specified	9
Gephart et al [44]	United States (4) and Sweden (1)	General health settings	Not specified	5
Goldstein et al [45]	United States (8), Austria (1), Brazil (1), Canada (1), and Switzerland (1)	General health settings	Not specified	12
Goldzweig et al [46]	United States (20), France (1), Canada (1), and Austria (1)	Academic medical centers	Classification of radiology ordering of EMR interventions into four categories: (1) display of information, (2) patients' clinical information linked with recommendations, (3) soft stop if order contradicts recommendations, and (4) hard-stop software preventing inappropriate ordering	23
Lau et al [47]	United States (11), United Kingdom (10), the Netherlands (5), Canada (4), Australia (4), Norway (2), and New Zealand (2)	General health settings	Not specified	43
Meißner and Schnepp [48]	United States (4) and Australia (3)	Residential aged care facilities	Not specified	7
Nguyen et al [49]	United States (62), Denmark (5), England (5), Norway (4), Canada (3), Sweden (1), Australia (2), the Netherlands (2), Ireland (2), Israel (2), Austria (1), Cyprus (1), France (1), Serbia (1), Sweden (1), Japan (1), Korea (1), Kuwait (1), Cameroon (1), and Uganda (1)	General health settings	Not specified	98
Strudwick and Eyasu [27]	Germany (1), England (2), France (1), Finland (1), United States (1), and Sweden (1)	Mental health/ psychiatric clinic settings	Not specified	7

[a] EMR: electronic medical record.

Quality Assessment

The primary studies scored highly on the modified Hawker appraisal tool [23], with an average score of 30.3 (SD 3.81) out of a possible 36. The reviews scored an average of 7.6 (SD 1.45) out of a possible score of 11 on the Joanna Briggs Institute Critical Appraisal Checklist for Systematic Reviews and Research Syntheses [25] (see Table S1 of Multimedia Appendix 2 for details).

Features of Implemented EMRs

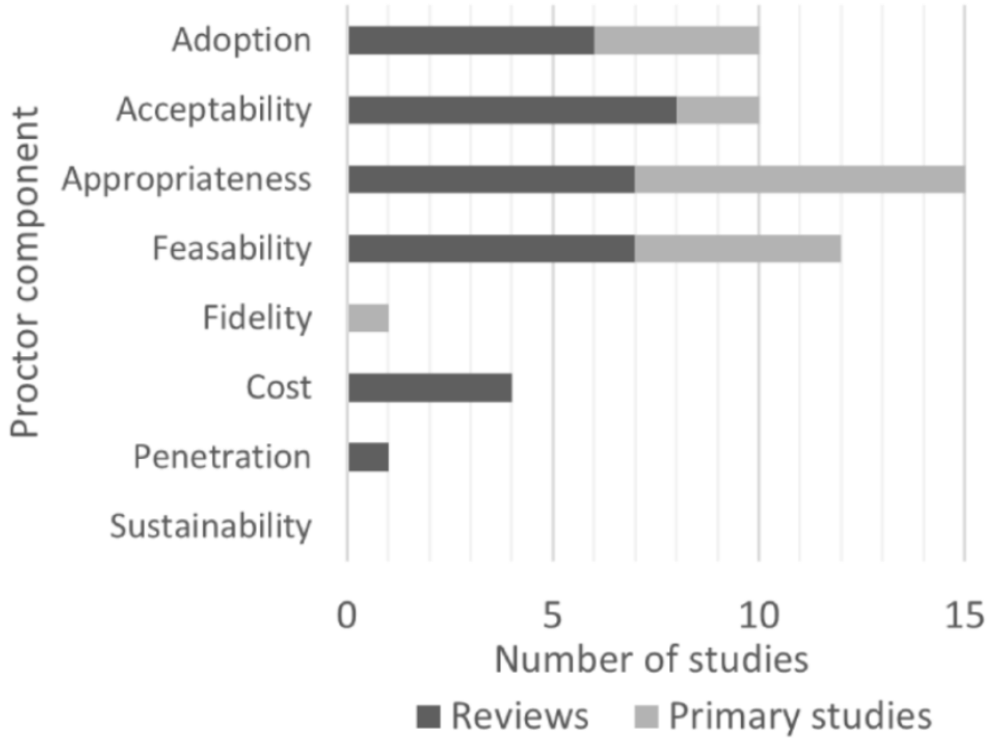
The features of the EMRs were described in 8 of the 12 (66.7%) primary studies in mental health settings. Features ranged from the simple electronic storage of personal and health information documentation [28], e-ordering of consultations [31], and capability to enter free-text notes [30] to features that aimed to improve care quality including embedded assessment tools [32,35,36], and care coordination plans [29,32,38]. Specific examples included implementing automated alerts to develop safety plans for children and youth with suicidal ideations [35] and embedding an e-consultation pathway prompt linking primary health providers with a psychiatrist [31]. Overall, the description of EMR features was limited among the included studies. Four studies did not report on specific features; instead, they simply described the EMRs as storage of clinical notes and test results to improve the accuracy and completeness of clinical information [33,34,37,39]. Only 1 of the 11 (9.1%) reviews provided a comprehensive description of EMRs among the included studies [46] (Table 4).

Implementation Outcomes and Determinants

Adoption

Adoption was reported in 10 of the 23 included studies (43.5%), namely 4 of the 12 primary studies (33.3%) [29,32,33,38] and 6 of the 11 reviews (54.5%) [27,41,42,45,48,49], as shown in Figure 2. Factors influencing the adoption of EMRs fell into three categories: organizational, technical, and financial.

Figure 2. Implementation outcomes and determinants in primary studies and reviews.



First, in the primary studies, high adoption rates were attributed to organizational support and prioritization [29], strong leadership and buy-in, greater capacity and willingness to change, engagement of staff, and formal training [32]. In contrast, poor leadership and buy-in, high staff turnover, and poor capacity or unwillingness to change, resulted in lower adoption rates [32]. Two primary studies suggested that adoption was high without reflecting on the reasons for this [29,38]. Similarly, the reviews reported that organizational structure, readiness for change, participation of leaders and end users in planning and implementation, and support for end users impacted adoption [41,42,49]. Specifically, adoption was facilitated by training [49], larger facility sizes [41,45], clinical champions/leaders [41,49], and the removal of all paper-based notes [49]. A lack of clear implementation plans was identified as an important limitation to adoption [49].

In 6 of the 11 (54.5%) reviews, adoption was reported to be limited by the technological functions and design of EMRs such as perceived limited functionality [41,45,48,49], interoperability [41,42,45,49], lack of technical support, limited clinician technical skills (real or perceived) [27,41,42,45,49], insufficient hardware [41,45,49], and system failures (software or hardware breakdowns, errors, and need for frequent rebooting) [49]. None of the primary studies reflected on technological factors influencing adoption.

One review concluded that the start-up financial cost of EMRs were the second most common barrier to adoption, after technical issues [45]. Three other reviews also cited high start-up costs as a barrier to adoption [41,45,49]. None of the primary studies reported on cost factors influencing adoption.

Acceptability

Among the included studies, 2 out of the 12 primary studies (16.7%) [35,38] and 8 out of the 11 reviews (72.7%) [27,41,42,44-46,48,49] reported on clinician acceptance of (or satisfaction with) the implemented EMRs or aspects of EMRs (Figure 2). Reviews reported that positive clinician attitudes were necessary for successful adoption of EMRs [42,45,48].

However, clinician satisfaction with EMRs varied in primary studies and reviews.

One primary study found that mental health clinicians were neutral about the addition of an alert for a mental health safety plan in EMRs [35], whereas another found there were fewer complaints regarding the quality of clinical handover following the introduction of out-of-hours electronic handover systems in the EMRs [38].

In reviews, poor clinician satisfaction was associated with perceptions that the new software was complex, it took time to learn and use, and that time could be used for patient care [41,45,46,49]. There were also concerns regarding patient data privacy [27,41,44,45,48]. Rigidly designed EMRs and exclusion of end users from design processes [27,41,44], poor trust in the quality of EMR vendors [41], the perception that the software demanded excessive detail [49], and previous negative experiences or negative beliefs about the usefulness of EMRs were additional important barriers to acceptability [41,49]. Likewise, one review identified that high satisfaction was associated with the perceived reliability and usability of EMRs, and adequate support for end users [49].

Appropriateness

The perceived appropriateness of EMRs was reported in 7 of the 11 reviews (63.6%) and 8 of the 12 primary studies, as shown in Figure 2. Clinicians often assessed EMRs as appropriate or inappropriate based on their perceived impact on the clinical workflow and productivity, quality of clinical documentation, quality of care, and patient-clinician relationships.

In the primary studies, mental health clinicians perceived EMRs as appropriate when access to documentation improved [28], the time needed to send reminders to patients decreased [29], administration time decreased [29], and time was saved on documenting follow-up appointments owing to prefilled data [32]. On the other hand, mental health clinicians believed that EMRs lacked appropriateness when workflows were blocked or slowed [28], and when clinicians needed to take additional time to design workarounds for EMRs that did not meet their needs [37,39]. Similarly, in the reviews, EMRs reportedly lacked appropriateness when documentation time increased [41], at least temporarily [48], whereas other reviews found EMRs to be appropriate when access to documentation improved [27], and when there was minimal impact on documentation time [49]. One review further identified that although EMRs saved documentation time, the standard forms were not always appropriate for documenting assessments, treatments, and goals for patients receiving mental health care [27].

In the reviews, perceptions of improved documentation quality in terms of legibility, accuracy, completeness, and consistency were associated with clinicians' views that EMRs were appropriate [44,48,49]. However, some clinicians in mental health settings [27,30] and in general health settings [44,49], believed that EMRs lacked appropriateness owing to the requirement of excessive or redundant information or when access to patient notes became a "watered-down" version of free-text clinical notes that lacked detail [30].

Across the primary studies and reviews, EMRs were perceived as appropriate if they were also perceived to be effective in terms of improving patient care [38] through supported decision-making based on availability of up-to-date information [30,31,48,49], better team communication, and averted potential medication errors [48,49].

One review suggested that EMRs improved patient-clinician interactions owing to the accessibility of information to clinicians [49]. Other reviews found EMRs that impacted decision-making processes and workflows left clinicians feeling devalued in their clinical role and were hence considered inappropriate [42,45]. No primary studies discussed the acceptability and impact of EMRs on the patient-clinician relationship.

Feasibility

Feasibility of the EMRs or EMR components was investigated in 5 out of the 12 primary studies (41.7%) [33-36,38] and 7 out of the 11 reviews (63.6%) [27,40,41,43,46,47,49] (Figure 2). Across all studies, the feasibility of implementation and use of EMRs by clinicians was assessed through proxies such as documentation outcomes (time taken and completeness), frequency of adverse events, quality of care, and face-to-face clinical time. These outcome measures differ from those used under adoption, acceptability, and appropriateness, as these include quantifiable impacts of the implemented EMRs or the actual fit for purpose rather than perceptions or opinions.

In the reviews, the measured impacts included improved documentation time, as mentioned in one review involving mental health settings [27], whereas others found no difference [40,41]. Documentation time was not quantified in any of the primary studies.

Completeness of documentation varied, with one review reporting increased completeness [49], whereas another one found no impact [43]. In the primary studies, an alert system increased the number of completed mental health safety plans [36] and reduced the amount of missing data [34]. However, another primary study found that events (eg, emergency department and hospital visits or mental health diagnoses and related procedures) for mental health patients were less likely to be recorded in EMRs compared with other types of patients [33].

The impact on patient outcomes was rarely reported. A primary study found that an electronic handover system was associated with a downward trend in adverse events, but this was not statistically significant [38]. A review found that EMRs had no impact or had a small impact on adverse events such as hospital readmission [43].

Impacts of EMRs on care quality in mental health settings were not reported. However, reviews reported that EMRs reduced the time from orders to procedures [43], decreased medication errors [47], and improved appropriate ordering of radiographic tests, although they increased the number of missed tests [46].

Cost

None of the primary studies assessed the cost-effectiveness of EMRs. However, 4 of the 11 reviews identified that cost was a barrier to adoption [41,42,49], and interoperability of EMRs could improve long-term costs [45]; there was no evidence that costs decreased owing to improved administrative effectiveness [49]. In addition, the ongoing costs of maintaining and upgrading EMRs were reported to be high and the return on investment uncertain [41].

Fidelity, Penetration, and Sustainability

These domains were seldom addressed across all the 23 included studies. One primary study reported improved patient-centered care, which was one of the intended impacts (fidelity) of that specific EMR system [39], and a review reported that the rate of EMR usage across clinical settings was exceedingly slow [49]. No study addressed the sustainability of the implemented EMRs.

Discussion

Principal Findings

In mental health settings, the adoption of EMRs is seemingly impacted by technical and organizational factors, as well as by clinician perceptions of appropriateness and acceptability. Clinicians perceived EMRs as acceptable and appropriate if they improved documentation completeness without interrupting workflow. Clinicians tend to value EMRs that support quality of care, are fit for purpose, have readily available technical support, and do not interfere with the clinician-patient relationship. Overall, the body of evidence specific to mental health was small. The implementation determinants and outcomes identified in general health settings aligned with and expanded on the mental health–specific findings. For example, the cost of implementation was identified as an additional barrier to adoption, apart from the technical and organizational factors identified in the mental health literature. However, evidence from general health settings did not consider the unique challenges of implementing EMRs in mental health settings. We have drawn on the evidence from general and mental health settings to make three recommendations for future implementation of EMRs in mental health settings.

Firstly, EMR implementation requires embedded long-term evaluation. In this review, we identified that approximately half of the studies focused on the early‐to-middle stage implementation outcomes (ie, adoption, acceptability, appropriateness, and feasibility) [13], whereas later‐stage implementation outcomes (ie, penetration and sustainability) [13] and implementation costs were rarely evaluated. Fidelity was assessed in only one primary study in a mental health setting. This is in contrast with the implementation research outside of research on EMRs, where implementation fidelity has more often been assessed compared with other outcomes [13]. This may be related to the nature of EMR technologies, which can be tailored and used flexibly to suit particular practices or service needs [50]. Sustainability was also not reported in any of the included studies, a finding that is consistent with implementation research outside of the EMR field where the assessment of program sustainability has been identified as a neglected area [13,51,52]. Limited research on the cost, fidelity, penetration, and sustainability of EMRs suggests limited evaluation and impact assessment, and the lack of long-term goal setting, particularly at the organizational level. We recommend that future implementation of EMRs in mental health settings must include continuous and embedded evaluation to explore long-term outcomes and impacts for health professionals and patients while identifying the determinants of cost, fidelity, penetration, and sustainability. Findings from thorough evaluations are needed to inform the future design, policies, and uptake of EMRs in mental health and other health settings.

Secondly, implementation of EMRs needs to adopt co-design principles and a human factors approach, including clinician participation in formative and summative usability testing prior to and during implementation [53,54]. The successful uptake of EMRs is influenced by clinicians' perceptions of appropriateness and acceptability. In mental health settings, this was negatively impacted when EMRs misaligned with established workflows. It was also affected by organizational factors such as high staff turnover, low staff buy-in, and low capacity or willingness to change shown by clinicians. Evidence from general health settings suggests that these determinants can be modified by specific facilitating features such as staff training, clinical champions, buy-in from clinicians and leaders, IT support, and, above all, good fit for purpose with minimal disruption to clinical workflows. However, EMRs are commonly designed by IT professionals; although well intentioned, the software is often insufficiently flexible to meet the needs of clinicians at the frontlines of care [55]. Good fit with clinical workflows and local clinical contexts can be achieved through user-centered design processes and collaboration between clinicians and IT professionals [56,57]. Outside of this review and in general health settings, authors have recommended routine use of co-design principles and frameworks, formative evaluations in consultation with clinicians, and frameworks to assess the fit of off-the-shelf EMRs [58]. In the mental health–specific literature covered in this review, co-designing was not analyzed. In future, to enhance the fit of EMRs to the unique and sensitive clinical work undertaken in mental health, we recommend that the development and implementation of EMRs include co-design and formative evaluations to achieve an optimal fit to support usability for clinicians and patient centeredness.

Lastly, the implementation of EMRs needs to be guided by theories and frameworks to successfully navigate behavior change, and interactions between people and technology. In an environment where sensitive issues are addressed and building rapport and trust with patients is especially important, simply "injecting technology" is unlikely to yield better care, experience for health professionals, or successful implementation. For example, in this review, organizational factors such as leadership and culture were the common determinants of EMR implementation [32,41,42]. It is also likely that external factors (eg, health system structure, funding, and governance) impact EMR implementation as seen in other areas of mental health [59]; however, this was not addressed in the included studies. Successful implementation of EMRs requires structured methodology and careful planning, as changes in a social environment often require new skills and can have unpredictable impacts [60]. We recommend that the development, planning, implementation, and evaluation of EMRs could be improved by applying appropriately structured guiding theories and frameworks (eg, behavior change theory [61] or the normalization process theory [62]).

Strengths and Limitations

Despite a rigorous search strategy, it is possible that some potentially relevant studies were missed owing to a wide range of terms used to describe EMRs (eg, health information systems and electronic health records). Nevertheless, our search strategy identified over 2000 potential publications across the two search strategies, reflecting its high level of comprehensiveness.

Further, the inconsistent use of implementation outcome terminologies across the literature and some degree of overlap among constructs as suggested by other publications [13,26] made it challenging at times to classify outcomes into the Proctor categories. Although this may have resulted in the misclassification of some findings, they were applied as closely as possible to the Proctor definitions. A robust process where classifications were reviewed by three of the authors (YZ, LAE, and IM) and any discrepancies were discussed until a consensus was reached is a methodological strength supporting our synthesis.

Lastly, although we assessed study quality using validated tools, owing to the limited evidence available, it was not feasible to exclude studies or distinguish findings based on quality. Quality assessment results are described in Table S2 of Multimedia Appendix 2.

Conclusion

The body of evidence about the implementation of EMRs in mental health settings is currently limited. Key enablers of the adoption of EMRs by clinicians in all health settings included clinician buy-in, staff training, IT support, and appropriate fit with the clinical context and workflows. Specific issues identified in mental health settings included limited suitability of the drop-down or checklist options and their impact on clinical workflows and patient-clinician interactions. Future implementation of EMRs could be facilitated through co-design with clinician end users, embedding routine implementation process evaluations, and including routine feedback from clinicians to facilitate adjustments and ensure usability and the best fit with the clinical context and person-centered care. Additionally, it is imperative that future implementations include embedded evaluations to assess long-term impacts on organizations, clinicians, and patients in mental health settings to inform future design, implementation, policy, and funding decisions. Lastly, the implementation of EMRs needs to recognize and address the interplay between the social factors and technical aspects of EMRs as a sociotechnical system to support successful uptake. Future research should consider the application of guiding social theories, implementation frameworks, and consistent use of terminology.

Acknowledgments

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Authors' Contributions

This study was designed by YZ, LAE, CT, RCW, and GS. The search strategy was executed by HLT and IM. Data extraction and screening were conducted by YZ, LAE, HLT, LL, LT, and IM. Quality was assessed by HLT, LT, and IM. The extracted data were assessed for consistency by YZ, HLT, LAE, and IM. The first draft of the results section was written by IM, LAE, and HLT. The final draft was completed by YZ, LAE and IM with inputs from LL, RCW, LT, IM, CT, and GS.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Inclusion and exclusion criteria.
[DOCX File , 17 KB - mental_v8i9e30564_app1.docx]

Multimedia Appendix 2
Quality appraisal results of primary studies and reviews.
[DOCX File , 22 KB - mental_v8i9e30564_app2.docx]

References

1. National Academy of Engineering (US), Institute of Medicine (US) Committee on Engineering and the Health Care System. Information and communications systems: the backbone of the health care delivery system. In: Building a Better Delivery System: A New Engineering/Health Care Partnership. Washington DC: National Academies Press; 2005.
2. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington DC: National Academy Press; 2001.
3. Lakbala P, Dindarloo K. Physicians' perception and attitude toward electronic medical record. SpringerPlus 2014;3:63 [FREE Full text] [doi: 10.1186/2193-1801-3-63] [Medline: 24516790]
4. Defining an electronic medical record. State of Victoria Department of Health. 2012. URL: http://www.health.vic.gov.au/divisions/fcs/cio.htm [accessed 2020-12-10]
5. Campanella P, Lovato E, Marone C, Fallacara L, Mancuso A, Ricciardi W, et al. The impact of electronic health records on healthcare quality: a systematic review and meta-analysis. Eur J Public Health 2016 Feb;26(1):60-64. [doi: 10.1093/eurpub/ckv122] [Medline: 26136462]
6. Imai C, Hardie R, Franco GS, Sezgin G, Tepper K, McLeod A, et al. Harnessing the potential of electronic general practice pathology data in Australia: an examination of the quality use of pathology for type 2 diabetes patients. Int J Med Inform 2020 Sep;141:104189 [FREE Full text] [doi: 10.1016/j.ijmedinf.2020.104189] [Medline: 32534436]
7. Delvaux N, Piessens V, Burghgraeve TD, Mamouris P, Vaes B, Stichele RV, et al. Clinical decision support improves the appropriateness of laboratory test ordering in primary care without increasing diagnostic error: the ELMO cluster randomized trial. Implement Sci 2020 Nov;15(1):100 [FREE Full text] [doi: 10.1186/s13012-020-01059-y] [Medline: 33148311]
8. Joukes E, Abu-Hanna A, Cornet R, de Keizer N. Time spent on dedicated patient care and documentation tasks before and after the introduction of a structured and standardized electronic health record. Appl Clin Inform 2018 Dec;9(1):46-53. [doi: 10.1055/s-0037-1615747] [Medline: 29342479]
9. Shah S. Addenbrooke's hospital £200m IT system proves an epic fail. Computing. 2015. URL: https://www.computing.co.uk/news/2427100/addenbrookes-hospital-gbp200m-it-system-proves-an-epic-fail [accessed 2020-12-10]
10. Bowman S. Impact of electronic health record systems on information integrity: quality and safety implications. Perspect Health Inf Manag 2013;10:1c [FREE Full text] [Medline: 24159271]
11. Ross J, Stevenson F, Lau R, Murray E. Factors that influence the implementation of e-health: a systematic review of systematic reviews (an update). Implement Sci 2016;11(1):146 [FREE Full text] [doi: 10.1186/s13012-016-0510-7] [Medline: 27782832]
12. Triplett P. Psychiatry and the meaningful use of electronic health records. Perspect Biol Med 2013;56(3):407-421. [doi: 10.1353/pbm.2013.0028] [Medline: 24375121]
13. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, et al. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Adm Policy Ment Health 2011;38(2):65-76 [FREE Full text] [doi: 10.1007/s10488-010-0319-7] [Medline: 20957426]
14. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med 2018 Oct;169(7):467-473 [FREE Full text] [doi: 10.7326/M18-0850] [Medline: 30178033]
15. Peters MDJ, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, et al. Updated methodological guidance for the conduct of scoping reviews. JBI Evid Synth 2020 Oct;18(10):2119-2126. [doi: 10.11124/JBIES-20-00167] [Medline: 33038124]
16. Kenyon LK, Krajenka VM, Lach K, VanBeek H, Williams B, Bower Russa M. Motivate-to-move: development of an intervention promoting parental adherence to early power mobility programs. Disabil Rehabil Assist Technol 2020 Nov:1-10. [doi: 10.1080/17483107.2020.1841310] [Medline: 33176102]
17. Country classification 2019 - as of 14 August 2019. Organisation for Economic Co-operation and Development. 2019. URL: https://www.oecd.org/trade/topics/export-credits/documents/oecd-export-credits-prevailing-list-of-countries-repayment-terms-and-aid-eligibility.pdf [accessed 2020-11-30]
18. Nilsen P. Making sense of implementation theories, models and frameworks. Implement Sci 2015 Apr;10:53 [FREE Full text] [doi: 10.1186/s13012-015-0242-0] [Medline: 25895742]
19. Clarivate Analytics. Endnote X8. Philadelphia: Clarivate Analytics; 2016.
20. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. Syst Rev 2016 Dec;5(1):210 [FREE Full text] [doi: 10.1186/s13643-016-0384-4] [Medline: 27919275]
21. Neely LC, Ganz JB, Davis JL, Boles MB, Hong ER, Ninci J, et al. Generalization and maintenance of functional living skills for individuals with autism spectrum disorder: a review and meta-analysis. Rev J Autism Dev Disord 2015 Nov;3(1):37-47. [doi: 10.1007/s40489-015-0064-7]
22. McHugh ML. Interrater reliability: the kappa statistic. Biochem Med (Zagreb) 2012;22(3):276-282 [FREE Full text] [Medline: 23092060]
23. Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: reviewing disparate data systematically. Qual Health Res 2002 Nov;12(9):1284-1299. [doi: 10.1177/1049732302238251] [Medline: 12448672]
24. Lorenc T, Petticrew M, Whitehead M, Neary D, Clayton S, Wright K. Crime, fear of crime and mental health: synthesis of theory and systematic reviews of interventions and qualitative evidence. Public Health Reserarch. Southampton, UK:

National Institute for Health Research; 2014. URL: https://www.journalslibrary.nihr.ac.uk/phr/phr02020/#/abstract [accessed 2021-08-27]

25. Checklist for systematic reviews and research syntheses. Joanna Briggs Insitute. 2017. URL: https://joannabriggs.org/sites/default/files/2019-05/JBI_Critical_Appraisal-Checklist_for_Systematic_Reviews2017_0.pdf [accessed 2020-06-20]
26. Long JC, Winata T, Debono D, Phan-Thien K, Zhu C, Taylor N. Process evaluation of a behaviour change approach to improving clinical practice for detecting hereditary cancer. BMC Health Serv Res 2019 Mar;19(1):180 [FREE Full text] [doi: 10.1186/s12913-019-3985-5] [Medline: 30894169]
27. Strudwick G, Eyasu T. Electronic health record use by nurses in mental health settings: a literature review. Arch Psychiatr Nurs 2015 Aug;29(4):238-241. [doi: 10.1016/j.apnu.2015.03.007] [Medline: 26165979]
28. Boyer L, Samuelian J, Fieschi M, Lancon C. Implementing electronic medical records in a psychiatric hospital: a qualitative study. Int J Psychiatry Clin Pract 2010 Sep;14(3):223-227. [doi: 10.3109/13651501003717243] [Medline: 24917324]
29. Bruns EJ, Hook AN, Parker EM, Esposito I, Sather A, Parigoris RM, et al. Impact of a web-based electronic health record on behavioral health service delivery for children and adolescents: randomized controlled trial. J Med Internet Res 2018 Jun;20(6):e10197 [FREE Full text] [doi: 10.2196/10197] [Medline: 29903701]
30. Erlingsdóttir G, Petersson L, Jonnergård K. A theoretical twist on the transparency of open notes: qualitative analysis of health care professionals' free-text answers. J Med Internet Res 2019 Sep;21(9):e14347 [FREE Full text] [doi: 10.2196/14347] [Medline: 31573905]
31. Golberstein E, Kolvenbach S, Carruthers H, Druss B, Goering P. Effects of electronic psychiatric consultations on primary care provider perceptions of mental health care: survey results from a randomized evaluation. Healthc (Amst) 2018 Mar;6(1):17-22. [doi: 10.1016/j.hjdsi.2017.01.002] [Medline: 28162990]
32. Jetelina KK, Woodson TT, Gunn R, Muller B, Clark KD, DeVoe JE, et al. Evaluation of an electronic health record (EHR) tool for integrated behavioral health in primary care. J Am Board Fam Med 2018;31(5):712-723 [FREE Full text] [doi: 10.3122/jabfm.2018.05.180041] [Medline: 30201667]
33. Madden JM, Lakoma MD, Rusinak D, Lu CY, Soumerai SB. Missing clinical and behavioral health data in a large electronic health record (EHR) system. J Am Med Inform Assoc 2016 Nov;23(6):1143-1149 [FREE Full text] [doi: 10.1093/jamia/ocw021] [Medline: 27079506]
34. Martin K, Ham E, Hilton NZ. Documentation of psychotropic pro re nata medication administration: an evaluation of electronic health records compared with paper charts and verbal reports. J Clin Nurs 2018 Aug;27(15-16):3171-3178. [doi: 10.1111/jocn.14511] [Medline: 29752835]
35. Reyes-Portillo JA, Chin EM, Toso-Salman J, Blake Turner J, Vawdrey D, Mufson L. Using electronic health record alerts to increase safety planning with youth at-risk for suicide: a non-randomized trial. Child Youth Care Forum 2018 Jan;47(3):391-402. [doi: 10.1007/s10566-018-9435-4]
36. Riahi S, Fischler I, Stuckey MI, Klassen PE, Chen J. The value of electronic medical record implementation in mental health care: a case study. JMIR Med Inform 2017 Jan;5(1):e1 [FREE Full text] [doi: 10.2196/medinform.6512] [Medline: 28057607]
37. Ser G, Robertson A, Sheikh A. A qualitative exploration of workarounds related to the implementation of national electronic health records in early adopter mental health hospitals. PLoS One 2014;9(1):e77669 [FREE Full text] [doi: 10.1371/journal.pone.0077669] [Medline: 24454678]
38. Skelton L, Rogers J, Kalafatis C. Development and implementation of electronic medical handovers across psychiatric hospitals: quality improvement initiative. BMJ Open Qual 2019;8(4):e000630 [FREE Full text] [doi: 10.1136/bmjoq-2019-000630] [Medline: 31799446]
39. Stanhope V, Matthews EB. Delivering person-centered care with an electronic health record. BMC Med Inform Decis Mak 2019 Aug;19(1):168 [FREE Full text] [doi: 10.1186/s12911-019-0897-6] [Medline: 31438960]
40. Baumann LA, Baker J, Elshaug AG. The impact of electronic health record systems on clinical documentation times: a systematic review. Health Policy 2018 Aug;122(8):827-836. [doi: 10.1016/j.healthpol.2018.05.014] [Medline: 29895467]
41. Boonstra A, Broekhuis M. Barriers to the acceptance of electronic medical records by physicians from systematic review to taxonomy and interventions. BMC Health Serv Res 2010 Aug;10:231 [FREE Full text] [doi: 10.1186/1472-6963-10-231] [Medline: 20691097]
42. Castillo VH, Martínez-García AI, Pulido JRG. A knowledge-based taxonomy of critical factors for adopting electronic health record systems by physicians: a systematic literature review. BMC Med Inform Decis Mak 2010 Oct;10:60 [FREE Full text] [doi: 10.1186/1472-6947-10-60] [Medline: 20950458]
43. Delardes B, McLeod L, Chakraborty S, Bowles K. What is the effect of electronic clinical handovers on patient outcomes? a systematic review. Health Informatics J 2020 Dec;26(4):2422-2434. [doi: 10.1177/1460458220905162] [Medline: 32114869]
44. Gephart S, Carrington JM, Finley B. A systematic review of nurses' experiences with unintended consequences when using the electronic health record. Nurs Adm Q 2015;39(4):345-356. [doi: 10.1097/NAQ.0000000000000119] [Medline: 26340247]
45. Goldstein DH, Phelan R, Wilson R, Ross-White A, VanDenKerkhof EG, Penning JP, et al. Brief review: adoption of electronic medical records to enhance acute pain management. Can J Anaesth 2014 Feb;61(2):164-179. [doi: 10.1007/s12630-013-0069-6] [Medline: 24233770]

46. Goldzweig CL, Orshansky G, Paige NM, Miake-Lye IM, Beroes JM, Ewing BA, et al. Electronic health record-based interventions for improving appropriate diagnostic imaging: a systematic review and meta-analysis. Ann Intern Med 2015 Apr;162(8):557-565 [FREE Full text] [doi: 10.7326/M14-2600] [Medline: 25894025]
47. Lau F, Price M, Boyd J, Partridge C, Bell H, Raworth R. Impact of electronic medical record on physician practice in office settings: a systematic review. BMC Med Inform Decis Mak 2012 Feb;12:10 [FREE Full text] [doi: 10.1186/1472-6947-12-10] [Medline: 22364529]
48. Meißner A, Schnepp W. Staff experiences within the implementation of computer-based nursing records in residential aged care facilities: a systematic review and synthesis of qualitative research. BMC Med Inform Decis Mak 2014 Jun;14:54 [FREE Full text] [doi: 10.1186/1472-6947-14-54] [Medline: 24947420]
49. Nguyen L, Bellucci E, Nguyen LT. Electronic health records implementation: an evaluation of information system impact and contingency factors. Int J Med Inform 2014 Nov;83(11):779-796. [doi: 10.1016/j.ijmedinf.2014.06.011] [Medline: 25085286]
50. Cohen DJ, Crabtree BF, Etz RS, Balasubramanian BA, Donahue KE, Leviton LC, et al. Fidelity versus flexibility: translating evidence-based research into practice. Am J Prev Med 2008 Nov;35(5 Suppl):S381-S389. [doi: 10.1016/j.amepre.2008.08.005] [Medline: 18929985]
51. Ellis LA, Augustsson H, Grødahl AI, Pomare C, Churruca K, Long JC, et al. Implementation of e-mental health for depression and anxiety: a critical scoping review. J Community Psychol 2020 Apr;48(3):904-920. [doi: 10.1002/jcop.22309] [Medline: 31944324]
52. Shelton RC, Cooper BR, Stirman SW. The sustainability of evidence-based interventions and practices in public health and health care. Annu Rev Public Health 2018 Apr;39:55-76. [doi: 10.1146/annurev-publhealth-040617-014731] [Medline: 29328872]
53. Carayon P, editor. Handbook of human factors and ergonomics in health care patient safety. Mahwah, NJ: Lawrence Erlbaum Associates; 2007.
54. Wiklund M, Kendler J, Strochlic A. Usability Testing of Medical Devices. Boca Raton: CRC Press; 2016.
55. Evans RS. Electronic health records: then, now, and in the future. Yearb Med Inform 2016 May;Suppl 1:S48-S61 [FREE Full text] [doi: 10.15265/IYS-2016-s006] [Medline: 27199197]
56. Bardach SH, Real K, Bardach DR. Perspectives of healthcare practitioners: an exploration of interprofessional communication using electronic medical records. J Interprof Care 2017 May;31(3):300-306 [FREE Full text] [doi: 10.1080/13561820.2016.1269312] [Medline: 28151026]
57. Elias B, Barginere M, Berry PA, Selleck CS. Implementation of an electronic health records system within an interprofessional model of care. J Interprof Care 2015;29(6):551-554. [doi: 10.3109/13561820.2015.1021001] [Medline: 25955512]
58. Ratwani RM, Zachary Hettinger A, Kosydar A, Fairbanks RJ, Hodgkins ML. A framework for evaluating electronic health record vendor user-centered design and usability testing processes. J Am Med Inform Assoc 2017 Apr;24(e1):e35-e39 [FREE Full text] [doi: 10.1093/jamia/ocw092] [Medline: 27375292]
59. Bruns EJ, Parker EM, Hensley S, Pullmann MD, Benjamin PH, Lyon AR, et al. The role of the outer setting in implementation: associations between state demographic, fiscal, and policy factors and use of evidence-based treatments in mental healthcare. Implement Sci 2019 Nov;14(1):96 [FREE Full text] [doi: 10.1186/s13012-019-0944-9] [Medline: 31722738]
60. Sales A, Smith J, Curran G, Kochevar L. Models, strategies, and tools. theory in implementing evidence-based findings into health care practice. J Gen Intern Med 2006 Feb;21 Suppl 2:S43-S49 [FREE Full text] [doi: 10.1111/j.1525-1497.2006.00362.x] [Medline: 16637960]
61. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci 2011 Apr;6:42 [FREE Full text] [doi: 10.1186/1748-5908-6-42] [Medline: 21513547]
62. Murray E, Treweek S, Pope C, MacFarlane A, Ballini L, Dowrick C, et al. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. BMC Med 2010 Oct;8:63 [FREE Full text] [doi: 10.1186/1741-7015-8-63] [Medline: 20961442]

Abbreviations

EMR: electronic medical record
IT: information technology
OECD: Organisation for Economic Co-operation and Development

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Original Paper

Designing Videos With and for Adults With ADHD for an Online Intervention: Participatory Design Study and Thematic Analysis of Evaluation

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Abstract

Background: Adults with attention deficit hyperactivity disorder (ADHD) represent a heterogeneous group with both strengths and difficulties associated with the diagnosis. An online intervention attuned to their needs may improve their everyday functioning. When designing online interventions, it is important to adapt the therapeutic content to the values and needs of the target group.

Objective: This paper describes and evaluates a participatory process used to produce content for an online intervention for adults with ADHD by producing video vignettes clarifying core training principles grounded in the participants' everyday experiences.

Methods: We report on the qualitative data from 2 research phases: the design and evaluation of video vignettes for an online intervention. In the first phase, 12 adults with ADHD, 2 clinicians, and 2 research assistants participated in the production of video vignettes for the online intervention. In the second phase, participants (n=109) gave feedback on the videos as part of a clinical trial of the intervention. A subgroup (n=7) was interviewed in-depth regarding their experiences with the videos. The qualitative data were analyzed using thematic analysis.

Results: In the first phase, the participants with ADHD contributed with experiences from challenging everyday situations. In the process, we navigated between therapeutic principles and the participants' experiential perspectives to create content relevant and consistent with the target group's values and experiences. In the second phase, we identified 3 themes related to the participants' experiences and interpretation of the video vignettes: (1) recognition of ADHD-related challenges, (2) connection with the characters and the situations, and (3) video protagonists as companions and role models for change.

Conclusions: A participatory design process for designing online mental health interventions can be used to probe and balance between the therapeutic principles defined by clinicians and the participants' experiences with mental health issues in the production of therapeutic content. In our study, the inclusion of video vignettes in an online intervention enabled a contextualized and relevant presentation of everyday experiences and psychosocial factors in the life of an adult with ADHD.

Trial Registration: ClinicalTrials.gov NCT04511169; https://clinicaltrials.gov/ct2/show/NCT04511169

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KEYWORDS

participatory design; ADHD; online intervention; video; therapeutic content; stigma; attention deficit hyperactivity disorder; design; participatory; intervention; experience; mental health

Introduction

Background

Interactive technology has the potential to enhance mental health treatments by improving their access, affordability, and effectiveness [1]. When designing online psychological interventions, emphasis on engagement and relevance for the users is a key element [2-5]. To achieve this engagement, a match between the intervention's content and the person's psychosocial and behavioral characteristics is essential [6], as it can lead to higher satisfaction and, thereby, higher engagement and better outcomes [7]. Moreover, considering the perspective of people with mental illnesses has been recognized as a way to ensure that the content is relevant and consistent with their values [8-10]. Previous studies have, therefore, employed person-centered approaches when designing content for online interventions, such as user-centered [4,9] and participatory [11] design methods.

In general, online interventions with guidance from a supporter (eg, a therapist) result in higher engagement and improved treatment outcomes when compared to unguided interventions [7,12]. This means that the social interaction with a supporter is a primary contributing factor to the success of the intervention [13]. Unguided interventions are still commonly chosen when searching for low-cost therapeutic resources for people with limited access to mental health care services [14]. Unguided interventions do, however, place new demands on how therapy should be presented to clients [7]. Without a relationship between client and a therapist, an unguided intervention regimen requires content that is clearly recognizable to the target group [7]. Generally, people expect a user experience (see [15]) that caters to their needs and desires related to the technology and the context of use [16]. In a similar vein, Borghouts et al [7] found that people are more likely to engage with an online intervention if they experience "the program to be useful and a good fit for them" [7].

Adults with attention deficit hyperactivity disorder (ADHD) are expected to benefit from an unguided online intervention, as it is a low-cost, easily accessible, and flexible alternative. This is related to the disorder's frequency, with an estimated prevalence of 2%-7% [17]; heterogeneity; and characteristics. ADHD in adults is defined by core symptoms of inattention, impulsivity, and hyperactivity [18] and persistence of symptoms from childhood [19,20]. They frequently report problems related to self-regulation [21,22] and commonly face several everyday challenges [23,24]. Pharmacological treatment is the first choice of intervention for this disorder, but many adults commonly ask for nonpharmacological alternatives [25]. Still, most individuals with ADHD do not have access to psychological treatment in adulthood [25]. Technology may, thus, represent an opportunity to support adults with ADHD [26].

Qualitative studies of everyday experiences of people with ADHD provide insight into the lived experiences of having ADHD and demonstrate how the term "people with ADHD" refers to a heterogeneous group and that there are several positive traits attributed to the disorder. In a study by Holthe and Langvik [27], a group of women with ADHD reported positive attributes such as "high energy, creativity, determination, ability to get easily interested and excited about new things, adventurousness, and willingness to take risks" [27]. In another study, diagnosed adults reported curiosity and hyperfocus as positive attributes of their disorder [28]. In a study by Wiklund et al [29], entrepreneurs with ADHD defined their impulsivity and hyperfocus as the major drivers of their entrepreneurial action. However, the participants in the study by Holthe and Langvik [27] also described challenges in everyday life, including poor time management of daily plans and procrastination of tasks that lead to a sense of constantly being behind schedule. Adults with ADHD who were diagnosed in adulthood (ie, growing up with undiagnosed and untreated ADHD) reported that they were ridiculed and received negative comments from their peers and families during childhood, such as being referred to as "stupid, lazy, and disruptive" [30]. The participants in this study also reported that they coped with the negative feedback by either accepting the remarks as accurate representations of their character or by ignoring the remarks altogether to evade feelings of low self-esteem [30].

Public stigma causes additional challenges for people with ADHD [31-38]. Stigma refers to socially situated characteristics of a person that enable the dehumanizing processes of prejudice, stereotypification, and discrimination [39]. Stigma toward people with mental disorders is common, imposing social misfortunes on them [35,40]. In adults with ADHD, public stigma is commonly converted into self-stigmatization, a tendency to internalize negative public attitudes and beliefs of one's characteristics [41,42]. Consequently, they may experience decreased quality of life, discontinuation of treatment, social isolation, and low self-esteem and self-efficacy [37,40]. Young et al [30] showed that adults with ADHD who learned to emotionally accept their diagnosis and themselves, ultimately, had enhanced self-esteem and received improved support from people close to them. Similarly, in a study with adolescents with ADHD reporting retrospectively on self-stigmatization [43], some participants had gained resilience against negative judgments through the confidence in themselves and the acceptance by those close to them.

Disclosures of mental health in social media have challenged public stigma and empowered people with mental health issues [44-48]. Visual stories have particularly influenced the connection and empowerment of those with lived experiences similar to those disclosed [46,49,50]. Feuston and Piper [51] focused on how people share narratives of their mental illness on social media, through the analytical framework of small stories [52], emphasizing their importance in understanding mental illness from an experiential point of view. This type of health communication differs from the prescriptive, fact-based style of clinicians' expertise since patients' expertise is characterized by a narrative style of coping with day-to-day challenges by trial and error [53]. Moreover, it is recognized that seeing how others handle everyday situations can contribute to learning of new behavior (eg, Bandura's social cognitive theory [54,55]). Studies on how people disclose their struggles with mental illness on social media and the associated engagement with these media should have implications on the content design of online interventions. Narrative communication has also been used as a tool in health behavior change [56], recently by the use of short videos in an intervention for reducing stigma towards people with schizophrenia [57,58] and increasing treatment seeking for depression [59]. In these videos, schizophrenia is presented "with a human face rather than as a 'brain disease'" [57] and show people with severe mental illness being capable of working and having meaningful relationships. Addressing the experiences of adults with ADHD through an everyday lens [51] was, therefore, our objective when designing therapeutic content that is relatable and relevant to the target group.

Aims and Objectives

This study goes beyond the focus on the management of core symptoms and considers everyday experiences of adults with ADHD in the design of an online intervention. We explored how a participatory approach can ensure that the participants' perspectives are included in the design of psychoeducative therapeutic content in mental health interventions. With this aim, we directly included adults with ADHD in the design process to empower their perspective through active participation. In this study, their experiences were ultimately represented as video vignettes in an online intervention, which aimed at communicating the therapeutic principles and coping techniques. A further aim of this study was to explore how participants in an online intervention experienced and made sense of the video vignettes.

Methods

Study Design

The qualitative research presented in this paper was conducted in 2 phases: (1) a participatory process for the design of video vignettes as psychoeducative, therapeutic content for an online intervention for adults with ADHD; (2) the collection and analysis of qualitative feedback on the video vignettes during and after a clinical trial of the online intervention.

Study Context: "MyADHD" Online Intervention

The intervention addressed in this paper, MyADHD, was designed as a modular web-based course. Once a module was opened, the participant could browse freely within all the available modules and revisit content as they saw fit. MyADHD is comprised of 7 modules representing different topics (Introduction, Breathing, Stop, Emotions, Planning, Acceptance, and Conclusion). Each of the first 6 modules included psychoeducative information, skill-building exercises, and coping techniques for everyday challenges for adults with ADHD. Additionally, each module featured 2 video vignettes that explained the use of coping techniques and contextualized their suitability and application.

The process of designing the intervention was established on the *person-based approach* [4,60]. In designing the program's content, the method was extended by including adults with ADHD as co-designers through a 3-year participatory process. The intervention builds on the therapeutic principles of cognitive behavioral therapy (CBT), Goal Management Training, and dialectical behavioral therapy (DBT). The intervention aims to improve everyday functioning in adults with ADHD by providing psychoeducation, skill-building exercises, and coping techniques.

Phase 1: Participatory Design Study

Participatory Design

We position our design process as participatory design [61-64]. According to Ehn [61], this approach to designing technology is strategically motivated from 2 different levels: (1) a democratic commitment to ensure the end users' representation in the processes of making technology that concerns them [61,64] and (2) "the importance of making the participants' (*sic*) tacit knowledge come into play in the design process" [61]. Our study was essentially concerned with the second level: the engagement of those with an ADHD diagnosis in the design process.

Participants

A total of 12 participants were recruited from a local division of a nationwide, voluntary patient organization for people with ADHD and their relatives. The participants were defined as experts by experience. Originally, 3 participants were recruited by convenience sampling. When the participatory design process reached a stage where we were designing content, the number of participants was increased to 12 to improve the representation of the diversity in the target group. This further recruitment was done by combining convenience and snowball sampling. Participants were given a gift certificate of 200 NOK (US $24) for their contribution to the design process.

The team also included 2 clinical psychologists (clinicians) and 2 clinical psychology students employed as research assistants in this study (assistants). These participants had a facilitating role in the design process.

Workshops

To understand preferences and needs for web-based services, the research team invited a small group of adults diagnosed with ADHD (n=3) to participate in meetings and workshops. In an early meeting, they were asked to discuss and evaluate the benefits of already available information (eg, social media, webpages, YouTube), and to present their evaluations at the next meeting with the research team. Videos on social media were their preferred format, exemplified by videos presented by a YouTube ADHD health vlogger (eg, "How to ADHD" on YouTube [65]). The participants emphasized the light-hearted, self-deprecating humor displayed on the YouTube videos and described the importance of not being talked down to by someone in a "superior position" (the participants' quote). From this and other follow-up discussions, the research team decided to design short video vignettes as the core content of the online intervention.

The participatory design process was predominantly performed through workshops where the different parties (ie, participants, clinicians, and assistants) discussed and committed to shared goals by the methods of ideation and co-design. The workshops were organized by the clinicians and the assistants and were documented by note-taking and archiving workshop materials. In the workshops, the facilitators asked open-ended questions to engage participants in discussions of how ADHD impacted their everyday lives and how they coped with challenging situations.

Phase 2: Evaluation

Overview

The evaluation presented in this paper was done as part of a clinical trial conducted between May 2020 and October 2020. Participants were expected to complete the MyADHD intervention over 7 weeks, with 1 new module becoming accessible every week regardless of the participants' progression. The intervention was unguided, with the only supporter interaction being a pretrial telephone screening and an automated SMS text messaging notification each time a new module was released. The criteria for inclusion in the study were (1) age 18 years or above at inclusion and (2) a self-reported diagnosis of ADHD. Exclusion criteria were (1) current self-reported diagnosis of a severe psychiatric disorder and (2) other ongoing psychological treatment. The patient organization distributed a recruitment website on their Facebook Pages in May 2020, 2 months into the global COVID-19 outbreak. The study was approved by The Regional Committee for Medical Research Ethics of Western Norway (2020/90483).

Participants

The clinical trial included 109 participants, 88 of whom (80.7%) identified as women and 21 (19%) as men. Participants' ages ranged from 22 to 62 years (mean 36 years, SD 9 years). More than half of the participants (62/109, 56.9%) reported having completed university- or college-level education. At the time of inclusion, 67.9% (74/109) reported being employed or students, and 32.1% (35/109) were on sick leave or unemployed or received a disability pension. The participants' pretrial scores on the Adult ADHD Self-Report Scale (ASRS) [66] are shown in Table 1. More specifically, 1 participant scored below threshold (17 points) on both the inattention and hyperactivity-impulsivity subscale, while 108 (99.1%) participants scored above the screening threshold on one of the subscales [67]. Informed consent was signed by the participants upon logging into the online intervention website for the first time. All participants were given a gift certificate of 400 NOK (US $48) upon completion of the study's posttrial questionnaires.

Table 1. Pretrial Adult ADHD Self-Report Scale (ASRS) scores for 109 participants.

Scale	Results, mean (SD)
Total ASRS scale	49.6 (9.2)
ASRS Inattention subscale	26.8 (4.6)
ASRS Hyperactivity-impulsivity subscale	22.8 (6.3)

Online Intervention Procedure and Data Collection

For each module, apart from the first Introduction and seventh Conclusion modules, participants watched 2 video vignettes: (1) a version of a situation where the protagonist experiences everyday challenges associated with the topic of the MyADHD module and (2) a version of the same situation where the protagonist successfully handles the situation with the use of a technique featured in the MyADHD intervention. Example videos are available in Multimedia Appendices 1-4. Descriptions of all videos are available in Table S1 in Multimedia Appendix 5.

At the end of each module, participants were asked to rate their satisfaction with the module's content and to provide qualitative feedback about their opinion on the module. The following 3 questions were asked, with an open-ended text input field for each question: (1) "What did you like best or what did you find most useful in this module?" (2) "What did you miss or what disappointed you in this module?" and (3) "In the module, you saw some videos. How would you evaluate them?" The seventh and final module was a summary of all the material and asked the participant for the key takeaways of each module. Lastly, participants completed a posttrial questionnaire on the entire intervention. Across 6 modules, 79 participants (79/109, 72.5%) provided feedback on the videos, with a total of 275 responses and 2850 words. See Table 2 for further descriptive statistics about data referring exclusively to videos (question number 3).

Table 2. Breakdown of qualitative feedback gathered from the module evaluation within the online intervention.

Feedback item	Number of words, mean (SD)	Responses, n
Intro video	10.5 (10)	51
Breathe videos	9.5 (13.8)	61
Stop videos	12.8 (17.1)	49
Emotion videos	13.2 (20.1)	35
Planning videos	8.3 (14.4)	43
Acceptance videos	6.5 (7.2)	36

All data recorded for this study, including the interview transcripts, were securely stored on a hospital research server. All participants were free to withdraw their participation and have their data removed at any time.

Data Collection: Interviews

In a posttrial survey, participants were asked to be interviewed in-depth regarding their experience with completing the intervention. The inclusion criterion was to live in the vicinity of the hospital that ran the main study. To this petition, 20 participants responded positively, and 13 did not qualify for inclusion due to their geographic location. Among the 7 interviewees, 6 self-identified as women and 1 as a man, and they were aged between 27 years and 47 years (mean 35 years, SD 8 years). Participants were interviewed for an average of 1.5 hours at 1-5 weeks after completing their participation in the study.

The interviews followed a semistructured interview guide [68]. The interview focused on the participants' experience with the videos and included the following open-ended questions: "What do you think of the videos?" "What do you think of the characters?" "What do you think about the situations in the video?" and "How did the videos help you to complete the program?" However, these questions were used more like a checklist for the interviewers rather than a guide, so that the conversation originating from the questions would flow as freely as possible. The interviews were conducted by 1 human-computer interaction researcher (HCI) and 1 research assistant.

Data Analysis

The qualitative feedback and the interviews were analyzed following the procedure by Braun and Clarke for reflexive thematic analysis [69,70]. Interviews were transcribed verbatim. Qualitative data from the online intervention were combined with the interview data. Each interview participant was given a gender-neutral pseudonym in the transcripts. Data excerpts from each participant in the online intervention were given a random numerical ID code, with no inclusion of identifying information in the transcripts.

The first author coded the dataset. The following research question was formulated to guide the analysis: "How do participants in the online intervention experience and make sense of video vignettes designed for the intervention?" A semantic, inductive approach was applied to the coding of excerpts, meaning that the coder aimed to understand the participants' statements as descriptions of their experience. The themes, with their codes and excerpts, were discussed between the first, second, and third authors. Then, codes were rearranged into 3 themes. Upon writing the report of the analysis, quotes that described characteristics and variations of the themes were carefully translated into English.

Results

Phase 1: Participatory Design Study

Design Process

The clinicians in the research team discussed the therapeutic rationale for designing videos as content for an online intervention, following the practice of defining guiding principles in the person-based approach [4]. They defined 3 core aims: (1) to increase engagement with the intervention using experience-centered content, (2) to clarify and provide examples of core training principles and help participants make connections between the material and their own experiences, (3) to address self-stigmatizing beliefs in adults with ADHD. These aims guided the process of designing videos for the MyADHD intervention.

In response to the participants' request, we made a pilot video intended to display a realistic view of the everyday life experiences of an individual with ADHD. One of the participants expressed an interest in sharing experiences from her everyday life and the impact of ADHD on these activities. Her inclusion in the video production was an effort to resonate with the target group's experiences and values in the video. The participant met with an actress hired for the production. Together, they constructed the character of Nora (Figure 1) as the protagonist of the pilot and wrote the outline based on the participant's experiences and characteristics. Following this activity, a film production company was hired to adapt the outline into a screenplay and make a video. Next, the participant, a clinician, and an assistant read through the screenplay and approved it after minor revisions to the humoristic tone. During the recording of the video, the participant, a clinician, and an assistant acted as consultants to the actor and the crew to help achieve a result close to the original vision.

Figure 1. Stills from the video vignettes: (1) Nora procrastinates at her office, (2) Nora is at home doing a planning activity to get her work done during overtime, (3) Erik stresses through the morning routines; his wife and the children's toys are visible in the background, (4) Erik takes a moment to perform a breathing exercise in a moment of distress.

The pilot video received positive feedback from health care professionals, students, and a local ADHD patient association. Participants advised the research team to address family life. A second character, Erik (Figure 1), was created. This protagonist represented those adults with ADHD meeting challenges when they combine family, work, and personal life, and a series of videos for the online intervention was produced (Figure 1).

Erik is a family man around the age of 40 years with ADHD. After meeting new demands in his role as a father and husband, he struggles with maintaining his emotional control in stressful situations. Combining work and family life creates situations in which he quickly loses his temper and, thereafter, feels ashamed.

Nora is a woman in her 20s with ADHD. She is a young professional in finance who has a higher education. She struggles with inattentiveness, being easily distracted and forgetful, and often puts off important tasks.

A workshop to generate ideas for MyADHD video vignettes was organized with 12 participants. The participants were asked to share their experiences related to the topics of the modules for MyADHD. The participants were divided into 3 groups, and a facilitator (clinician or assistant) would ask them to describe challenges, daily situations, and coping strategies for each of the topics. In addition, the 2 actors who would play the protagonists attended the workshop, listened to the participants, and asked questions of the participants to better understand their roles.

The participants contributed with experiences from their everyday lives. For example, one participant told a story of being distracted from pressing matters at work by a bird outside her office. Another said that “one time, while at work, I drifted away and searched the web for ‘what is the difference between a magpie and a crow?’” Participants also described difficulties in relation to others, such as not feeling accepted as “a person with ADHD” because their behavior was not within others’ expectations of people with ADHD, or that their challenges were not taken seriously by their acquaintances (eg, “when people tell me that ‘everyone’s like that’ and that ‘everyone forgets things or are unfocused,’ it becomes difficult to accept that I have ADHD, and I need help coping with my symptoms”). Regarding coping strategies, they found breathing exercises to be helpful, but often difficult to follow and complete because their focus could drift away from the activity. Many participants made “to-do lists” daily and set alarms on their phones to remember appointments. For further examples of the participants’ experiences and suggested coping strategies, please refer to Table S2 in Multimedia Appendix 6.

After the workshop, a clinician and the assistants created outlines for video vignettes to accompany the 6 modules of MyADHD. Notes from each of the 3 focus groups were compared and analyzed to extract topics and experiences appropriate for each module. Based on this analysis, outlines for 14 video vignettes were written. These outlines were rewritten into movie scripts in cooperation with the film production team.

During film production, a clinician acted as the consultant and oversaw the process. The film crew applied cinematic techniques of comic timing in acting, pacing in editing, and the use of music to make the videos engaging.

The final videos were shown to the participants who took part in designing the vignettes. Feedback was overall positive, but some found the videos a little too light, because several of the described challenges tend to be experienced simultaneously.

Nonetheless, the participants also expressed an understanding for this reduction due to the pedagogical purposes. Overall, the videos were described as recognizable, pedagogical, and easy to follow. They were considered humorous, which was emphasized as a positive trait. The participants reported recognizing themselves in the video and a feeling of being less alone with their challenges. The participants requested additional examples of challenging social situations and how to improve the handling of such situations and more context to understand the challenges and exercises shown in the videos. Subsequently, the clinicians wrote text to introduce the context of each video for the online intervention. The participants approved the final version of the videos.

Phase 2 Findings: Evaluation

In this section, we present the analysis of qualitative data collected from participants (n=109) who participated in the clinical trial of MyADHD, phase 2 of our study. Common themes included how the participants viewed the characters and their situations and how the videos reflected their own everyday experiences. Furthermore, the participants responded to the videos by showing empathy with the characters, relived their own past experiences in similar situations, and reported that they felt less alone with their challenges and that they used the characters as role models for coping with their everyday problems.

Some participants reported that the videos were the most positive part of the MyADHD intervention. They described them as the main motivation to register for the study, among other things. They declared that watching others experiencing challenges like theirs was self-affirming. Although the use of video was received positively, some participants did not appreciate them: They found the videos boring and too long or too slow, while others found them too short. One participant reported that:

> *I have not seen them. #impatient* [*P* #22]

Theme 1: "You Can See the Experience"—Recognizing ADHD-Related Challenges

The participants described how the videos depicted situations they recognized from their lives. In addition to the concrete situations, the participants also recognized themselves in the fictional characters of Nora and Erik. In this theme, we unpack how the videos were perceived by the participants as renditions of life with ADHD. We give attention to the participants' experiences of whether the depictions are perceived as realistic to what it means to have ADHD in everyday situations.

In one of the videos, Nora is distracted at work by various events (eg, a bird outside the window of her office) and must work overtime to complete her economic report. Participant #60 recognized this situation and wrote:

> *The movies show just the way I feel in everyday life. The hours fly by, and I do not know what I have done.*

Certain story elements were recognizable for other participants:

> *I have several times lost concentration due to birds when I am at work. So that example was a bit funny. :)* [*P* #3]

Seeing that the presence of a bird outside Nora's office could consume so much of Nora's day was easy to relate to in a humorous manner. The response of Participant #63 further shows that it was possible to recognize oneself in the video while finding it funny, as they simply put it: "[It] was like seeing myself [emoji: Face with Tears of Joy]."

As the videos portrayed relatable characters and situations because of their ADHD symptoms, it is interesting to investigate their level of credibility. In the interview, Charlie explained that seeing the way that the characters handled challenging situations resembled similar experiences they had:

> *You can see the experience from [the videos], and it is not made in such a way that seems fake. You know...you can watch a feature film and you can see that it is fake. This is realistic.*

The content of the video appeared credible to Charlie, and they went on to explain how seeing the videos made it possible to see their own actions in a new light:

> *[The videos are] done in a way that allows me to see my negative things without it becoming uncomfortable. I do not feel offended.*

Elliot shared how the situations displayed in the videos reminded them of concrete experiences and similar situations, such as driving off without noticing or remembering the coffee cup on the roof of the car before it is too late. However, regarding the experience with having ADHD, Elliot was not convinced that the videos gave a credible impression of the felt experience. Elliot said that the videos do not capture the turmoil of having a family and explained how ADHD is heritable and, thus, something their children struggle with as well:

> *I think [the videos] fall flat. Because it...it does not say anything about the seriousness, in a way, how fierce those [situations] actually are [...] So, I have been sitting in the mornings [after the family is out for work or school] crying. And it is not something I had been doing much before. And I am not afraid of emotions per se, but I am not used to crying. But I have been left behind with such...deep, deep despair and, uh...crying after being called the most insane things by my teenage daughter and her brother, who is a little younger.*

The way the participants related to the videos depended on their experiences with similar situations. Elliot criticized the video of Erik's morning routine, based on a personal comparison.

The characters in the videos were portrayed by actors that followed an agreed-upon script. As such, the videos communicated a certain understanding of what it means to have ADHD. One participant wrote about the first video with Nora:

> *I do not identify with the character; I get the feeling she was chosen to "look like" she has ADHD. However, some parts of what she said were more relatable.* [*P* #15]

The participant distinguished between what is shown and what is said. The use of quotation marks can be interpreted as an ironic remark, and, therefore, such a depiction (ie, to "look like" having ADHD) is an inconceivable feat to truly accomplish. Looking like something includes imitating the mannerisms supposedly associated with it.

By the third module, the same participant had now changed their mind about whether Nora as a character was relatable:

> *This time, the video with Nora was "spot on." It is definitely like me.* [P #15]

They went on to describe how Nora's postponing chores was relatable. Here, the participant qualified the character of Nora as realistic because what she does is what the participant does. However, the participant did not revisit the previous theme of "looking like ADHD." Elliot, who said the videos did not depict their experiences with ADHD accurately, was much more positively inclined to how Erik represents a "person with ADHD":

> *He is like many, many others with ADHD. He is a dude that lives a family life and tries to handle his shit. He is not a caricature. He is...a normal dude, and that is nice.*

Overall, the participants did not report a feeling of being misrepresented as a caricature of people with ADHD, except for participant #15 who gave a statement that could be interpreted in that direction.

Theme 2: Relating to the Characters and Their Situations

In this theme, we take a closer look at how the participants related socially and emotionally to the characters and their situations.

Alex said that the videos showing how to apply the techniques in corresponding situations were motivating:

> *I see that they can cope or make a change. [...] It inspires and motivates me to use the techniques shown in the videos, and the others* [that are not covered in videos]

Furthermore, Alex said that the videos show how the techniques are meant to be used:

> *Of course, I could have made the connections [between the technique and their intended outcomes] myself, but there is something extra with those videos: You get to see* [how it is done]

Thus, by setting an example of how to use a technique in the videos, the participants further understood the application of the technique in a certain context.

The video in which Nora is distracted during housework by a phone call from a friend who needed help purchasing a new dress (see example 2 in the Phase 1 Results section) received varied interpretations by the participants. Dylan speculated that Nora's decision to go shopping with her friend was an act of procrastination because shopping with a friend is generally a more attractive option than housework:

> *It's a lot more fun to be with your friend, [...] it is really just that simple, that you do what is fun, right? But then things are constantly postponed, and then you come home, like Nora, to a messy apartment.*

On the contrary, another participant related personally to Nora's video, having a bad conscience when putting her needs before an important task:

> *[I] see that personality also plays a role here. [To what extent] do you get a bad conscience for your friend if you postpone or drop her [need for help]? I, myself, have had to do a major cleanup in my head over the past year to make more room for myself and my chores. It feels a little selfish and it is hard. But necessary.* [P. #81]

Similarly, Dylan explained the turmoil that postponing chores can lead to:

> *And then, for me, for example, that's when the negative self-talk begins: "That is what you should have done." And then, you start cleaning, and then, it becomes a very big thing, a very negative thing.*

The participants emphasized different aspects of the videos that made sense in relation to their own experiences in social situations where dilemmas can create feelings of uneasiness. Participant #81 and Dylan agreed that Nora represents how the negative outcomes of the dilemma commonly are turned inwards, either towards the self as feelings of guilt (#81) or as the negative self-talk described by Dylan. The participants showed empathy with the characters and used the situation in the video to contemplate their own experiences with everyday challenges and self-stigma.

We now turn to how the videos aroused negative feelings and recollections of past experiences in some of the participants. Alex found similarities between his or her own life and Erik's morning routine in the videos for Module 2 (Breathe):

> *It is a situation I want to handle better. I should be able to do it, a few minutes for myself without an audio file, where I could breathe and relax the way he did in the video. I have not managed that yet, because I do not remember to do it.*

Alex saw that Erik handled the situations in a better way because he had internalized techniques for controlled breathing to alleviate stress. Alex, on the other hand, said that they "should be able to do it," but has not yet been able to implement the technique in everyday life. Alex needed a reminder for the breathing exercise, which seemed to be disappointing in comparison to the character Erik's apparent mastered application of the technique.

In Module 6 (Acceptance), Erik is in a video conference planning a party with his friends. Erik loses focus and, when asked a question, becomes agitated and slams the laptop computer shut. Participant #62 wrote in the evaluation of this module:

> *[It] is useful to have a reminder to be kind to yourself. [I] realize that I still have a way to go when it comes to self-acceptance.*

However, in the evaluation of the videos, the participant stated that "I thought this video was painful to watch, I cried afterward.” In the posttrial evaluation of the entire intervention program, the participant wrote that “[...] I could not complete the module [on acceptance] after the first video.” The negative experience with the video impeded the completion of the module, although this participant had identified it as useful. Unfortunately, we lack additional information on the participant’s experience of the situation. However, this example of adverse effects shows how videos that depict sensitive issues can be painful for participants that have lived such issues.

In this theme, we have seen how the participants reacted to the videos, sometimes by showing empathy with the characters and other times reflecting on their similar challenges.

Theme 3: Video Protagonists as Companions and Role Models for Change

The videos were motivating for the participants when there was a certain agreement between the depiction of ADHD in the video and the participant’s own experiences. In this theme, we explore how some participants related to the protagonists as role models for change.

One participant wrote the following as feedback to the videos that were shown in Module 6 (Acceptance):

> *For me, the videos are the best! At the same time, it hurts. But they show an educated, well-versed lady who struggles with the same things as me, and this is motivating.* [P #50]

Here, the participant described how they were motivated by the protagonist Nora, despite the videos provoking negative feelings. For participant #50, Nora impressed and motivated them. The protagonist appeared to be a “educated, well-versed lady” at the same time as she struggled with relatable challenges in everyday life.

The protagonists in the video served as role models for the motivation of the participants. Participant #81 found it helpful to see that others had similar thoughts and actions and used Nora as starting point for a reflection on their present situation:

> *Nora says that she will be better at using her time more constructively. [And] she will not be impatient if she does not see results right away. It is the same with me. [...] [I] do not have everyday routines yet. [I have a] new job, a new place to live, and I am looking for a romantic partner. So, making routines can be a bit of a challenge now.*

Even though the participant does not explain how Nora influenced their perspective, their attitude toward their own life is influenced by knowing Nora as a character.

Participant #60 further elaborated on Nora being a role model, in the posttrial evaluation of the intervention program:

> *My biggest challenge in everyday life is postponing boring things, and it was precisely the video with Nora where I recognized myself. I set goals in everyday life. Thus, I have pushed myself to do all these routine chores better than before. I tidy up the apartment more often. The dirty dishes do not stay that long; instead, I clean them daily. I do the laundry, hung it up. This has been better almost throughout the training program.*

It is striking how the participant’s reported improvements on everyday chores mirrored the challenges that Nora faces in the videos. The way that the participants addressed the protagonists shows that the videos contributed a social component to the intervention program.

Another social response to watching the videos is reflected in the report of feeling less alone:

> *It is good to watch the videos; it gives a feeling of not being alone when struggling with various things. And it gives me a sense of mastery in knowing I can do a lot of things that others are struggling with.* [P #19]

Alex found comfort in the videos:

> *I was looking forward to the movie clips because they felt so familiar. I saw myself, and it was amazing — what can I say? — good to feel that others are like that too.*

Dylan, who struggled with feelings of low self-esteem and mental turmoil, found comfort in learning that others may feel the same way:

> *It has actually been a huge relief to find out that there are others who have it just like you; you are not as unique as you thought!*

The experience of feeling less alone when struggling with everyday life was a relief for the participants. They learned about what it was like to have ADHD as an adult through participating in the intervention. For example, Dylan had little knowledge about ADHD, other than receiving the diagnosis and medication from their local psychiatric clinic, before participating. The study and the videos taught Dylan that their struggles with self-esteem and negative self-talk were something that others also experience.

Finally, participant #74 wrote in the posttrial evaluation that seeing the characters live ordinary lives was a positive aspect of the intervention program:

> *Seeing other adults with ADHD, who live ordinary lives, in the videos, has been very nice, and [...] the focus on the fact that there is a lot of positive [aspects of] the diagnosis. I live a very good life myself* [emoji: Heart]

Discussion

Principal Findings

Overview

In this study, we addressed the design of therapeutic content, in particular video vignettes, for adults with ADHD founded on the experiences of their peers. It was carried out as a participatory design study, followed by qualitative feedback from participants in a clinical trial of an online intervention.

Our findings show that the video vignettes’ depiction of everyday situations resonated with the participants and, as a result, reflected their experiences. The participants recognized the situations and used the characters as role models for change.

Maintaining Authenticity in Narratives for Online Interventions

Personal narratives on social media have become an increasingly important and popular source of information about physical [46-48] and mental health [44,51]. Here, we discuss how videos based on personal narratives were used to create engaging content for the MyADHD intervention. We further discuss the trade-offs between maintaining authenticity and stylizing characteristics of mental health and how they affect stigmatization.

The use of video vignettes was an engaging feature of the MyADHD intervention, and by producing our videos, we could ensure that the content would abide by the therapeutic principles. Video as a design material offers diverse ways to contextualize narratives. For example, the choice of actors, location, set decoration, editing, and general style of the video lay the foundations for the viewer's experience with the content. However, in our intervention, the protagonist Nora seemed to be "chosen to 'look like' she has ADHD," as reported in theme 1 in the thematic analysis. This remark is timely because ADHD is associated with public stigma, often perpetuated in media reports [31-34]. In the video vignettes of MyADHD, the actors who portrayed the protagonists acted as if they had an ADHD diagnosis. The actors' performance can come off as a caricature that, in turn, reinforces self-stigmatizing beliefs in people of the target group or may cause skepticism about the authenticity of the narrative. Perhaps the credibility of the narrative could be better maintained if the video vignettes followed people with ADHD. A documentary style might resemble more the way health vloggers share their experiences with diagnosis and illness [46-48] and have been utilized in the studies by Amsalem et al [57,58], using people with the lived experience of schizophrenia in videos to reduce public stigma.

Honary et al [49] found that using actors as "talking heads" representing the lived experience of mental illness in videos was important for the protection of the identity and anonymity of the participants in their study. However, in some cases such as interventions for groups that experience public stigma, active participation in the content may be a meaningful and empowering activity for the participants. Designers of interventions for people with mental disorders could explore the possibility of the participants participating in video vignettes narrating their everyday life, provided they are motivated and informed about the implications of such exposure. Representatives of the target group are excellent communicators of authentic experiences of mental health issues in everyday life. Such participation, however, requires careful considerations of the ethical implications. Whereas sharing personal experiences of mental health on social media is a private initiative, to disclose a person's mental health in the context of a research study is essentially a public matter. Research-led disclosure would require a thorough assessment and follow-up of the participants' safety.

Based on our thematic analysis, we found that the participants perceived the protagonists Nora and Erik as characters. The participants related to them as examples of how ADHD symptoms may manifest in everyday life while being aware of the boundaries of the characters and understanding that they do not necessarily generalize the ADHD experience. Looking like someone with ADHD, however, can take many forms since people with ADHD represent a heterogeneous group with diverse characteristics and experiences. For example, the video content designed in this study is limited to a dichotomy between male and female ADHD. However, people's gender identities are known to be fluid, implying that inclusive intervention content is needed. Future research should explore how we represent the diversity of mental health in online interventions. For example, including people with multiple marginalized identities as reported in former studies (eg, [71]) is an exciting possibility in the processes of designing more diverse and inclusive online interventions.

In designing video vignettes that apply narratives of the everyday lives of people with mental health disorders, designers must be aware of the trade-off between preserving the authenticity and reinforcing stigmatizing characteristics of mental health. Using actors protects the identities of people with mental health problems, while, on the other hand, affects the authenticity and may contribute to stigmatizing caricatures of the experience of mental health.

Grounding Therapeutic Content in Everyday Life Situations

Online clinical health communication has been described as fact-based and prescriptive [53]. In our experience, this conceptualization is transferable to the communication of therapeutic content in psychological online interventions. In this part, we discuss how we have explicitly focused on everyday situations to help adults with ADHD integrate the MyADHD intervention in their daily lives. We emphasize the importance of striking a balance between the experiential, lived perspective of mental health with the more prescriptive, clinical presentation of how to self-manage mental health when designing video vignettes.

In online interventions, exercises and coping techniques from CBT, DBT, and other therapies are presented through text, audio, or video; they guide the participant in successfully applying these techniques and self-managing their mental health. However, in the design of unguided online interventions, it is particularly important to consider how the techniques are presented. In this case, the absence of a therapeutic relationship places greater demands on the design of the therapeutic content. Exercises and techniques can be difficult to understand as they are intended. They presuppose the understanding of both the application and the relevance to one's everyday life. For the intervention to be effective and meaningful, the exercises and coping techniques should be exemplified by everyday relatable situations. By doing so, the techniques can be transferable and implemented into day-to-day challenging situations. Seeing peers cope with challenging situations may enhance one's sense of self-efficacy [54,55].

The video vignettes in MyADHD offer contextualization of difficult everyday situations in scenarios recognizable and relatable to adults with ADHD, based on their own experiences.

For example, in the first video for Module 2 (Breathe; see Table S1, Multimedia Appendix 5), the protagonist, Erik, was overwhelmed with stress by the morning routine with the family. In the follow-up video, Erik applied a coping technique to prepare himself before getting on with the morning routine and, thus, had a less stressful morning with his family. In this way, the videos contextualized psychological coping techniques by showing their intended use and outcomes in a variety of everyday situations. We established the psychological coping techniques using examples of mundane everyday situations. Thus, we followed Feuston and Piper's [51] focus on the lived experience of mental health through an everyday lens. By grounding the therapeutic content in the daily struggles, we sought to challenge sensationalized [32,34] and stigmatizing [35,37] narratives of what it means to live with ADHD.

The video vignettes portrayed people with ADHD through characters that held steady jobs, good relationships, and meaningful everyday lives. In this way, we tried to formulate an alternative to didactic, theory-driven narrations of therapeutic content. By providing a clear context to both the symptoms of and coping techniques for ADHD-related challenges, we sought to offer a nonsensationalized view of the disorder that resonated with our participants. In theme 3 of the phase 2 findings, we analyzed how the participants were inspired by the character Nora's actions. The participants' reports of feeling motivated when seeing the characters coping with ADHD-related challenges could be seen in light of Bandura's [54,55] social cognitive theory, where observing role models is essential to facilitate learning. However, the videos might be less relatable and motivating when they show the coping techniques perfectly applied, especially to those that know how difficult those efforts can be. This is exemplified by Elliot's statement in theme 1 of the phase 2 findings: According to the participant, the videos "fell flat" regarding the depiction of everyday life with ADHD. This shortcoming can be explained by the context (ie, an online intervention with therapeutic aims) or the participatory process of designing the video vignettes.

Blandford et al [10] addressed how health and HCI research understand user needs from diametrically opposing positions: from a theoretical and evidence-based viewpoint (top-down) [72] and from consulting or involving users directly as participants in design activities (bottom-up) [63], respectively. For therapeutic content to be properly grounded in the everyday experiences of the target group, a bottom-up approach is required. Involving participants in design activities permits the creation of realistic and relatable scenarios. However, it is necessary to be conscious of the activity one is designing for, which, in this study, was an online unguided therapy aimed to improve the management of everyday challenges for adults with ADHD. The design of content that is both effective in mediating therapy as well as relevant and consistent with the target group's experiences and values must be guided by both therapeutic aims and an experiential perspective on mental health. This, in the context of online interventions, requires a balance between the sometimes conflicting prescriptive and experiential views on mental health.

Configuring Participatory Design of Intervention Content

Here, we discuss how participatory design can complement and extend specialized approaches to the design of online interventions to align the content with the values and experiences of the target groups. Furthermore, we discuss how the participatory process applied here could be adapted for the design of online interventions destined for other target groups.

Designing narratives of mental health as content in an online intervention requires understanding mental health from an experiential perspective. Therefore, careful consideration of representing the diversity of experiences and identities of the target group is necessary to be inclusive of a variety of identities. Here, we argue that a participatory design process that includes people with first-hand experiences of relevant mental health issues is an appropriate method. Participatory design can include the voices of people with a breadth of experiences and help strike a balance between the lived experience and the therapeutic expertise of clinicians.

The MyADHD intervention was developed following the person-based approach [4]. Although this approach is partly rooted in user-centered design methods, Yardley et al [4] explicitly differentiated this approach from participatory approaches that include co-design activities:

> *A potential problem with [the co-design] approach is that it encourages users to try to anticipate the needs of others, which they are unlikely to do well, rather than simply reporting their own experiences and views, which they do very well. We find that users are naturally expert at telling us what they like or dislike about our intervention, but most users are understandably less able to generate effective behavior change techniques or good design solutions.*

In the development of MyADHD, however, we used the co-design method of participatory design to specifically engage people with ADHD and make their voices heard in the process of designing therapeutic content. We found that the participants were not just experts on "what they like or dislike," but intimately knowledgeable of ADHD as it is lived by their first-hand experience and tacit knowledge of being diagnosed with ADHD. Building on their knowledge, we designed content that represented the participants of the intervention study. So, we have constructively extended the person-based approach by including participatory design in the process of designing content for the *MyADHD* intervention.

In this paper, we showed that the core therapeutic aims defined by clinicians are retained while, at the same time, people's experiences with ADHD are directly included in an online intervention through participatory design. According to Yardley et al [4], participants are "less able" to generate behavior change techniques. It has been recommended that the behavior change techniques of online interventions should be based on sound theory and evidence to substantiate their effect [4,72,73]. In this study, the participants primarily contributed to co-designing the presentation of behavior change techniques. In the ideation workshop, participants did, however, also contribute by suggesting coping strategies that they used to manage their everyday lives (see Table S2, Multimedia Appendix 5 for a diverse selection of suggestions). It is our position from conducting this study that participants can be *enabled* to contribute to the design of behavior change techniques — this is a matter of proper design process facilitation.

According to Bratteteig and Wagner [63], participatory design "may have to operate in a highly structured environment that imposes particular 'rules' and surely it has to define its own ways of operating" [63]. Referring to this, we took a pragmatic position: The clinicians defined the clinical needs and the treatment outcomes according to theoretical models and their expertise. In this study, the use of principles and techniques from psychological interventions coupled with psychoeducation enhanced the perceived mastery of everyday life challenges for adults with ADHD. Experts by experience contributed by narrating their everyday life and were, thus, in a position to share "what the user wants." Here, it was a request to use videos to narrate content that the participants not only suggested but also took part in designing.

The design process led to mutual learning among the parties (ie, clinicians, participants, and the film production team) involved in the design of the video vignettes. This learning was developed within meetings, workshops, and film production sets. For example, clinicians would learn about specific difficult situations for the adults, whereas the participants learned how their experiences fit within a clinical viewpoint and boundaries for the management of ADHD symptoms. The film production team conceptualized these ideas into a video format. The video scripts would then be reworked under the other parties' perspectives. The presentation of the video vignettes was further enhanced as engaging content by the skillful execution of the film production team. The video vignettes were, in a sense, grounded in the tacit knowledge [61] of the participatory design participants. The lived experience of having an ADHD diagnosis was not available to the clinicians initially; the participants brought their experiences into the process through the mutual learning facilitated by the participatory design process.

The design process of making video vignettes for the MyADHD was costly and time-intensive: It required resources for a film production team that would realize the vision of the participatory design process. However, we encourage the application of our process in the development of psychological online interventions that aim to create therapeutic content grounded in everyday contexts for their target groups. Similar to how health vloggers produce technically simple productions with consumer products (eg, smartphones, web cameras), designers of content for psychological interventions can do the same.

We suggest that resonance with the participant's values and experiences is vital for this kind of content to be perceived as meaningful and further suggest that researchers and designers of online interventions should strive to achieve this in their efforts to produce narrative content that supports therapeutic principles.

Person-centered approaches to design have been emphasized as essential to create content that is adapted to the target group's shared values and experiences [8,9]. In this regard, we found the co-design activities of the participatory design method complemented the person-based approach in developing online interventions. The participatory design approach comes from a democratic perspective of giving future users a say in the design of information technology solutions [61,62] and, therefore, can be used to align the intervention with the values, experiences, and needs of potential adopters. However, for the designed content to be successful in supporting therapeutic principles, the participatory design for online interventions needs to be carefully facilitated. We recommend that researchers and designers of online interventions adapt co-design to their target group and specific purpose — there is no one-size-fits-all approach to meaningful co-design.

Regarding the involvement of people with ADHD in our process, we found, contrary to Yardley et al [4], that the "users" were indeed competent in generating adequate design solutions. In our experience, the participants contributed with interest and determination in designing creative, novel narrative content. Their contributions possessed qualities in ways we could not have anticipated. We found their involvement in this study decisive in designing content that represented the target group's values and experiences.

Limitations

This qualitative study has limitations. First, in the clinical trial and the follow-up interviews, women were overrepresented compared to men. Thus, our findings may not be representative of men with ADHD. Second, the ADHD diagnosis was self-reported. Last, this is a qualitative study and thus does not ascertain the videos' or the intervention's clinical effects. Further details of the study design and dissemination of the effects and clinical outcomes will be reported in a separate publication.

Conclusions

In this paper, we presented our process for designing video vignettes portraying challenging situations of living with ADHD, with the participation of and directed to adults with ADHD in a therapeutic context. Based on our findings, the approach of using an everyday lens and describing ostensibly mundane and everyday contexts in the videos was well-received by the participants in a clinical trial of an unguided online intervention. The videos provided rich and contextualized illustrations of life with ADHD, designed beyond the need for self-management in core symptoms. Applying a participatory approach when designing for online interventions, however, requires a balance between the lived experience as reported by the participants and the therapeutic expertise of the clinicians to be relevant to the target group.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
This is the first video of Module 2: Breathe where we are presented with Erik and his problems with morning routines.
[MP4 File (MP4 Video), 33487 KB - mental_v8i9e30292_app1.mp4]

Multimedia Appendix 2
This is the second video of Module 2: Breathe, where we see Erik handle his family's morning routines better now that he is applying a technique taught in the MyADHD intervention.
[MP4 File (MP4 Video), 20253 KB - mental_v8i9e30292_app2.mp4]

Multimedia Appendix 3
In Module 3: Stop, we meet Nora who is struggling to maintain focus on completing everyday chores.
[MP4 File (MP4 Video), 46775 KB - mental_v8i9e30292_app3.mp4]

Multimedia Appendix 4
In this video, from Module 3: Stop, we see how Nora handles interruptions in her everyday chores by applying a "Stop"-technique.
[MP4 File (MP4 Video), 23811 KB - mental_v8i9e30292_app4.mp4]

Multimedia Appendix 5
Video vignettes designed for the MyADHD intervention.
[DOCX File , 14 KB - mental_v8i9e30292_app5.docx]

Multimedia Appendix 6
A selection of excerpts from Ideation Workshop in Phase One. Quotes are from clinicians' notes. The examples stylized in italics were used directly in the video vignettes.
[DOCX File , 22 KB - mental_v8i9e30292_app6.docx]

References

1. Doherty G, Coyle D, Matthews M. Design and evaluation guidelines for mental health technologies. Interacting with Computers 2010 Jul;22(4):243-252. [doi: 10.1016/j.intcom.2010.02.006]
2. Doherty G, Coyle D, Sharry J. Engagement with online mental health interventions: an exploratory clinical study of a treatment for depression. 2012 Presented at: SIGCHI Conference on Human Factors in Computing Systems; May 5-10, 2012; Austin, TX. [doi: 10.1145/2207676.2208602]
3. Yardley L, Spring BJ, Riper H, Morrison LG, Crane DH, Curtis K, et al. Understanding and Promoting Effective Engagement With Digital Behavior Change Interventions. Am J Prev Med 2016 Nov;51(5):833-842. [doi: 10.1016/j.amepre.2016.06.015] [Medline: 27745683]
4. Yardley L, Morrison L, Bradbury K, Muller I. The person-based approach to intervention development: application to digital health-related behavior change interventions. J Med Internet Res 2015 Jan 30;17(1):e30 [FREE Full text] [doi: 10.2196/jmir.4055] [Medline: 25639757]
5. Karekla M, Kasinopoulos O, Neto DD, Ebert DD, Van Daele T, Nordgreen T, et al. Best Practices and Recommendations for Digital Interventions to Improve Engagement and Adherence in Chronic Illness Sufferers. European Psychologist 2019 Jan;24(1):49-67. [doi: 10.1027/1016-9040/a000349]
6. Short C, Rebar A, Plotnikoff R, Vandelanotte C. Designing engaging online behaviour change interventions: A proposed model of user engagement. The European Health Psychologist 2015;17(1):32-38 [FREE Full text]
7. Borghouts J, Eikey E, Mark G, De Leon C, Schueller S, Schneider M, et al. Barriers to and Facilitators of User Engagement With Digital Mental Health Interventions: Systematic Review. J Med Internet Res 2021 Mar 24;23(3):e24387 [FREE Full text] [doi: 10.2196/24387] [Medline: 33759801]
8. Eysenbach G. The law of attrition. J Med Internet Res 2005 Mar 31;7(1):e11 [FREE Full text] [doi: 10.2196/jmir.7.1.e11] [Medline: 15829473]

9. Honary M, Fisher NR, McNaney R, Lobban F. A Web-Based Intervention for Relatives of People Experiencing Psychosis or Bipolar Disorder: Design Study Using a User-Centered Approach. JMIR Ment Health 2018 Dec 07;5(4):e11473 [FREE Full text] [doi: 10.2196/11473] [Medline: 30530457]
10. Blandford A, Gibbs J, Newhouse N, Perski O, Singh A, Murray E. Seven lessons for interdisciplinary research on interactive digital health interventions. Digit Health 2018 May 03;4:2055207618770325 [FREE Full text] [doi: 10.1177/2055207618770325] [Medline: 29942629]
11. Wadley G, Lederman R, Gleeson J, Alvarez-Jimenez M. Participatory design of an online therapy for youth mental health. 2013 Presented at: 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration; November 25-29, 2013; Adelaide, Australia. [doi: 10.1145/2541016.2541030]
12. Baumeister H, Reichler L, Munzinger M, Lin J. The impact of guidance on Internet-based mental health interventions — A systematic review. Internet Interventions 2014 Oct;1(4):205-215. [doi: 10.1016/j.invent.2014.08.003]
13. Chikersal P, Belgrave D, Doherty G, Enrique A, Palacios JE, Richards D, et al. Understanding Client Support Strategies to Improve Clinical Outcomes in an Online Mental Health Intervention. 2020 Presented at: 2020 CHI Conference on Human Factors in Computing Systems; April 25-30, 2020; Honolulu, HI. [doi: 10.1145/3313831.3376341]
14. May C, Montori VM, Mair FS. We need minimally disruptive medicine. BMJ 2009 Aug 11;339(aug11 2):b2803-b2803. [doi: 10.1136/bmj.b2803] [Medline: 19671932]
15. Hassenzahl M. User experience (UX): towards an experiential perspective on product quality. 2008 Presented at: 20th Conference on l'Interaction Homme-Machine; September 2-5, 2008; Metz, France.
16. McCarthy J, Wright P. Technology as experience. Interactions 2004 Sep;11(5):42-43. [doi: 10.1145/1015530.1015549]
17. Fayyad J, Sampson NA, Hwang I, Adamowski T, Aguilar-Gaxiola S, Al-Hamzawi A, WHO World Mental Health Survey Collaborators. The descriptive epidemiology of DSM-IV Adult ADHD in the World Health Organization World Mental Health Surveys. Atten Defic Hyperact Disord 2017 Mar 19;9(1):47-65 [FREE Full text] [doi: 10.1007/s12402-016-0208-3] [Medline: 27866355]
18. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®). Washington, DC: American Psychiatric Publishing; 2013.
19. Kessler RC, Adler L, Barkley R, Biederman J, Conners CK, Demler O, et al. The prevalence and correlates of adult ADHD in the United States: results from the National Comorbidity Survey Replication. Am J Psychiatry 2006 Apr;163(4):716-723 [FREE Full text] [doi: 10.1176/ajp.2006.163.4.716] [Medline: 16585449]
20. Barkley RA. Behavioral inhibition, sustained attention, and executive functions: constructing a unifying theory of ADHD. Psychol Bull 1997 Jan;121(1):65-94. [doi: 10.1037/0033-2909.121.1.65] [Medline: 9000892]
21. Barkley R, editor. Attention-deficit hyperactivity disorder: A handbook for diagnosis and treatment. New York, NY: The Guilford Press; 2015.
22. Faraone SV, Rostain AL, Blader J, Busch B, Childress AC, Connor DF, et al. Practitioner Review: Emotional dysregulation in attention-deficit/hyperactivity disorder - implications for clinical recognition and intervention. J Child Psychol Psychiatry 2019 Feb 06;60(2):133-150. [doi: 10.1111/jcpp.12899] [Medline: 29624671]
23. Turgay A, Goodman DW, Asherson P, Lasser RA, Babcock TF, Pucci ML, ADHD Transition Phase Model Working Group. Lifespan persistence of ADHD: the life transition model and its application. J Clin Psychiatry 2012 Feb;73(2):192-201. [doi: 10.4088/JCP.10m06628] [Medline: 22313720]
24. Franke B, Michelini G, Asherson P, Banaschewski T, Bilbow A, Buitelaar JK, et al. Live fast, die young? A review on the developmental trajectories of ADHD across the lifespan. Eur Neuropsychopharmacol 2018 Oct;28(10):1059-1088 [FREE Full text] [doi: 10.1016/j.euroneuro.2018.08.001] [Medline: 30195575]
25. Solberg B, Haavik J, Halmøy A. Health Care Services for Adults With ADHD: Patient Satisfaction and the Role of Psycho-Education. J Atten Disord 2019 Jan;23(1):99-108. [doi: 10.1177/1087054715587941] [Medline: 26088028]
26. Cibrian F, Hayes G, Lakes K. Research Advances in ADHD and Technology. Synthesis Lectures on Assistive, Rehabilitative, and Health-Preserving Technologies 2020 Dec 10;9(3):i-156. [doi: 10.2200/s01061ed1v01y202011arh015]
27. Holthe MEG, Langvik E. The Strives, Struggles, and Successes of Women Diagnosed With ADHD as Adults. SAGE Open 2017 Mar 29;7(1):215824401770179. [doi: 10.1177/2158244017701799]
28. Sedgwick JA, Merwood A, Asherson P. The positive aspects of attention deficit hyperactivity disorder: a qualitative investigation of successful adults with ADHD. Atten Defic Hyperact Disord 2019 Sep;11(3):241-253. [doi: 10.1007/s12402-018-0277-6] [Medline: 30374709]
29. Wiklund J, Yu W, Tucker R, Marino LD. ADHD, impulsivity and entrepreneurship. Journal of Business Venturing 2017 Nov;32(6):627-656. [doi: 10.1016/j.jbusvent.2017.07.002]
30. Young S, Bramham J, Gray K, Rose E. The experience of receiving a diagnosis and treatment of ADHD in adulthood: a qualitative study of clinically referred patients using interpretative phenomenological analysis. J Atten Disord 2008 Jan;11(4):493-503. [doi: 10.1177/1087054707305172] [Medline: 17712173]
31. Kooij JJS, Bijlenga D, Salerno L, Jaeschke R, Bitter I, Balázs J, et al. Updated European Consensus Statement on diagnosis and treatment of adult ADHD. Eur Psychiatry 2019 Feb;56:14-34 [FREE Full text] [doi: 10.1016/j.eurpsy.2018.11.001] [Medline: 30453134]

32. Ponnou S, Gonon F. How French media have portrayed ADHD to the lay public and to social workers. Int J Qual Stud Health Well-being 2017 Jun 22;12(sup1):1298244 [FREE Full text] [doi: 10.1080/17482631.2017.1298244] [Medline: 28532330]
33. Hinshaw SP. Attention Deficit Hyperactivity Disorder (ADHD): Controversy, Developmental Mechanisms, and Multiple Levels of Analysis. Annu Rev Clin Psychol 2018 May 07;14(1):291-316. [doi: 10.1146/annurev-clinpsy-050817-084917] [Medline: 29220204]
34. Ray L, Hinnant A. Media Representation of Mental Disorders: A Study of ADD and ADHD Coverage in Magazines from 1985 to 2008. Journal of Magazine Media 2009;11(1):1-21. [doi: 10.1353/jmm.2009.0004]
35. Lebowitz M. Stigmatization of ADHD: A Developmental Review. J Atten Disord 2016 Mar;20(3):199-205. [doi: 10.1177/1087054712475211] [Medline: 23407279]
36. Lebowitz MS, Rosenthal JE, Ahn W. Effects of Biological Versus Psychosocial Explanations on Stigmatization of Children With ADHD. J Atten Disord 2016 Mar 20;20(3):240-250. [doi: 10.1177/1087054712469255] [Medline: 23264369]
37. Mueller AK, Fuermaier ABM, Koerts J, Tucha L. Stigma in attention deficit hyperactivity disorder. Atten Defic Hyperact Disord 2012 Sep 8;4(3):101-114 [FREE Full text] [doi: 10.1007/s12402-012-0085-3] [Medline: 22773377]
38. Schmitz MF, Filippone P, Edelman EM. Social Representations of Attention Deficit/Hyperactivity Disorder, 1988–1997. Culture & Psychology 2016 Jul 21;9(4):383-406. [doi: 10.1177/1354067x0394004]
39. Goffman E. Stigma: Notes on the Management of Spoiled Identity. Kent, OH: Prentice Hall; 1986.
40. Hinshaw SP, Stier A. Stigma as related to mental disorders. Annu Rev Clin Psychol 2008 Apr;4(1):367-393. [doi: 10.1146/annurev.clinpsy.4.022007.141245] [Medline: 17716044]
41. Bathje GJ, Marston HN. Self-Stigmatization. In: Teo T, editor. Encyclopedia of Critical Psychology. New York, NY: Springer; 2014. [doi: 10.1007/978-1-4614-5583-7_395]
42. Corrigan PW, Larson JE, Kuwabara SA. Social psychology of the stigma of mental illness: Public and self-stigma models. In: Maddux JE, Tangney JP, editors. Social psychological foundations of clinical psychology. New York, NY: The Guilford Press; 2010:51-68 URL: https://psycnet.apa.org/record/2010-17975-004
43. McKeague L, Hennessy E, O'Driscoll C, Heary C. Retrospective accounts of self-stigma experienced by young people with attention-deficit/hyperactivity disorder (ADHD) or depression. Psychiatr Rehabil J 2015 Jun;38(2):158-163. [doi: 10.1037/prj0000121] [Medline: 25799297]
44. Andalibi N, Ozturk P, Forte A. Sensitive Self-disclosures, Responses, and Social Support on Instagram: The Case of #Depression. 2017 Presented at: 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing; February 25-March 1, 2017; Portland, OR. [doi: 10.1145/2998181.2998243]
45. Andalibi N, Haimson O, De Choudhury M, Forte A. Understanding Social Media Disclosures of Sexual Abuse Through the Lenses of Support Seeking and Anonymity. 2016 Presented at: 2016 CHI Conference on Human Factors in Computing Systems; May 7-12, 2016; San Jose, CA. [doi: 10.1145/2858036.2858096]
46. Davis H, Waycott J, Zhou S. Beyond YouTube: Sharing Personal Digital Stories on a Community Display. 2015 Presented at: Annual Meeting of the Australian Special Interest Group for Computer Human Interaction; December 7-10, 2015; Parkville, VIC, Australia. [doi: 10.1145/2838739.2838771]
47. Liu LS, Huh J, Neogi T, Inkpen K, Pratt W. Health Vlogger-Viewer Interaction in Chronic Illness Management. Proc SIGCHI Conf Hum Factor Comput Syst 2013;2013:49-58 [FREE Full text] [doi: 10.1145/2470654.2470663] [Medline: 24634895]
48. Huh J, Liu LS, Neogi T, Inkpen K, Pratt W. Health Vlogs as Social Support for Chronic Illness Management. ACM Trans Comput Hum Interact 2014 Aug 01;21(4):1-31 [FREE Full text] [doi: 10.1145/2630067] [Medline: 26146474]
49. Honary M, McNaney R, Lobban F. Designing Video Stories around the Lived Experience of Severe Mental Illness. 2018 Presented at: 10th Nordic Conference on Human-Computer Interaction; September 29-October 3, 2018; Oslo, Norway. [doi: 10.1145/3240167.3240188]
50. Clarke R, Wright P, Balaam M, McCarthy J. Digital portraits: Photo-sharing after domestic violence. 2013 Presented at: SIGCHI Conference on Human Factors in Computing Systems; April 27-May 2, 2013; Paris, France. [doi: 10.1145/2470654.2481348]
51. Feuston JL, Piper AM. Everyday Experiences: Small Stories and Mental Illness on Instagram. 2019 Presented at: 2019 CHI Conference on Human Factors in Computing Systems; May 4-9, 2019; Glasgow, Scotland. [doi: 10.1145/3290605.3300495]
52. Georgakopoulou A. Small Stories Research. In: De Fina A, Georgakopoulou A, editors. The Handbook of Narrative Analysis. Hoboken, NJ: John Wiley & Sons, Inc; 2015:255-271. [doi: 10.1002/9781118458204.ch13]
53. Hartzler A, Pratt W. Managing the personal side of health: how patient expertise differs from the expertise of clinicians. J Med Internet Res 2011 Aug 16;13(3):e62 [FREE Full text] [doi: 10.2196/jmir.1728] [Medline: 21846635]
54. Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. Psychological Review 1977;84(2):191-215. [doi: 10.1037/0033-295X.84.2.191]
55. Bandura A. Social learning theory. Oxford, England: Prentice-Hall; 1977.
56. Hinyard L, Kreuter M. Using narrative communication as a tool for health behavior change: a conceptual, theoretical, and empirical overview. Health Educ Behav 2007 Oct;34(5):777-792. [doi: 10.1177/1090198106291963] [Medline: 17200094]

57. Amsalem D, Markowitz JC, Jankowski SE, Yang LH, Valeri L, Lieff SA, et al. Sustained Effect of a Brief Video in Reducing Public Stigma Toward Individuals With Psychosis: A Randomized Controlled Trial of Young Adults. Am J Psychiatry 2021 Jul 26;178(7):635-642. [doi: 10.1176/appi.ajp.2020.20091293] [Medline: 33900809]
58. Amsalem D, Yang LH, Jankowski S, Lieff SA, Markowitz JC, Dixon LB. Reducing Stigma Toward Individuals With Schizophrenia Using a Brief Video: A Randomized Controlled Trial of Young Adults. Schizophr Bull 2021 Jan 23;47(1):7-14 [FREE Full text] [doi: 10.1093/schbul/sbaa114] [Medline: 33484269]
59. Amsalem D, Martin A. Reducing depression-related stigma and increasing treatment seeking among adolescents: randomized controlled trial of a brief video intervention. J Child Psychol Psychiatry 2021 Apr 06:13427. [doi: 10.1111/jcpp.13427] [Medline: 33821507]
60. Yardley L, Ainsworth B, Arden-Close E, Muller I. The person-based approach to enhancing the acceptability and feasibility of interventions. Pilot Feasibility Stud 2015 Oct 26;1(1):37 [FREE Full text] [doi: 10.1186/s40814-015-0033-z] [Medline: 27965815]
61. Ehn P. Participation in design things. 2008 Presented at: Tenth Anniversary Conference on Participatory Design; October 1-4, 2008; Bloomington, IN.
62. Robertson T, Simonsen J, editors. Routledge international handbook of participatory design. Milton Park, UK: Routledge; 2012. [doi: 10.4324/9780203108543]
63. Bratteteig T, Wagner I. Unpacking the Notion of Participation in Participatory Design. Comput Supported Coop Work 2016 Sep 2;25(6):425-475. [doi: 10.1007/s10606-016-9259-4]
64. Muller MJ. Participatory design: The third space in HCI. In: Sears A, Jacko JA, editors. The human-computer interaction handbook: fundamentals, evolving technologies and emerging applications. Hillsdale, NJ: Lawrence Erlbaum Associates Inc; 2002:1051-1068.
65. What is ADHD? How to ADHD - YouTube. URL: http://youtube.com/howtoadhd [accessed 2021-08-10]
66. Kessler RC, Adler L, Ames M, Demler O, Faraone S, Hiripi E, et al. The World Health Organization Adult ADHD Self-Report Scale (ASRS): a short screening scale for use in the general population. Psychol Med 2005 Feb;35(2):245-256. [doi: 10.1017/s0033291704002892] [Medline: 15841682]
67. Yeh CB, Gau SSF, Kessler RC, Wu YY. Psychometric properties of the Chinese version of the adult ADHD Self-report Scale. Int J Methods Psychiatr Res 2008;17(1):45-54 [FREE Full text] [doi: 10.1002/mpr.241] [Medline: 18286465]
68. Kvale S. Doing Interviews. London, United Kingdom: SAGE Publications, Ltd; 2007.
69. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
70. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qualitative Research in Psychology 2020 Aug 12;18(3):328-352. [doi: 10.1080/14780887.2020.1769238]
71. Russell ST, Fish JN. Mental Health in Lesbian, Gay, Bisexual, and Transgender (LGBT) Youth. Annu Rev Clin Psychol 2016;12:465-487 [FREE Full text] [doi: 10.1146/annurev-clinpsy-021815-093153] [Medline: 26772206]
72. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci 2011 Apr 23;6:42 [FREE Full text] [doi: 10.1186/1748-5908-6-42] [Medline: 21513547]
73. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M, Medical Research Council Guidance. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 2008 Sep 29;337:a1655 [FREE Full text] [doi: 10.1136/bmj.a1655] [Medline: 18824488]

Abbreviations

ADHD: attention deficit hyperactivity disorder
ASRS: Adult ADHD Self-Report Scale
CBT: cognitive behavioral therapy
DBT: dialectical behavioral therapy
HCI: human-computer interaction

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Original Paper

Mobile App for Parental Empowerment for Caregivers of Children With Autism Spectrum Disorders: Prospective Open Trial

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Abstract

Background: Conflicting data emerge from literature regarding the actual use of smartphone apps in medicine; some considered the introduction of smartphone apps in medicine to be a breakthrough, while others suggested that, in real-life, the use of smartphone apps in medicine is disappointingly low. Yet, digital tools become more present in medicine daily. To empower parents of a child with autism spectrum disorder, we developed the Smartautism smartphone app, which asks questions and provides feedback, using a screen with simple curves.

Objective: The purpose of this study was to evaluate usage of the app by caregivers of individuals with autism spectrum disorders.

Methods: We conducted a prospective longitudinal exploratory open study with families that have a child with autism spectrum disorder. Data were recorded over a period of 6 months, and the outcome criteria were (1) overall response rates for a feedback screen and qualitative questionnaires, and (2) response rates by degree of completion and by user interest, based on attrition.

Results: Participants (n=65) had a very high intent to use the app during the 6-month period (3698/3900 instances, 94.8%); however, secondary analysis showed that only 46% of participants (30/65) had constant response rates over 50%. Interestingly, these users were characterized by higher use and satisfaction with the feedback screen when compared to low ($P<.001$) and moderate ($P=.007$) users.

Conclusions: We found that real or perceived utility is an important incentive for parents who use empowerment smartphone apps.

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KEYWORDS

autism spectrum disorders; empowerment, smartphone application; autism; smartphone; app; children; caregivers

Introduction

Autism spectrum disorder is a chronic disorder that affects daily life and can be a burden on parents, with consequences on their quality of life [1,2]. Parents of children with autism spectrum disorders have greater anxiety levels than parents of children without developmental disorders [3]. Some major autism symptoms, such as communication disorders and aggression [4], along with behavioral symptoms (such as agitation, feeding difficulties, sleep disturbances, obsessive behavior, or refusal of authority), are well-known stressors.

Management of children's inappropriate behaviors by professionals (or advice from professionals) is not accessible at all times of the day, and families often criticize the short duration or low frequency of their consultations [5-9]. Digital tools might be of particular interest in such situations by filling the gap between psychiatric consultations.

Digital mental health interventions have been of interest to the medical community for the past decade. Patients, caregivers, and medical practitioners are surrounded by apps and digital tools in everyday life; therefore, it seems natural that the mental health community, despite their initial criticism and poor initial acceptance [10], should now attempt to understand and develop digital mental health interventions programs. The benefits of digital mental health interventions are known: (1) low cost at a time when there are not enough professionals to help all patients, (2) no commute, and thus a gain of time, (3) increased patient involvement, and (4) increased patient accessibility, when needed. However, recent studies [11-13] have shown a gap between the alleged, and sometimes scientifically validated, purposes of such digital interventions and their actual use by patients and professionals. The American Psychiatric Association proposed a 5-level hierarchical framework to evaluate an app: quality of information, basic medical decision making (and nonmaleficence), scientific evidence usability, and interoperability [14].

We developed Smartautism—a smartphone app for parents with children with autism spectrum disorders—to meet the need for parental support between medical appointments. The app collects data through ecological momentary assessment [15] or the experience sampling method [16] from parents, who answer simple questions about daily life [17]. The app then provides a feedback screen with a graphical representation of their score, allowing parents to see the evolution of the scores during the weeks before to help parents be objective about the difficulties they are facing

But, even for tools with state-of-the-art development, validity, and usefulness, the rate of attrition may remain high. Eysenbach [18] defined this phenomenon as "nonusage attrition" and proposed influential factors such as the nature of the perceived advantage of an innovation. Likewise, usability, determined by its complexity, contributes to intention to use. It is fundamental that participants fit within the intended scope of users of the apps; therefore, appropriate information about the main purpose of the apps must be provided in order to avoid unrealistic user expectations. Finally, the nature of the feedback given by the apps may encourage users to continue and reinforce their engagement.

Moreover, the effect of the "law of attrition" can be a confounding factor in eHealth studies [18]. Yet, thorough analysis of these factors can explain the difference between the optimism of the designers and the reality of the rate of use. These considerations should drive the development of a digital tool as well as the interpretation of study results.

Our main objectives were to evaluate the usefulness, usability, and reliability of our smartphone app during a 6-month period (level 4 of the American Psychiatric Association hierarchical framework) to determine the acceptability of the app and to qualitatively evaluate the factors that could explain differences in use (in accordance with the principles of specific attrition bias [18]).

Methods

Ethics

Ethical approval was obtained from the *Comité de Protection des Personnes, Ouest V* (January 2017). All participants gave consent.

Participants

Parents of individuals diagnosed with autism spectrum disorders, using Autism Diagnostic Interview-Revised diagnoses based on National Health Authority recommendations [19], from 3 to 16 years of age (at the time of the study) in the *Pays de la Loire* region of France were recruited. All families at the Department of Child and Adolescent Psychiatry of *Centre Hospitalier Universitaire* de Nantes and from the Regional Center for Autism (*Pays de la Loire*) were eligible. Inclusion criteria were having a child with an autism spectrum disorder diagnosis based on International Classification of Diseases tenth revision criteria, having a smartphone (iOS Apple or Android), and signing the consent form for participation. Exclusion criteria were having several children with autism spectrum disorder diagnoses, having children living in more than 2 houses, having an old smartphone with which there would be a significant decrease in user experience, or having no personal smartphone. We included the first 100 families that agreed to participate and that met the criteria. Because the study was exploratory, we decide that it was not necessary to randomize patients.

Data Security

To obtain approval from the National Center for Informatics and Liberty, we designed a secure data-handling pathway. Data were stored in the app on parents' smartphones and were inaccessible by unauthorized people (an individual code was required when the app was opened). Families included in this study transmitted these data to the investigators using a strict, secure 5-step process: (1) Data in the smartphone of the participant (in-app coding) were encrypted with a 16-digit encryption key and a personal temporary code for access to data. (2) Encrypted data were transmitted to a secure server (Ivory Healthcare Inc). (3) Data were physically transferred by USB stick or disk from the server to Nantes University Hospital secure medical server at the end of the study period. (4) Once the data were uploaded on the intranet of the University Hospital, decryption was performed *in situ* using specific software after the principal investigator entered a short automatically generated validation code. (5) Data were organized in a data spreadsheet for analysis and calculation.

App

The idea for the Smartautism [17] app emerged during discussions with associations of parents of people with autism, who were informally involved in the development process. The acceptability assessment of Smartautism was one step of a large digital empowerment project. The app is a combination of ecological momentary assessment with feedback that may be used by parents to adapt their educational behavior. The parents must provide regular ratings (mandatory twice a week but additional on-demand ratings were possible if needed by the parents) for a long period, and the feedback screen provides a synthesis of the ratings.

Parents rated behavior in several day-to-day basic situations (meal, lunch, etc) and answered questions (Figures 1 and 2) in the app. Parents had the opportunity to answer ecological questions about their children and their own psychological state [17]. The feedback screen converted user scores to graphs in order to allow users to data visualize their responses to provide an overview of the information.

Smartautism is freely downloadable from the Apple Appstore and the Google Play Store but requires a key code for access.

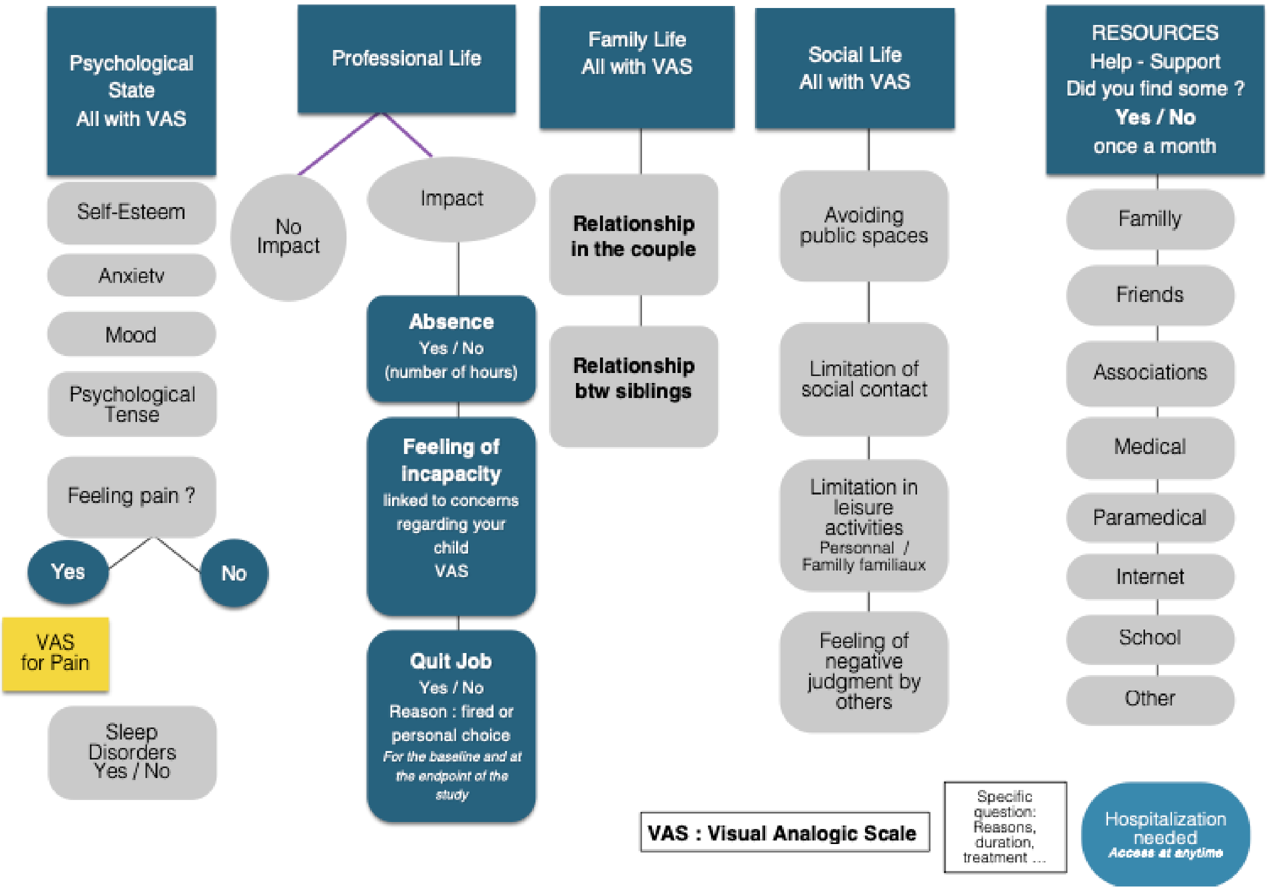
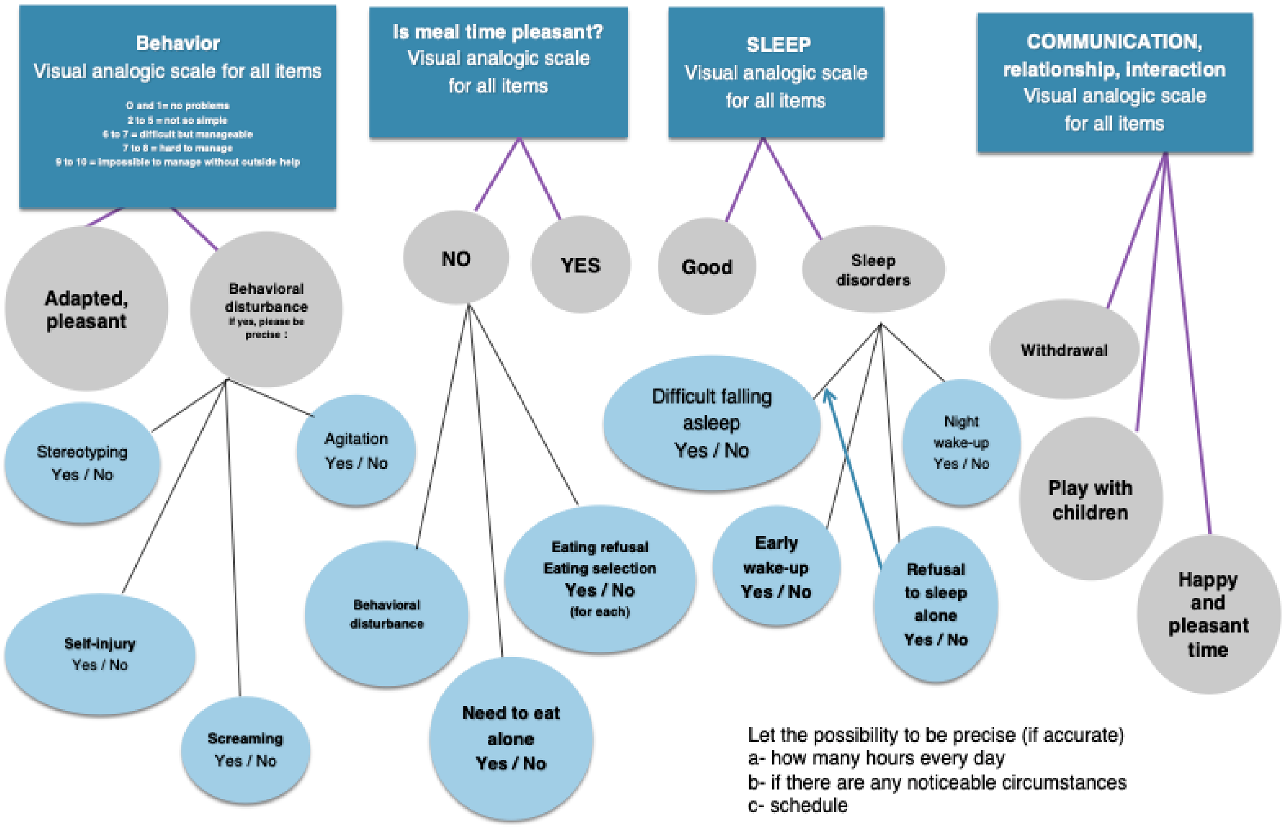


Figure 1. Smartautism app questions for parents (1b) about their children and themselves (1a) (image adapted from [17]).

Figure 2. Smartautism app questions for parents about their children, two times every week (image adapted from [17]).



Study Design

We conducted a prospective longitudinal exploratory open study. We collected qualitative and quantitative data over a 6-month period to assess acceptability of the app. Acceptability has several aspects. In digital technology, it may be reduced to 4 dimensions: (1) usefulness, (2) usability, (3) reliability, and (4) risk [10]. Usefulness reflects intent to use, which is a good predictor of usage behavior. Acceptability encompasses several concepts, for example, in ISO standards [20], usability comprises 3 dimensions: effectiveness, efficiency, and satisfaction.

To assess usefulness and intent to use, our primary outcome was overall response rate, *R* = (*number of dates with responses*) / (*possible instances with responses over the 6-month period*). In this case, there were 60 possible instances. All data were directly extracted from the app.

Primary Analysis

Completion rate was categorized into 5 levels: 100%, 99% to 80%, 79% to 50%, 49% to 20%, and <20%. The choice of intervals was not based on a specific theory, but on facilitating ranking of user behavior; the size of the intervals was modeled on Cohen effect size intervals.

We were able to determine the total number of views of the feedback screen because the screen requires activation by the user. Raw attrition proportions at different steps in time can be illustrated as attrition curves, and the shape of these curves (logarithmic or sigmoid) allows formulation of hypotheses about the causes of attrition [18].

We assessed attrition criteria [18] in the form of a questionnaire (Table 1). This questionnaire was given to users at the end of the 6-month period. Responses were rated on a 5-point Likert scale (where 1 indicated the worst satisfaction and 5 indicated high satisfaction).

We categorized patients according to their completion rate (high: ≥80%, moderate: 20-80, and low: <20) and used the Kruskal-Wallis test to isolate questions for which there was at least1 difference between groups (high, moderate, low). To determine posthoc stochastic dominance, we used the Dwass-Steel-Critchlow-Fligner pairwise comparison test.

Table 1. Use and user experience question content (adapted from [18]).

Item	Question content	Impact on nonusage and dropout attrition rate
1	Quality and relevance of information given before the trial	If low, risk of unrealistic expectations which results in a disengagement
2	Ease of the inclusion process (consent, implementation)	Quality of recruitment affects attrition. if it is too easy to enroll then the dropout rate may be high
3	Ease of drop out/stop using it	This parameter can negatively influence the use of the app
4	Ease of use and reliability of the technical interface	Poor usability (complexity of the interaction between an object and its user) contributes to a high rate of attrition
5	“Incentive” or “push” factors (callbacks, reminders, research assistants chasing participants)	This parameter can positively influence the use of the app (staying more in the trial)
6	Personal contact (during registration and inclusion) via face-to-face or by phone, rather than virtual contacts	Human contact promotes the use of the app
7	General quality of the feedback information and of the information summary screen	Positive feedback and encouragement positively influence the use of the app
8	Perceived benefits of interest in completing the study	Motivational factor that decreases attrition
9	Free to use	Paying more commits the user and decreases attrition
10	Time and workload required by the apps	If the burden is too high, it may result in higher attrition
11	Existence of concurrent interventions (web, therapy)	Risk that the user no longer perceives the specific interest of the app
12	Major life events, or of society, which could have stopped using the app	Lead to distraction and nonuse by shifting priorities
13	Experience of the other user (or being able to obtain help)	Indirectly through to dropout and nonusage

Secondary Analysis

Based on initial results that showed different app use behaviors, we separated participants into 2 groups. Group A comprised participants who consistently had completion rates above 50%, and group B comprised participants who consistently had completion rates below 50%.

Results

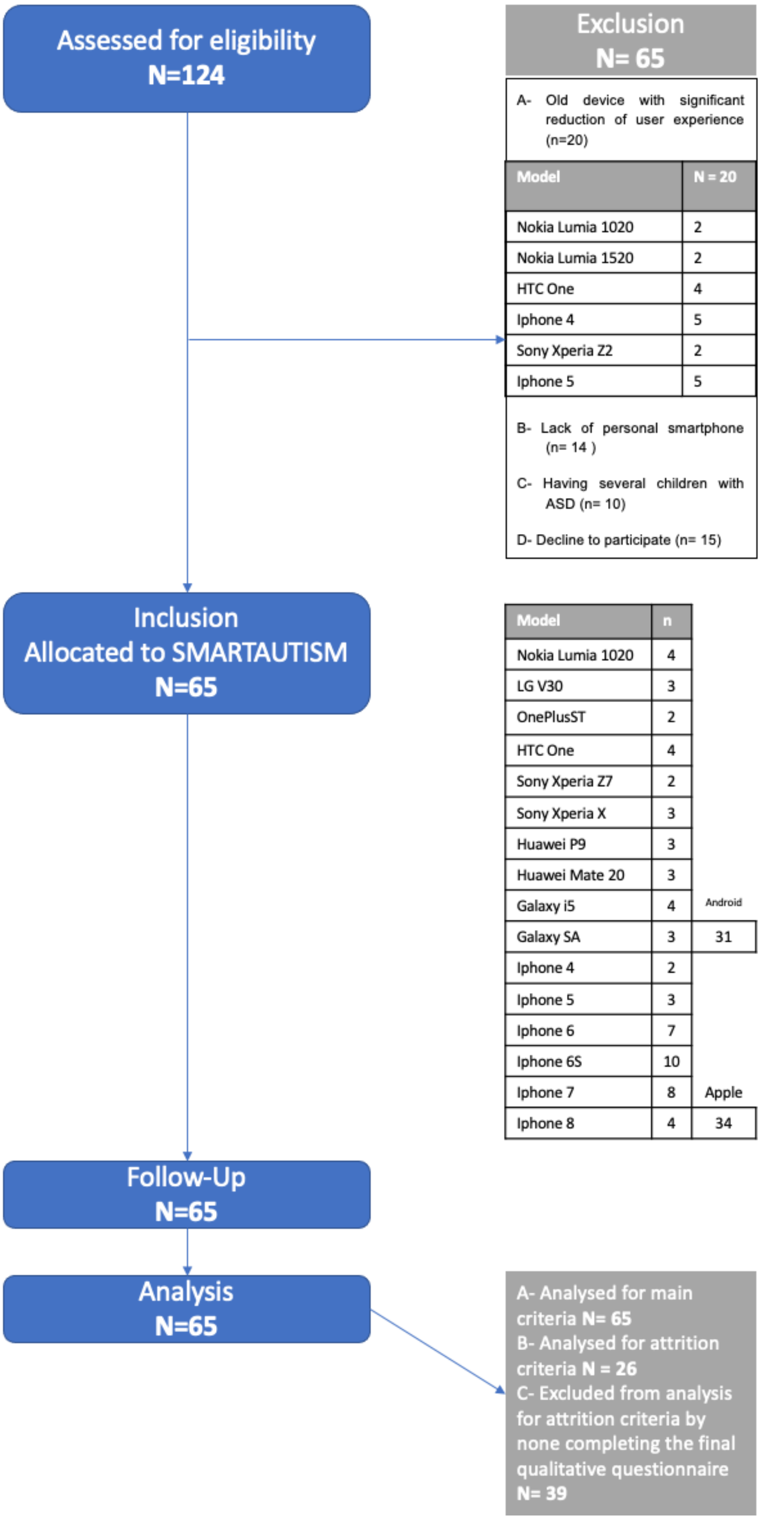
General

A total of 124 families were consecutively screened during an 18-month recruitment period (Figure 3), of which, 65 families, with 46 boys and 19 girls, were included in our study (Table 2).

The overall response rate was high (3698/3900, 94.8%). Of the 3900 instances (for n=65 participants), only 1347 were completed in full, while 837 instances were more than 80% complete, 509 instances were between 50% and 79% complete, 897 instances were between 20% and 49% complete, and 310 instances were less than 20% complete (of which, 202 were 0% complete).

The number of responses completed by participants tended to decrease over time, mainly after the third month (Figure 4). However, responses were consistently completed throughout the study by participants who completed over 90%. Only 13 of the 65 participants (20%) completed all responses. Of the 65 participants, only 1 participant had a 0% completion rate, while 17 participants (26%) had completion rates that remained above 50%, and 34 participants (52%) had progressively decreasing completion rates. Overall, 46% of participants (30/65) consistently had completion rates over 50%, and 54% (35/65) had completion rates under 50%.

Figure 3. Flow diagram.



Model	N = 20
Nokia Lumia 1020	2
Nokia Lumia 1520	2
HTC One	4
Iphone 4	5
Sony Xperia Z2	2
Iphone 5	5

Model	n
Nokia Lumia 1020	4
LG V30	3
OnePlusST	2
HTC One	4
Sony Xperia Z7	2
Sony Xperia X	3
Huawei P9	3
Huawei Mate 20	3
Galaxy i5	4
Galaxy SA	3
Iphone 4	2
Iphone 5	3
Iphone 6	7
Iphone 6S	10
Iphone 7	8
Iphone 8	4

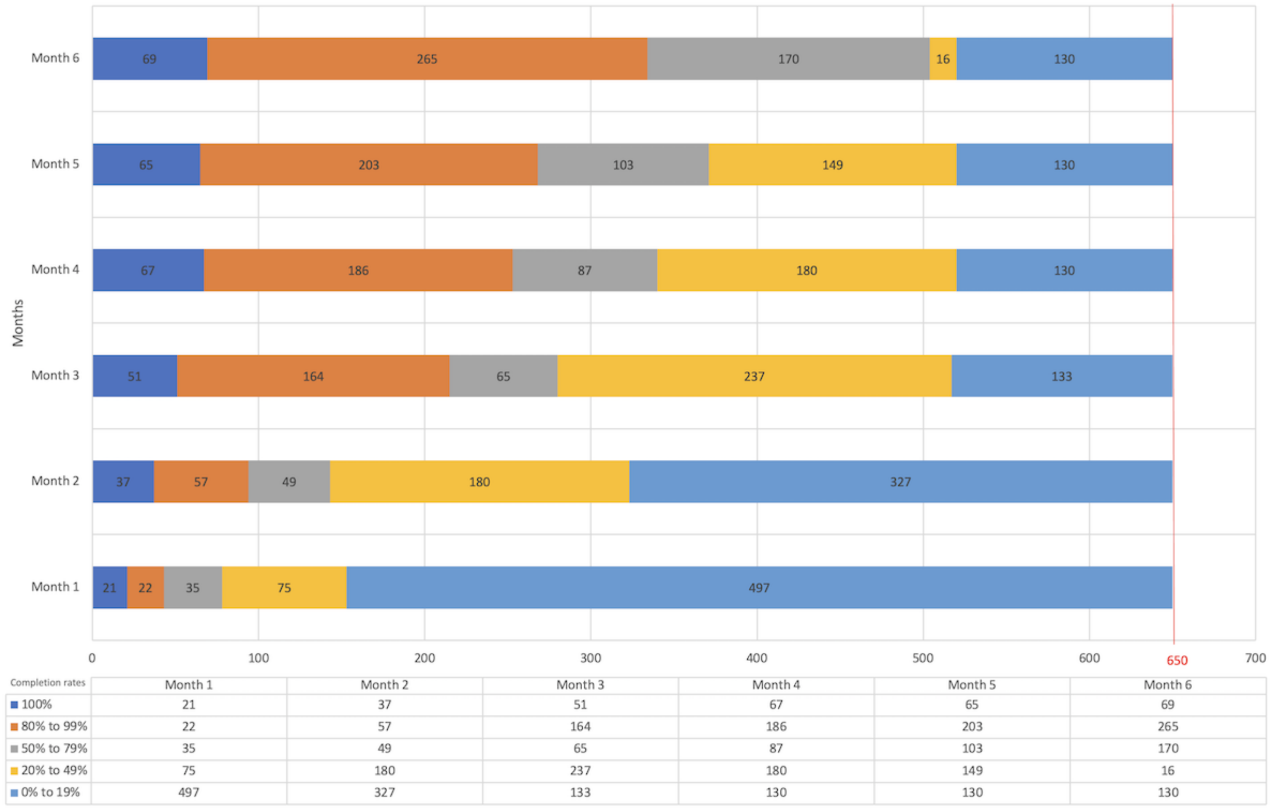
Table 2. Study population of parents with children with autism spectrum disorders.

Characteristics	Value (n=65)
Age at diagnosis[a] (months), mean (SD)	20.3 (6.3)
Age of the father (years), mean (SD)	34.52 (6.52)
Age of the mother (years), mean (SD)	33.63 (3.32)
Age of the children (years), mean (SD)	7.56 (4.52)
Associated disease[b], n (%)	
None	52(80)
Epilepsy	8 (12.3)
Chromosomal abnormalities	9 (13.8)
Endocrine	2 (3)
Gender of the children, n (%)	
Male	46 (72)
Female	19 (28)
Phone, n (%)	
Apple iPhone	34 (52.3)
Android	31 (47.7)

[a] Autism Diagnostic Interview-Revised assessed diagnosis.

[b] Some patients may have >1 association; therefore, percentages do not add to 100%.

Figure 4. Distribution of the answers by month of use and completion rate (each month 650 answers were expected).



Completion rates	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6
■ 100%	21	37	51	67	65	69
■ 80% to 99%	22	57	164	186	203	265
■ 50% to 79%	35	49	65	87	103	170
■ 20% to 49%	75	180	237	180	149	16
■ 0% to 19%	497	327	133	130	130	130

Grouped by Usage

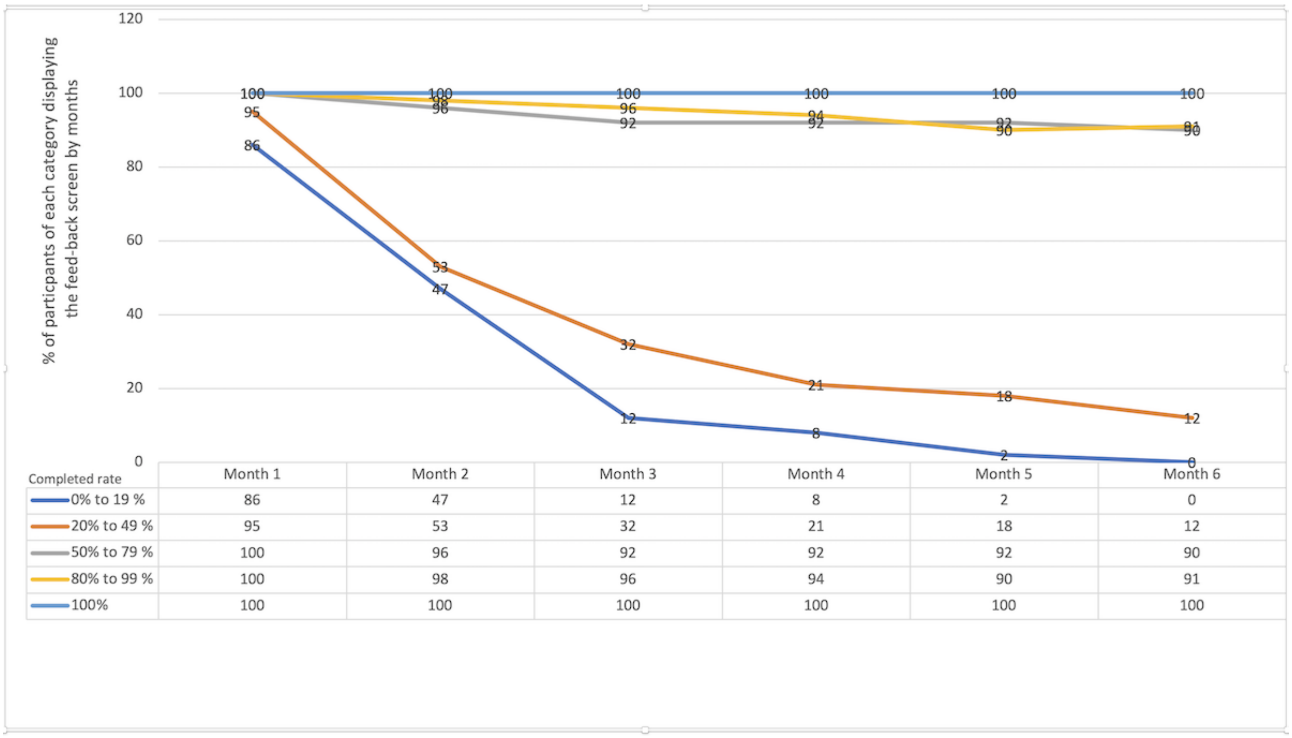
The distribution of Android and Apple smartphones for participants with completion rates >50% (group A; Android: 48%, Apple: 52%) was similar to that for participants with completion rates <50% (group B; Android: 46%, Apple: 54%).

The ages of the fathers and mothers in group A (father: mean 24.3 years, SD 3.5; mother: mean 25.5 years, SD 4.0; *P*=.01) were lower than those in group B (father: mean 29.0 years, SD 6.0; mother: mean 32.0 years, SD 6.4; *P*=.03). We did not find any significant differences for age of the child (*P*=.31) or city type (more or less than 20,000 inhabitants: *P*=.117).

The individuals most likely to fully answer the questions were those who were most likely to display the feedback screen (Figure 5). There were 39 attrition questionnaires with responses: 9 participants were low users, 3 participants were moderate users, and 27 participants were high users.

There were 7 questions (questions 1, 2, 4, 5, 7, 8, and 10) with between-group differences (Table 3). For question 7, which evaluated user satisfaction with the feedback screen, there were significant differences both between high and moderate (*P*=.007) and high and low (*P*<.001) users; however, the difference between low and moderate users was not significant (*P*=.14).

Figure 5. Participants who displayed the feedback screen by month, based on their completion rate.



Completed rate	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6
0% to 19 %	86	47	12	8	2	0
20% to 49 %	95	53	32	21	18	12
50% to 79 %	100	96	92	92	92	90
80% to 99 %	100	98	96	94	90	91
100%	100	100	100	100	100	100

Table 3. Comparison between high, moderate, and low users of the Smartautism app for each item of the attrition questionnaire.

Item			Pairwise[a]		Between-group		
			W test statistic	*P* value	Chi-square (*df*)	*P* value	Effect size
1					19.70 (2)	<.001	0.519
	High	Moderate	−3.88	.02			
	High	Low	−5.72	<.001			
	Moderate	Low	—[b]	—			
2					19.70 (2)	<.001	0.519
	High	Moderate	−3.88	.02			
	High	Low	−5.72	<.001			
	Moderate	Low	—	—			
3					—	—	—
4					30.10 (2)	<.001	0.792
	High	Moderate	−4.92	.001			
	High	Low	−7.10	<.001			
	Moderate	Low	4.69	.003			
5					8.76 (2)	.01	0.231
	High	Moderate	−1.27	.64			
	High	Low	−3.99	.01			
	Moderate	Low	−1.56	.51			
6					—	—	—
7					26.45 (2)	<.001	0.696
	High	Moderate	−4.27	.007			
	High	Low	−6.57	<.001			
	Moderate	Low	−2.71	.135			
8					32.31 (2)	<.001	0.850
	High	Moderate	−5.68	<.001			
	High	Low	−7.51	<.001			
	Moderate	Low	−1.56	.51			
9					—	—	—
10					29.06 (2)	< .001	0.765
	High	Moderate	−4.92	.001			
	High	Low	−7.04	<.001			
	Moderate	Low	0	>.999			
11					—	—	—
12					—	—	—
13					—	—	—

[a] Pairwise comparisons are presented for significant items.

[b] Missing or unquantifiable data.

Discussion

As expected from previous literature [21], in our study population, there were more male children than female children with autism spectrum disorder. We found that participants had a very high intent to use the app during the 6-month period (3698/3900, 94.8%); however, secondary analysis showed that only 46% of participants (30/65) consistently had completion rates over 50%. High users were characterized by having higher satisfaction (question 7) with the feedback screen when compared to low (P<.001) and moderate (P=.007) users.

These results are consistent with those in previous studies [13] on real-life use of smartphone apps in digital medicine and in psychiatry, which show disappointing use rates despite the high expectations of professionals. We did not take the high overall response rate (94.8%) into account in our interpretations and discussions because we recruited families and patients who were already very dedicated to our facility. There were many screened families (59/124 47.5%) that were not included in the study because they lacked a smartphone or had old devices, despite the fact that overall rate of 79% of people in France have smartphones [22]. Moreover, the distribution of smartphone type in our study population was not representative of that of the French population—half of the participants used iPhones, whereas iPhones are used by only 15% of the population in France [22].

Despite encouraging results, our study shows that half of the users (35/65, 54%) did not use the empowerment app regularly. We can assume that the specific parent population in our study (known from our facility) was intrinsically motivated; therefore, we can consider several reasons to explain the constant gap between real usage and expectation in digital health care [23]: (1) the app did not offer sufficient gain for the families for regular use, which is suggested by the fact that only high users were the most interested by the feedback screen, (2) security concerns are always present even if we did explain (orally and with notice inside the app) the data protection measures that we used, and (3) design and ergonomics were tidy and elegant in our app, but we suspect it is very difficult to develop an app that can compete with those developed by large corporations and used in everyday life by our population.

Often, individuals use health apps only for a short period of time. This “law of attrition,” corresponding to the loss of participants during an experiment, raises some questions [18]. Eysenbach [18] highlighted that this rate decreases if a user perceives a relative advantage with the app (perception that this innovation is superior to the idea that it replaces). Our attrition questionnaire results (responses from partial study population: 39/65, 60%) also strongly suggest that reminders and feedback, when appreciated and accepted, are a strong motivation and may drive participants to be high users instead of low users. If engagement can be viewed as a product of experience or interaction, the presence of push factors (reminders) or positive feedback appears to be efficient for engagement.

Recently, the components of engagement in technology, in particular with respect to apps, were evaluated and a user scale based on 4 dimensions was proposed [24]: focused attention, perceived usability, aesthetic appeal, and reward. The *reward* dimension corresponds to the hedonistic aspects of the experience; the feedback screen could enhance this dimension of the app when used; therefore, this component needs to be further developed.

Low users demonstrated low levels of satisfaction in various areas. They expressed reluctance to spend too much time using the app (question 10, high vs low: *P*<.001). They also were annoyed by technical issues (question 4, high vs low: *P*<.001). It appears that too much complexity in the interaction between an app and its users may contribute to a high rate of attrition. These parameters can negatively influence the use of the app. Interestingly, low users were also significantly more dissatisfied by the information and inclusion process of the study.

Perfect engagement with apps will never exist; O’Brien and Toms [25] argue that engagement is not a static, but multistage, process—with a point of engagement, then a period of engagement, a point of disengagement, and a period of reengagement. Moreover, when behavioral symptoms are not present, engagement may decrease due to lack of necessity. Our results show that motivation for long-term use is strongly associated with perceived benefits in completing the study (high vs moderate: *P*<.001; high vs low: *P*<.001), which emphasizes the importance of precise framing during the patient inclusion process (quality of information, explanation of consent, purpose, and benefit). There is a need for stronger collaboration between academics and digital specialists to provide accurate empowerment tools. Indeed, laws of attrition encompass classic motivational rules for study enrollment and new digital constraints related to technical aspects (design, acceptability, stability) [18]. App development requires academic studies that take laws of attrition into account, mainly because, for the past decade, empowerment and enhancement of patients’ responsibilities in their own health care have been growing [26]. Our app is only a first step, but it is consistent with the on-going shift toward the use of such technologies in psychiatry, especially for outpatients.

The Smartautism app is a first and encouraging step in digital empowerment for families of individual with autism spectrum disorders. Our results suggest that users need to perceive the utility of digital tools in order to use them. We plan to add an advice section, through the feedback screen, providing guidance and suggestions generated by Bayesian network algorithm [27] because more powerful algorithms (enhanced by artificial intelligence) might be useful in providing accurate and personalized advice for users.

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Authors' Contributions

OB, VA, DB, FGB, and SM were involved in the conception and design of the study. OB, VV, and FGB recruited patients. OB, VA, and SM drafted the manuscript, and DB, FGB, VV, and VA revised it critically for important intellectual content. The figures were prepared by SM, FGB, and OB. All authors gave final approval for publication.

Conflicts of Interest

None declared.

References

1. Baghdadli A, Pry R, Michelon C, Rattaz C. Impact of autism in adolescents on parental quality of life. Qual Life Res 2014 Aug;23(6):1859-1868. [doi: 10.1007/s11136-014-0635-6] [Medline: 24504623]
2. Farnik M, Brożek G, Pierzchała W, Zejda JE, Skrzypek M, Walczak. Development, evaluation and validation of a new instrument for measurement quality of life in the parents of children with chronic disease. Health Qual Life Outcomes 2010;8:151 [FREE Full text] [doi: 10.1186/1477-7525-8-151] [Medline: 21182754]
3. Hayes SA, Watson SL. The impact of parenting stress: a meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. J Autism Dev Disord 2013 Mar;43(3):629-642. [doi: 10.1007/s10803-012-1604-y] [Medline: 22790429]
4. Davis NO, Carter AS. Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: associations with child characteristics. J Autism Dev Disord 2008 Aug;38(7):1278-1291. [doi: 10.1007/s10803-007-0512-z] [Medline: 18240012]
5. Chamak B, Bonniau B. Trajectories, long-term outcomes and family experiences of 76 adults with autism spectrum disorder. J Autism Dev Disord 2016 Mar;46(3):1084-1095. [doi: 10.1007/s10803-015-2656-6] [Medline: 26572660]
6. Dickson KS, Suhrheinrich J, Rieth SR, Stahmer AC. Parent and teacher concordance of child outcomes for youth with autism spectrum disorder. J Autism Dev Disord 2018 May;48(5):1423-1435 [FREE Full text] [doi: 10.1007/s10803-017-3382-z] [Medline: 29164440]
7. Edwards AG, Brebner CM, McCormack PF, MacDougall CJ. From 'parent' to 'expert': how parents of children with autism spectrum disorder make decisions about which intervention approaches to access. J Autism Dev Disord 2018 Jun;48(6):2122-2138. [doi: 10.1007/s10803-018-3473-5] [Medline: 29396727]
8. Locke J, Ibanez LV, Posner E, Frederick L, Carpentier P, Stone WL. Parent perceptions about communicating with providers regarding early autism concerns. Pediatrics 2020 Apr;145(Suppl 1):S72-S80. [doi: 10.1542/peds.2019-1895J] [Medline: 32238533]
9. Timberlake MT, Leutz WN, Warfield ME, Chiri G. "In the driver's seat": Parent perceptions of choice in a participant-directed medicaid waiver program for young children with autism. J Autism Dev Disord 2014 Apr;44(4):903-914. [doi: 10.1007/s10803-013-1942-4] [Medline: 24057132]
10. Bourla A, Ferreri F, Ogorzelec L, Peretti C, Guinchard C, Mouchabac S. Psychiatrists' attitudes toward disruptive new technologies: mixed-methods study. JMIR Ment Health 2018 Dec 14;5(4):e10240 [FREE Full text] [doi: 10.2196/10240] [Medline: 30552086]
11. Lipschitz J, Hogan TP, Bauer MS, Mohr DC. Closing the research-to-practice gap in digital psychiatry: the need to integrate implementation science. J Clin Psychiatry 2019 May 14;80(3):E1-E3 [FREE Full text] [doi: 10.4088/JCP.18com12659] [Medline: 31091029]
12. Torous J, Haim A. Dichotomies in the development and implementation of digital mental health tools. Psychiatr Serv 2018 Dec;69(12):1204-1206. [doi: 10.1176/appi.ps.201800193]
13. Torous J, Wisniewski H, Liu G, Keshavan M. Mental health mobile phone app usage, concerns, and benefits among psychiatric outpatients: comparative survey study. JMIR Ment Health 2018 Nov 16;5(4):e11715-eE1174 [FREE Full text] [doi: 10.2196/11715] [Medline: 30446484]
14. The app evaluation model. American Psychiatric Association. 2019. URL: https://www.psychiatry.org/psychiatrists/practice/mental-health-apps/app-evaluation-model [accessed 2021-08-11]
15. Shiffman RN. Informatics and general pediatrics. Curr Opin Pediatr 1994 Oct;6(5):538-543. [Medline: 7820200]
16. Csikszentmihalyi M, Larson R. Validity and reliability of the experience-sampling method. J Nerv Ment Dis 1987 Sep;175(9):526-536. [Medline: 3655778]
17. Bonnot O, Bonneau D, Doudard A, Duverger P. Rationale and protocol for using a smartphone application to study autism spectrum disorders: smartautism. BMJ Open 2016 Nov 22;6(11):e012135 [FREE Full text] [doi: 10.1136/bmjopen-2016-012135] [Medline: 27881525]
18. Eysenbach G. The law of attrition. J Med Internet Res 2005;7(1):e11 [FREE Full text] [doi: 10.2196/jmir.7.1.e11] [Medline: 15829473]
19. Autisme. Haute Autorité de Santé. URL: https://www.has-sante.fr/jcms/c_468812/fr/recommandations-pour-la-pratique-professionnelle-du-diagnostic-de-l-autisme [accessed 2021-09-03]
20. ISO 9141-11. International Standards Organization. URL: http://www.iso.org [accessed 2021-09-03]

21. Lord C, Elsabbagh M, Baird G, Veenstra-Vanderweele J. Autism spectrum disorder. Lancet 2018 Aug 11;392(10146):508-520 [FREE Full text] [doi: 10.1016/S0140-6736(18)31129-2] [Medline: 30078460]
22. Autorité de Régulation des Communications Electroniques et des Postes (. Barometre du numérique. Gouvernement Français. 2019. URL: https://www.economie.gouv.fr/files/files/directions_services/cge/barometre-numerique-2019.pdf [accessed 2021-08-11]
23. The Lancet Psychiatry. Digital health: the good, the bad, and the abandoned. Lancet Psychiatry 2019 Apr;6(4):273. [doi: 10.1016/S2215-0366(19)30102-6] [Medline: 30904114]
24. Holdener M, Gut A, Angerer A. Applicability of the user engagement scale to mobile health: a survey-based quantitative study. JMIR Mhealth Uhealth 2020 Jan 3;8(1):e13244-eE1328. [doi: 10.2196/13244]
25. O'Brien HL. Theoretical perspectives on user engagement. In: O'Brien HL, Cairns P, editors. Why Engagement Matters:Cross-Disciplinary Perspectives of User Engagement in Digital Media: Cham. Cham: Springer; 2016:1-26.
26. Pulvirenti M, McMillan J, Lawn S. Empowerment, patient centred care and self-management. Health Expect 2014 Jun;17(3):303-310 [FREE Full text] [doi: 10.1111/j.1369-7625.2011.00757.x] [Medline: 22212306]
27. Mouchabac S, Leray P, Adrien V, Gollier BF, Bonnot O. Beyond big data in behavioral psychiatry, the place of Bayesian Network. JMIR. 2021 (in Press) 2021 Sep 09:00-00 (forthcoming). [doi: 10.2196/24560]

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Original Paper

Tablet-Based Cognitive Impairment Screening for Adults With HIV Seeking Clinical Care: Observational Study

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Abstract

Background: Neurological complications including cognitive impairment persist among people with HIV on antiretrovirals; however, cognitive screening is not routinely conducted in HIV clinics.

Objective: Our objective for this study was 3-fold: (1) to determine the feasibility of implementing an iPad-based cognitive impairment screener among adults seeking HIV care, (2) to examine the psychometric properties of the tool, and (3) to examine predictors of cognitive impairment using the tool.

Methods: A convenience sample of participants completed Brain Baseline Assessment of Cognition and Everyday Functioning (BRACE), which included (1) Trail Making Test Part A, measuring psychomotor speed; (2) Trail Making Test Part B, measuring set-shifting; (3) Stroop Color, measuring processing speed; and (4) the Visual–Spatial Learning Test. Global neuropsychological function was estimated as mean T score performance on the 4 outcomes. Impairment on each test or for the global mean was defined as a T score ≤40. Subgroups of participants repeated the tests 4 weeks or >6 months after completing the first test to evaluate intraperson test–retest reliability and practice effects (improvements in performance due to repeated test exposure). An additional subgroup completed a lengthier cognitive battery concurrently to assess validity. Relevant factors were abstracted from electronic medical records to examine predictors of global neuropsychological function.

Results: The study population consisted of 404 people with HIV (age: mean 53.6 years; race: 332/404, 82% Black; 34/404, 8% White, 10/404, 2% American Indian/Alaskan Native; 28/404, 7% other and 230/404, 58% male; 174/404, 42% female) of whom 99% (402/404) were on antiretroviral therapy. Participants completed BRACE in a mean of 12 minutes (SD 3.2), and impairment was demonstrated by 34% (136/404) on Trail Making Test A, 44% (177/404) on Trail Making Test B, 40% (161/404) on Stroop Color, and 17% (67/404) on Visual-Spatial Learning Test. Global impairment was demonstrated by 103 out of 404 (25%). Test–retest reliability for the subset of participants (n=26) repeating the measure at 4 weeks was 0.81 and for the subset of participants (n=67) repeating the measure almost 1 year later (days: median 294, IQR 50) was 0.63. There were no significant practice effects at either time point (*P*=.20 and *P*=.68, respectively). With respect for validity, the correlation between global impairment on the lengthier cognitive battery and BRACE was 0.63 (n=61; *P*<.001), with 84% sensitivity and 94% specificity to impairment on the lengthier cognitive battery.

Conclusions: We were able to successfully implement BRACE and estimate cognitive impairment burden in the context of routine clinic care. BRACE was also shown to have good psychometric properties. This easy-to-use tool in clinical settings may facilitate the care needs of people with HIV as cognitive impairment continues to remain a concern in people with HIV.

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KEYWORDS

cognitive complications; people with HIV; digital assessment; HIV; tablet; screening

Introduction

Thirty-six years into the HIV epidemic, North America has had markedly improved clinical outcomes and prolonged life. Death from non-AIDS comorbidities is now more common than AIDS-related death, and life-expectancy has increased markedly among those on antiretroviral therapy [1-5]. Similarly, AIDS-related comorbidities are now less common than noncommunicable, age-related comorbidities. Cognitive impairment among people with HIV persists despite effective antiretroviral therapy [6-9]. Cognitive impairment in the current treatment era is often mild and not readily detectable to the practicing clinician. At present, only clinical criteria and neuropsychological testing are used to diagnose cognitive impairment, and no single laboratory test or biomarker has been established to effectively detect mild cognitive impairment. Current screening measures (eg, the International HIV Dementia Scale [10], Montreal Cognitive Assessment [11], HIV Dementia Scale [12]) lack sensitivity for detecting milder forms of cognitive impairment [13-18], and the resources (eg, time, cost, training) required for comprehensive neuropsychological assessments limits their widespread use during routine clinic visits. Thus, there is a pressing need for brief screening measures that could be easily implemented into routine clinic care in order to determine persons in need of comprehensive neuropsychological evaluation.

Tablet computing tools, such as the Apple iPad, are increasingly ubiquitous and offer an opportunity to potentially implement an intuitive interface for primarily self-directed brief cognitive assessments with automated scoring, data aggregation, and preliminary screening of impairment in real time, thus minimizing clinician and staff burden and increasing the opportunity to identify individuals in need of neuropsychological evaluation. Recently, a brief iPad tool was developed to screen cognitive impairment. The testing platform has automated data aggregation, which provides global data to facilitate and or support computational epidemiological applications, pharmaceutical development, and clinical trial monitoring, including monitoring of the effectiveness of antiretroviral therapy and nonantiretroviral therapy medications on cognitive impairment in the context of clinical care. The largely self-administered testing, survey, and automated reporting has the potential to be used as a model for the design and development of mobile app to quantify cognition, behavior, mental health, and mobility in the clinic and through emerging mobile technologies worldwide.

Herein we first aimed to determine the feasibility of using an iPad-based tool (BRACE, Brain Baseline Assessment of Cognition and Everyday Functioning) to screen for cognitive impairment among adults with HIV seeking clinical care in Baltimore, Maryland. Second, we aimed to examine the psychometric properties of the iPad-based cognitive screener including test–retest reliability and practice effects (improvement in performance from repeated exposures to testing materials) as well as validity. Third, we aimed to understand predictors (sociodemographic, clinical, and behavioral data) of cognitive impairment using the iPad-based tool among people with HIV.

Methods

Study Population

From January 29, 2019 to December 30, 2019, a convenience sample of patients was recruited during routine clinic visits (via the clinic's research desk or by provider referral) in the John G. Bartlett HIV Practice at the Johns Hopkins Hospital in Baltimore, Maryland. Inclusion criteria were minimal and only included (1) English-language proficiency and (2) being able to provide informed consent. There were no postconsent exclusion criteria because our goal was to determine feasibility of integrating BRACE in the context of routine clinic care for people with HIV rather than focus on HIV-associated neurocognitive disorders, which are only deemed present if the cognitive impairment cannot be attributed to any other comorbid condition or other confounders [19]. This study was conducted in accordance with ethical standards for human experimentation and was approved by the Johns Hopkins School of Medicine Institutional Review Board.

Procedure

Staff at the clinic's research desk and providers directed interested patients to trained study research assistants. After confirming that patients met initial eligibility criteria, research assistants explained the study and obtained informed consent. Patients who enrolled completed the BRACE and the Computerized Adaptive Test for Mental Health. All visits were conducted in exam rooms with a research coordinator to help with administration (no staff monitoring). After completing the study visit, participants were added to our Clinical Research Management System to ensure that each patient only consented once to the study. Clinical Research Management System data entry was also important to identify when patients were due for their routine clinic visits. Due to the nature of the study, there was more flexibility in administration of follow-up visits (eg, follow-up completion of the BRACE occurred when participants' clinic visits fell on or after the 6-month follow-up mark). This study only relied on performance on the BRACE at these visits. A subset of patients also completed a lengthier cognitive test battery as part of other ongoing neuroHIV clinical studies the same day as the completion of BRACE. The order of administration (BRACE before or after the lengthier battery) was based on patients' schedules; we typically schedule our neuroHIV studies on the same day as clinic appointments.

Cognitive Function Outcomes

This self-administered tool (automated audio and video instructions) used 4 validated neuropsychological tests.

The BRACE tool includes the Trail Making Test (TMT) Part A, which measures psychomotor speed, TMT Part B, which measures set-shifting and mental flexibility, Stroop Color Test, which measures processing speed, and Visual-Spatial Learning Test, which measures visuospatial learning and memory. BRACE has been shown to have high sensitivity to HIV-related or other brain dysfunction; during its development, *T* scores (mean 50, SD 10) were generated using a normative based regression approach (adjusted for age, sex, race/ethnicity, and education) based on a sample of 144 HIV-uninfected, healthy individuals free from significant confounds that might affect cognitive performance (eg, recent or significant traumatic brain injury, neurologic disorder, central nervous system infections, etc). The normative group was a mean age of 42.2 years (SD 15.7, range 18-70), with education level of 15.2 years (SD 2.26, range 9-20) with 45.8% being male and 56.9% White (T Marcotte, unpublished data). Six-month test–retest reliability (n=110) for the overall score was *r*=0.84. In an independent validation (T Marcotte, unpublished data) with 109 participants (66 people with HIV, 43 HIV-uninfected), a significant difference ($P<.001$) and a large effect size of 1.18 between the people with HIV and HIV-uninfected were found; the HIV-uninfected group had a mean *T* score of 50.8, suggesting the norms worked well when applied to this additional group.

A global neuropsychological score was computed by averaging performance across the 4 outcomes [9]. Impairment was defined as *T* score <40, based upon maximizing sensitivity and specificity relative to the full neuropsychological battery. The tool also includes an abbreviated version of the Patient's Assessment of Own Functioning Inventory, a measure of self-reported cognitive complaints consisting of 5 dimensions, and the Patient Health Questionnaire–2, a measure inquiring about the frequency of depressed mood and anhedonia over the past 2 weeks. Significant self-reported cognitive symptoms were determined based upon regression-based analyses of the full Patient's Assessment of Own Functioning Inventory. A score of 3 or greater on the Patient Health Questionnaire–2 was considered being at-risk for depression [20].

We retested BRACE in a subset of individuals within 30 days of initial testing (n=26) and more than 6 months after initial testing (n=67).

Neuropsychological Test Battery

Within our study population, a subset of 61 participants also completed a lengthier cognitive test battery as part of other ongoing neuroHIV clinical studies on the same day that they completed BRACE. This subset was similar to rest of the study population on most factors except for sex, with the subsample having more women than the larger group had (Table S1 in Multimedia Appendix 1). The neuropsychological test battery included the following tests: (1) Hopkins Verbal Learning Test revised, which measures auditory-verbal learning and memory, (2) TMT Parts A and B, (3) Grooved Pegboard Test, which measures fine motor speed and dexterity, (4) Digit Symbol Modalities Test, which measures processing speed, and (5) Animal Fluency, which measures semantic verbal fluency. The completion order of the neuropsychological test battery and BRACE was not systematically assigned or tracked; some participants went from a routine clinical visit to a neuroHIV clinical study visit or vice versa. All outcome measures from these tests were standardized using regression-based equations from HIV-uninfected individuals participating in the Women's Interagency HIV Study and the Multicenter AIDS Cohort Study [21,22]. Thus, all outcomes were in *z* score units (mean 0, SD 1). A global neuropsychological function score was computed by averaging all outcome measures. Impairment was defined a priori as performing 1 SD below the global neuropsychological mean [9].

Covariates: Demographic Characteristics, HIV Biomarkers, Antiretroviral Therapy Medication, and Comorbidities

Patient-level variables were extracted and validated by 2 research coordinators. Sociodemographic factors included age, sex, race/ethnicity, and years of education. HIV-related clinical factors included the closest (until or on the day of assessment) plasma CD4 count and HIV RNA (lower limit of detection: 20 copies per mL) in the electronic medical record, and antiretroviral therapy medications (name and class of medication).

Additionally, we focused on extracting medical comorbidities within 4 general International Statistical Classification of Diseases and Related Health Problems (ICD-10) categories in the electronic medical record: (1) endocrine, nutritional, and metabolic diseases (ICD-10 codes E00-E99); (2) mental, behavioral, and neurodevelopmental disorders including substance use disorders (ICD-10 codes F01-F99); (3) nervous system disorders (ICD-10 codes G00-G99); and (4) circulatory system issues (ICD-10 codes I00-I99). These problems were selected as our focus as these comorbidities have known associations with cognitive health in HIV [23-26].

Statistical Analysis

Descriptive statistics were used to characterize the study population and the prevalence of cognitive impairment. Pearson correlations were used to examine the association between performance on the BRACE initially and at a subsequent time point. Practice effects (performance initially vs a subsequent time point) were examined using a paired-sample *t* test. Pearson correlations were also used to examine the association between performance on BRACE and performance on the lengthier neuropsychological test battery. Logistic regression models were used to explore the univariable and multivariable associations of the covariates with the outcomes. Covariates included in the multivariable logistic regression models included those with a statistically significant univariable association and demographic characteristics with face validity, including age, sex, race/ethnicity, and HIV acquisition risk group. All analyses were conducted in SAS software (version 9.4; SAS Institute Inc), and a *P* value <.05 indicated statistical significance.

Results

Participant Characteristics

The study population included 404 people with HIV (Table 1; age: range 21.6 to 79.3 years). Of the population, 99.5% (402/404) were currently on antiretroviral therapy, and 66.1% (267/404) had an undetectable viral load (<20 copies per mL) near the time of cognitive impairment assessment (median 10 days, IQR 63). The median CD4 level was 631 cells/µL (IQR 476) near the time of cognitive assessment (median 31 days, IQR 63). The most commonly prescribed antiretroviral therapy agents included nucleoside reverse-transcriptase inhibitors emtricitabine (258/404, 63.9%) and tenofovir alafenamide (245/404, 60.6%), protease inhibitor darunavir (94/404, 23.3%), and integrase inhibitors dolutegravir (170/404, 42.1%) and bictegravir (92/404, 22.8%).

Table 2 provides the most common (>5%) ICD-10 problems listed under 4 categories of comorbidities (endocrine, nutritional, and metabolic diseases; mental, behavioral, and neurodevelopmental disorders and substance use disorders; nervous system disorders; circulatory system issues).

On the iPad, 18.1% (73/404) had Patient Health Questionnaire-2 scores suggesting possible risk for depression, and 66.1% (267/404) perceived significant impairments in daily activities.

Table 1. Sociodemographic, behavioral, and clinical characteristics in the overall sample of people with HIV seeking clinical care and by cognitive impairment status based upon Brain Baseline Assessment of Cognition and Everyday Functioning performance.

Characteristic	Overall (N=404)	Impaired (n=103)	Not impaired (n=301)	*P* value
Age, mean (SD)	53.6 (10.7)	50.2 (10.5)	54.8 (10.5)	<.001
Age >50 years, n (%)	290 (71.8)	64 (62.1)	226 (75.1)	.01
Age >60 years, n (%)	123 (30.4)	13 (12.6)	110 (36.5)	<.001
Male, n (%)	230 (56.9)	63 (61.2)	167 (55.5)	.31
Education[a], n (%)				.97
Less than high school	119 (29.5)	30 (29.1)	89 (29.6)	
High school	172 (42.6)	44 (42.7)	128 (42.5)	
More than high school	111 (27.5)	27 (26.2)	84 (27.9)	
Race, n (%)				.36
African-American/Black	332 (82.2)	81 (78.6)	251 (83.4)	
Caucasian/White	34 (8.4)	8 (7.8)	26 (8.6)	
American Indian/Alaskan Native	10 (2.5)	3 (2.9)	7 (2.3)	
Other	28 (6.9)	11 (10.7)	17 (5.6)	
Hispanic/Latino ethnicity, n (%)	12 (3.0)	7 (6.8)	5 (1.7)	.008
Current CD4 count[b], n (%)				.24
Less than 200	43 (10.6)	15 (14.6)	28 (9.3)	
200-500	91 (22.5)	24 (23.3)	67 (22.3)	
More than 500	264 (65.3)	61 (59.2)	203 (67.4)	
Current HIV RNA (copies per milliliter)[b], n (%)				.43
Undetectable (<20)	266 (65.8)	62 (60.2)	204 (67.8)	
Less than 200	83 (20.5)	26 (25.2)	57 (18.9)	
Greater than 200	49 (12.1)	12 (11.7)	37 (12.3)	
On antiretroviral therapy, n (%)	402 (99.5)	103 (100)	299 (99.3)	.41
On antiretroviral therapy and undetectable HIV RNA, n (%)	265 (65.6)	62 (60.2)	203 (67.4)	.18
Nucleoside reverse-transcriptase inhibitor, n (%)				
Emtricitabine	258 (63.9)	67 (65.0)	191 (63.5)	.77
Tenofovir alafenamide	245 (60.6)	64 (62.1)	181 (60.1)	.72
Abacavir	82 (20.3)	21 (20.4)	61 (20.3)	.98
Lamivudine	77 (19.1)	19 (18.4)	58 (19.3)	.85
Nonnucleoside reverse-transcriptase inhibitor, n (%)				
Rilpivirine	39 (9.7)	8 (7.8)	31 (10.3)	.45
Protease inhibitor, n (%)				
Darunavir	94 (23.3)	25 (24.3)	69 (22.9)	.78
Ritonavir	44 (10.9)	10 (9.7)	34 (11.3)	.65
Integrase inhibitor, n (%)				
Dolutegravir	170 (42.1)	46 (44.7)	124 (41.2)	.54
Bictegravir	92 (22.8)	25 (24.3)	67 (22.3)	.67
Elvitegravir	52 (12.9)	11 (10.7)	41 (13.6)	.44
Raltegravir	21 (5.2)	4 (3.9)	17 (5.6)	.49

[a] Data are missing from 2 participants.

[b] Data are missing from 4 participants; antiretroviral therapy included are agents used by more than 5% of the sample.

Table 2. Common ICD-10 codes from medical records in the overall sample of people with HIV seeking clinical care and by Brain Baseline Assessment of Cognition and Everyday Functioning cognitive impairment status.

ICD-10[a]	Overall (N=404), N (%)	Impaired (n=103), n (%)	Normal (n=301), n (%)	*P* value
Endocrine, nutritional, and metabolic diseases (ICD-10 E00-E89)	239 (59.2)	57 (55.3)	182 (60.5)	.36
Metabolic disorders (ICD-10 E70-E88)	144 (35.6)	32 (31.1)	112 (37.2)	.26
Overweight, obesity and other hyperalimentation (ICD-10 E65-E68)	73 (18.1)	14 (13.6)	59 (19.6)	.17
Diabetes (ICD-10 E8-E13)	71 (17.6)	17 (16.5)	54 (17.9)	.74
Disorders of other endocrine glands (ICD-10 E20-E35)	30 (7.4)	5 (4.9)	25 (8.3)	.25
Mental, behavioral, and neurodevelopmental disorders (ICD-10 F00-F99)	330 (81.7)	83 (80.6)	247 (82.1)	.74
Mood [affective] disorders (ICD-10 F30-F39)	234 (57.9)	58 (56.3)	176 (58.5)	.70
Mental and behavioral disorders due to psychoactive substance use (F10-F19)	222 (55.0)	53 (51.5)	169 (56.1)	.41
Other psychoactive substance related disorders (ICD-10 F19)	117 (29.0)	31 (30.1)	86 (28.6)	.77
Nicotine dependence (ICD-10 F17)	84 (20.8)	18 (17.5)	66 (21.9)	.34
Alcohol related disorders (ICD-10 F10)	61 (15.1)	16 (15.5)	45 (15.0)	.88
Opioid (ICD-10 F11)	63 (15.6)	19 (18.4)	44 (14.6)	.35
Cocaine (ICD-10 F14)	59 (14.6)	15 (14.6)	44 (14.6)	.99
Cannabis (ICD-10 F12)	15 (3.7)	2 (1.9)	13 (4.3)	.27
Anxiety, dissociative, stress-related, somatoform (ICD-10 F40-F48)	64 (15.8)	11 (10.7)	53 (17.6)	.10
Psychosis (ICD-10 F20-F29)	13 (3.2)	5 (4.9)	8 (2.7)	.28
Diseases of the nervous system (ICD-10 G00-G99)	163 (40.3)	43 (41.7)	120 (39.9)	.74
Episodic and paroxysmal disorders (ICD-10 G40-G47)	82 (20.3)	22 (21.4)	60 (19.9)	.76
Polyneuropathies and other disorders of the PNS (ICD-10 G60-G65)	66 (16.3)	13 (12.6)	53 (17.6)	.24
Nerve, nerve root and plexus disorder (ICD-10 G50-G59)	29 (7.2)	7 (6.8)	22 (7.3)	.86
Diseases of the circulatory system (ICD-10 I00-I99)	244 (60.4)	54 (52.4)	190 (63.1)	.06
Hypertensive diseases (ICD-10 I10-I16)	192 (47.5)	41 (39.8)	151 (50.2)	.07
Ischemic heart disease (ICD-10 I20-I25)	64 (15.8)	7 (6.8)	57 (18.9)	.004
Other forms of heart disease (ICD-10 I30-I55)	51 (12.6)	6 (5.8)	26 (8.6)	.36
Diseases of veins, lymphatic vessels and lymph nodes (ICD-10 I80-I89)	40 (9.9)	8 (7.8)	32 (10.6)	.40
Pulmonary heart disease and disease of pulmonary circulation (ICD-10 I26-I28)	33 (8.2)	5 (4.9)	28 (9.3)	.15
Disease of arteries, arterioles and capillaries (ICD-10 I70-I79)	32 (7.9)	6 (5.8)	26 (8.6)	.36
Cerebrovascular disease (ICD-10 I60-I69)	25 (6.2)	9 (8.7)	16 (5.3)	.21

[a] ICD-10 International Statistical Classification of Diseases, tenth revision.

Cognitive Function in People With HIV Seeking Clinical Care

The mean completion time for BRACE for the older individuals in the study population was 12 minutes (SD 3.2). The average *T* score on TMT A was 44.9 (SD 10.7), TMT B was 42.4 (SD 9.3), Stroop was 43.2 (SD 10.5), Visual-Spatial Learning Test was 47.7 (SD 8.4), and global neuropsychological function was 44.6 (SD 7.2) (Figure 1 and Figure 2; Tables S2 and S3 in Multimedia Appendix 1). When using the definition of impairment of 1 SD below the mean (*T* score <40), 33.7% (136/404) were impaired on TMT A, 43.8% (177/404) on TMT B, 39.9% (161/404) on Stroop, 16.6% (67/404) on Visual-Spatial Learning Test, and 25.5% (103/404) on global neuropsychological function.

Figure 1. Performance on iPad cognitive assessment tool of people with HIV seeking clinical care. The red line indicates the mean, the grey shaded section indicates the score is in the range of impairment (T score <40); the dotted grey line is T score=35 (1.5 SD below the mean). TMT: Trail Making Test; VSLT: Visual Spatial Learning Test.

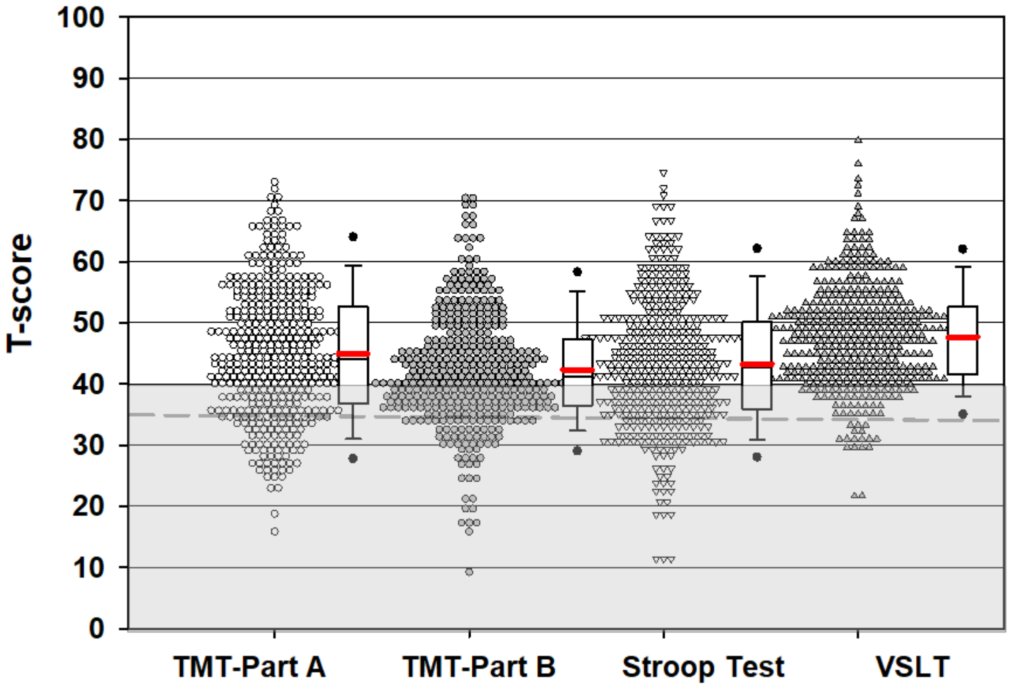
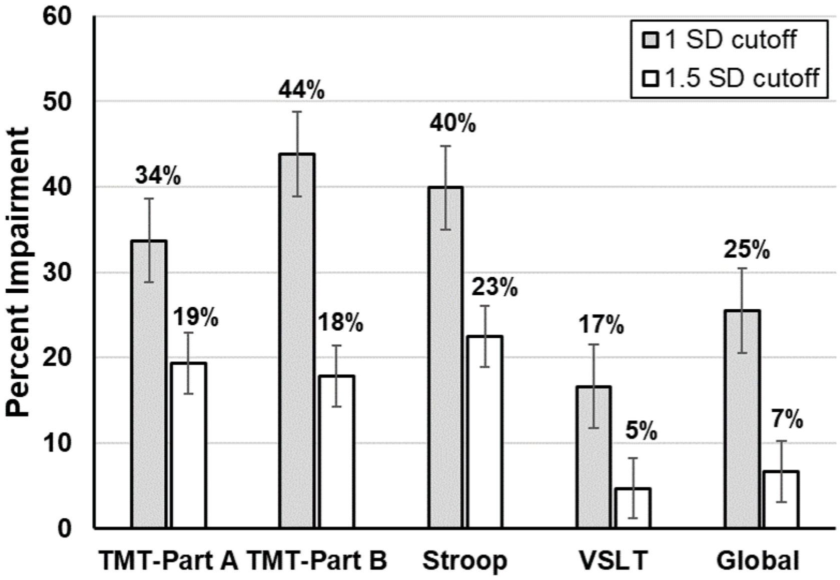


Figure 2. Percentage impairment in study population of people with HIV seeking clinical care. TMT: Trail Making Test; VSLT: Visual Spatial Learning Test.



Of the 404 participants, 26 completed BRACE 30 days later. Test–retest reliability for the subset of participants repeating the measure was 0.81 (Figure 3). There were no significant practice effects (*P*=.20) as the global neuropsychological mean at the first assessment was 46.6 (SD 5.8) and that at the second assessment was 47.72 (SD 6.7). Of the 404 participants, 67 (16.6%) completed BRACE more than 6 months later (days: median 294 days, IQR 50). Test–retest reliability for the subset of participants repeating BRACE almost 1 year later was 0.63 (Figure 4). There were no significant practice effects (*P*=.68) as the global neuropsychological mean at the first assessment was 43.9 (SD 6.2) and the second assessment was 44.1 (SD 5.9).

Figure 3. Associations between global neuropsychological function assessed with the tool at the initial time point and 30 days later in 26 people with HIV assessed via the gold standard neuropsychological battery in 61 people with HIV.

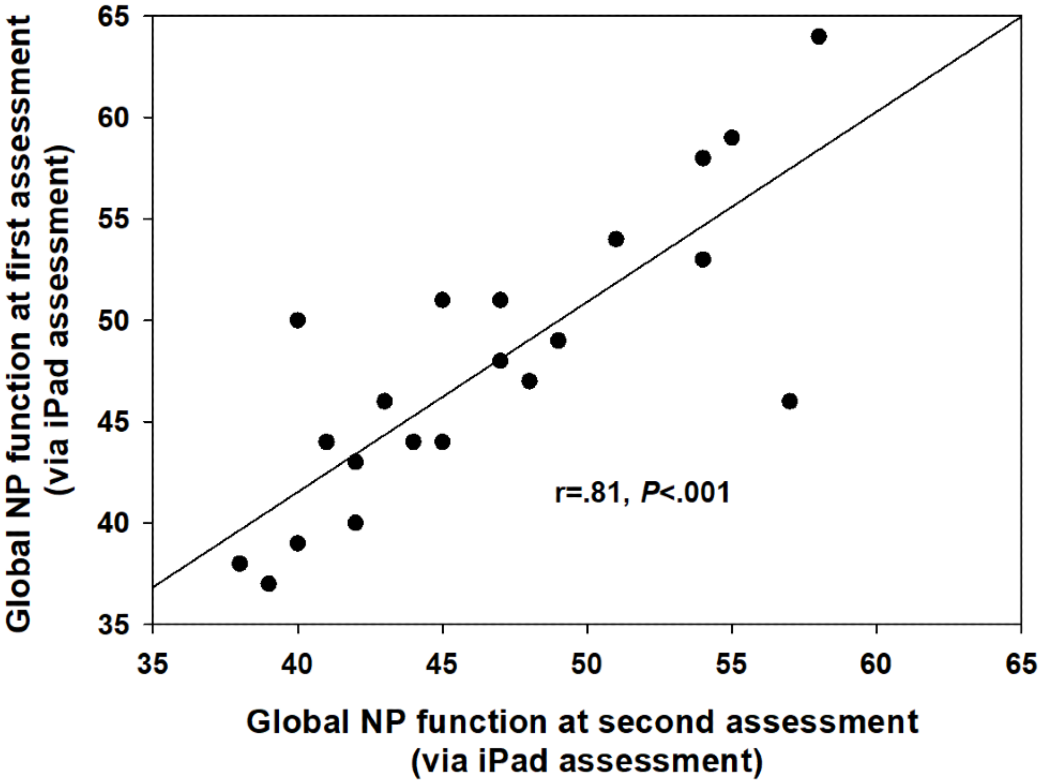
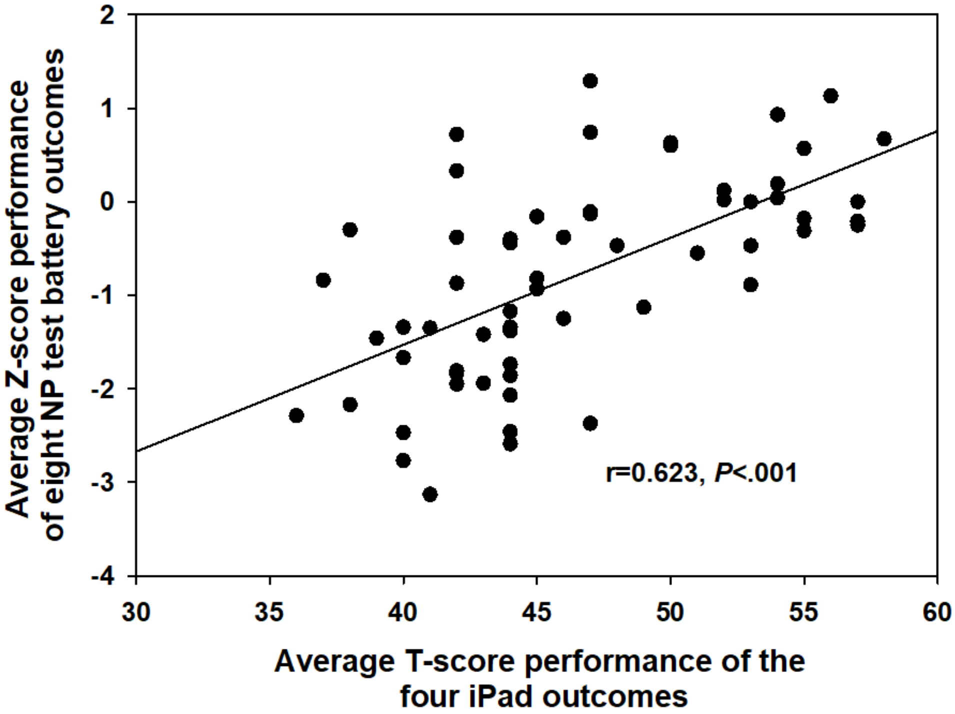


Figure 4. Associations between global neuropsychological function assessed with the tool at the initial time point and almost 1 year later in 67 people with HIV assessed via the gold standard neuropsychological battery in 61 people with HIV.



The correlation between the lengthier cognitive test battery and global neuropsychological function via the iPad-based assessment in the subgroup of 61 at the first visit was 0.634 (*P*<.001; Figure 5). This subgroup comprised significantly fewer males (14/61, 23.0%) than the larger sample (216/343, 63.0%, *P*<.001). When examining the degree to which the BRACE outcomes were correlated with the lengthier cognitive test battery outcomes, all associations were in the expected direction, with higher performance on BRACE outcomes correlated with higher performance on neuropsychological test battery outcomes

(Figure 6). BRACE also demonstrated good discriminant validity when differentiating between people with HIV with and without global neuropsychological impairment (using a *T* score cutoff of 40) on the gold standard neuropsychological test battery (Figure 7). Using a *T* score cutoff of 40 for global neuropsychological function on BRACE yielded 0.84 sensitivity and 0.94 specificity when compared to global neuropsychological impairment using gold standard neuropsychological tests.

Figure 5. Associations between global neuropsychological function assessed with the tool at the initial time point and global neuropsychological function assessed via the gold standard neuropsychological battery in 61 people with HIV.

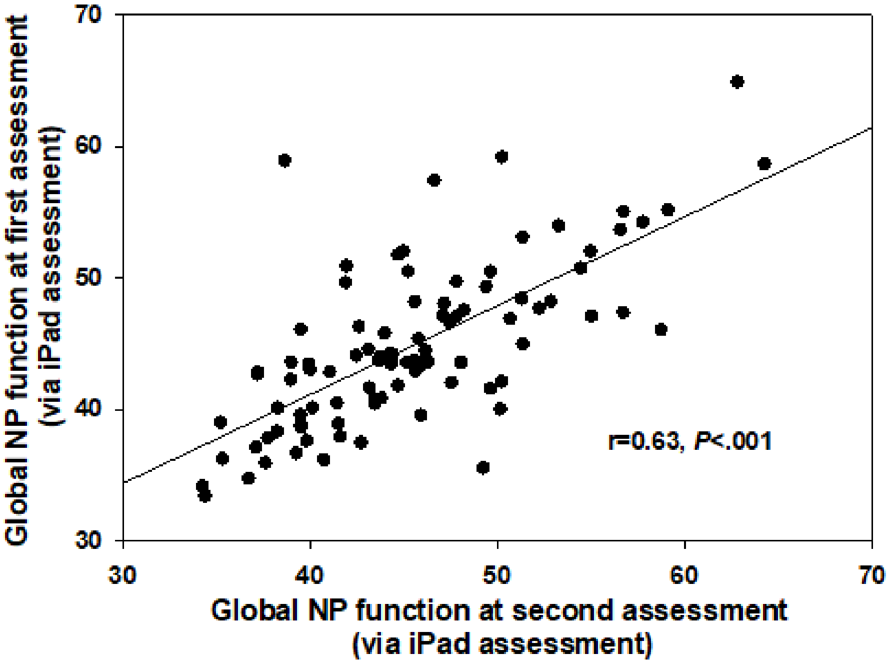


Figure 6. Correlation heatmap between the individual outcomes assessed with the tool and the gold standard neuropsychological test battery. ****P*<.001; ***P*<.01; **P*<.05. SDMT: Symbol Digit Modalities Test; DMT: Symbol Digit Modalities Test; TMT: Trial Making Test; HVLT: Hopkins Verbal Learning Test-Revised; SEMFLU: semantic fluency; GPEG-D: Grooved Pegboard dominant hand; GPEG-ND: Grooved Pegboard nondominant hand; VSLT:Visual Spatial Learning Test.

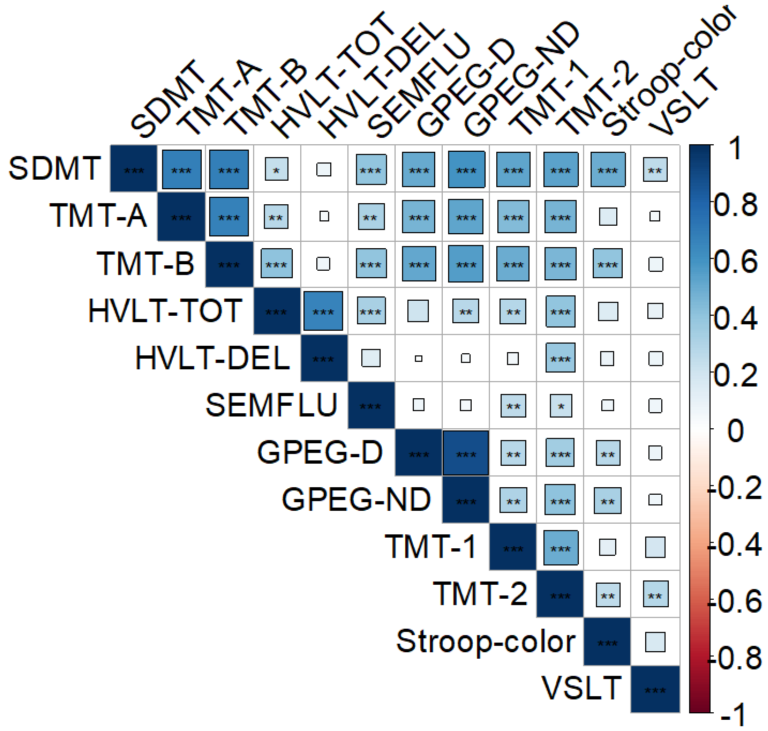
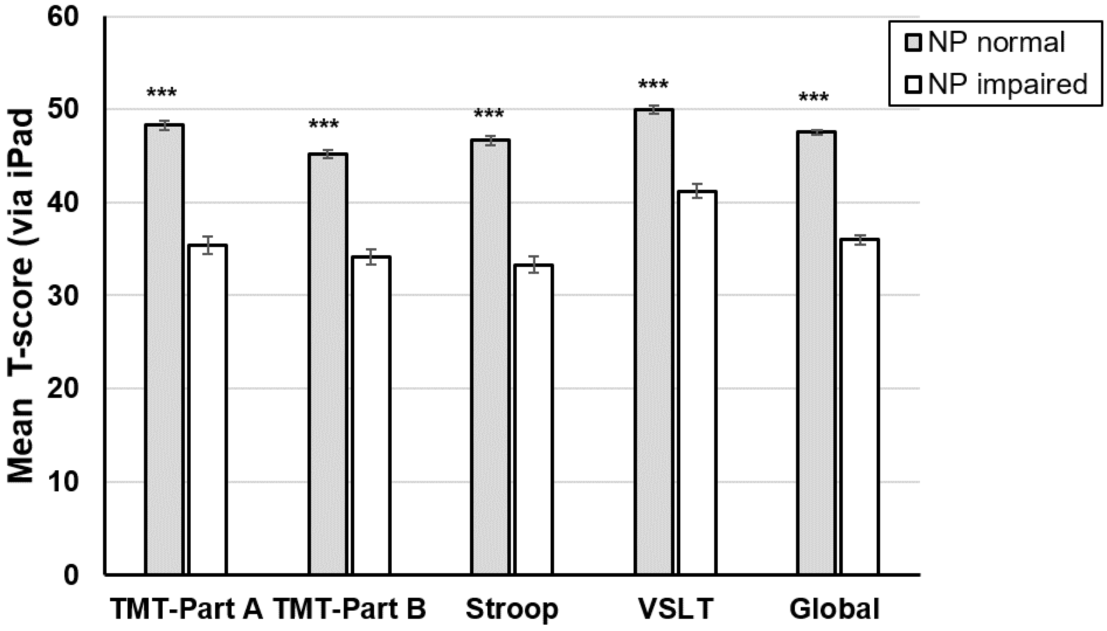


Figure 7. Performance (T scores) on the Brain Baseline Assessment of Cognition and Everyday Functioning iPad cognitive assessment as a function of global neuropsychological impairment (normal vs impaired based on a z score <1) using the gold standard neuropsychological test battery in people with HIV. ***P<.001. TMT: Trail Making Test; VSLT: Visual Spatial Learning Test.



Predictors

People with HIV demonstrating global neuropsychological impairment using the 1 SD cutoff on the BRACE screen were similar to cognitively healthy people with HIV on the majority of sociodemographic, clinical, and behavioral characteristics (Tables 1, 2, and 3). However, individuals demonstrating global neuropsychological impairment were younger (*P*<.001), more likely to be Hispanic/Latino (*P*=.008), and less likely to have ischemic heart disease (*P*=.004). In a multivariable logistic regression model, both age (*P*=.03) and Hispanic/Latino ethnicity (*P*=.02) were the only significant predictors of global neuropsychological impairment.

Table 3. Unadjusted and adjusted odds of cognitive impairment (1 SD cutoff) on Brain Baseline Assessment of Cognition and Everyday Functioning for sociodemographic, clinical, and behavioral factors in the overall sample of people with HIV seeking clinical care.

Factors	Univariable analyses, OR[a] (95% CI)	Multivariable analysis, OR (95% CI)
Greater than or equal to 50 years of age (vs less than 50 years of age)	0.54 (0.34-0.88)[*]	0.56 (0.33-0.96)[*]
Female (vs male)	1.26 (0.80-1.99)	1.27 (0.76-2.12)
Less than high school (vs high school or more)	0.98 (0.60-1.60)	1.07 (0.62-1.85)
African-American/Black	1.36 (0.78-2.39)	1.03 (0.55-1.93)
Hispanic/Latino	4.32 (1.34-13.91)[**]	4.31 (1.25-14.90)[*]
Current CD4 count fewer than 200 (vs > 200)	1.72 (0.88-3.37)	1.65 (0.80-3.40)
On antiretroviral therapy+ undetectable current HIV RNA (vs antiretroviral therapy+ detectable HIV RNA[b])	0.71 (.45-1.12)	0.86 (0.51-1.44)
ICD-10 codes (any vs none)		
Endocrine, nutritional, and metabolic diseases	0.81 (0.52-1.27)	1.04 (0.62-1.74)
Mental, behavioral, and neurodevelopmental disorders	0.91 (0.51-1.61)	0.90 (0.49-1.65)
Diseases of the nervous system	1.08 (0.69-1.70)	1.10 (0.67-1.80)
Diseases of the circulatory system	0.64 (0.41-1.01)	0.87 (0.51-1.48)

[a] OR: odds ratio.

[b] 2 cases were not on antiretroviral therapy and were undetectable.

[*] *P*<.05.

[**] *P*<.01.

Discussion

BRACE was developed to briefly screen for cognitive impairment, particularly mild impairment that is not readily detectable by the practicing clinician. In our sample of 404 adults with HIV seeking outpatient clinical care, we demonstrated that this brief, self-administered screener of cognitive impairment can be self-administered rather rapidly in clinic (approximately 7-10 minutes; slightly longer in older adults, approximately 12 minutes) during routine clinic visits. Important to note is that our sample comprised predominately older, African-American/Black individuals with low education and a high burden of mental and behavioral health disorders, hypertension, and metabolic disorders based on electronic medical record. Thus, one of the strengths of the tool is that it can be used in persons who are nonreaders or with low literacy; the tests are not literacy dependent as both written and verbal instructions (via video) are provided. Importantly, the tool has excellent test–retest reliability, no practice effects over a 30-day or a median of approximately 10 months, strongly correlates to a briefer cognitive test battery, and has good classification accuracy compared to the lengthier cognitive test battery, which required 20 to 30 minutes to complete.

The global burden of cognitive impairment in this population using the standard 1 SD cutpoint on BRACE was 25% (103/404) with varying estimates of impairment across each test (67/404, 16.6% to 177/404, 43.8%). Estimates of global neuropsychological impairment using BRACE are consistent with those in previous studies—7% to 60% of people with HIV demonstrated cognitive impairment via neuropsychological testing [6-9,27,28] or other tablet-based tools to assess cognitive impairment, such as NeuroScreen [29].

In addition to estimating the burden of cognitive impairment, our large sample size enabled us to also examine covariates and risk factors for global neuropsychological impairment. Relative to the number of factors extracted from medical records, very few of these factors were associated with global neuropsychological impairment. Some of the factors that emerged are well-established sociodemographic factors including age and ethnicity [30]. Age emerged as a significant predictor of global neuropsychological impairment with higher performance among older versus younger people with HIV (P=.03). While the types of factors relating to cognition were expected [26,31], the relationships were not always in the anticipated direction. For example, our finding global neuropsychological impairment was higher in younger compared to older people with HIV is counterintuitive. At present, we are uncertain as to why this pattern was present. However, this finding is hypothesis generating and suggests the importance of cognitively screening people before the age of 50 years. It also remains unclear as to why people with HIV with Hispanic ethnicity were more likely to be impaired (P=.03). The T scores were demographically corrected for race/ethnicity as well as adjusted for age, sex, and education; and the tests in BRACE are not literacy dependent as both written and verbal instructions (via video) are provided.

The prevalence of cognitive impairment detected in outpatient clinical care suggests the need for HIV services that incorporate routine, brief cognitive screening into patient management for numerous reasons. Detection of cognitive impairment is necessary to adequately manage patient care and potentially improve clinical outcomes because, in its severe form, impairment may impact everyday functioning including attending routine HIV clinic care, financial and medication management, driving, multitasking, and vocational functioning [30,32-34]. Continued cognitive screening also allows for the ability for early detection, management, and intervention of mild forms of cognitive impairment that may either progress or fluctuate over time. As the mechanisms underlying cognitive impairment are likely complex and multifactorial, routine cognitive screening is necessary at minimum to determine whether modifiable factors (eg, medications with anticholinergic burden or polypharmacy for comorbid conditions [35], antiretroviral therapy medications such as efavirenz- [36] or dolutegravir-based regimens) can lead to impairment (although not seen in the present study) and thus remedied by the clinician. To accomplish routine cognitive screening, resources would need to be allocated to cognitive screening. For instance, iPads would be needed if BRACE were to be implemented in clinic. Clinicians would also need to be trained on the tool for examining the results and determining any subsequent recommendations. For instance, if individuals demonstrate impairment via cognitive screening, further neuropsychological evaluation by a trained professional (ie, neuropsychologist) should be recommended to better understand domain-specific impairment because there is significant heterogeneity in cognitive function in people with HIV [9,37,38]. Not all individuals demonstrate the same neuropsychological profile and different impairment profiles may result from different predictors or different mechanisms. Further evaluation is also necessary to determine whether impairment identified by BRACE may have been due to disinterest or poor engagement with testing or malingering for secondary gain (eg, disability).

There are a number of study limitations including the cross-sectional study design, which precludes any discussion of causality, as well as possible self-selection bias or lack of generalizability as participants voluntarily chose to enroll in this study. Our lack of an HIV seronegative, at-risk comparison group was also a major study drawback. An HIV-uninfected control group would have enabled the direct comparison of the prevalence of cognitive impairment using the BRACE in people with HIV seeking routine clinic care compared to an uninfected control group after adjusting for any relevant sociodemographic, behavioral, and clinical factors. As our primary interest was in the implementation of BRACE in the context of routine clinic HIV care and the prevalence estimates of cognitive impairment among these patients, we did not seek a control group. However, it is important that our cohort of people with HIV was standardized to an external group of HIV-uninfected individuals, which is standard practice in clinical neuropsychology. While our T scores were estimated using a normative based regression approach (adjusted for age, sex, race/ethnicity, and education; T Marcotte, unpublished data), follow-up scores were not adjusted for practice at this point as those regression equations are currently being developed. This is important as the lack of a practice effect in people with HIV may suggest impairment. Furthermore, it is also important to note that our *T* scores were estimated based on a sample of only 144 HIV-uninfected individuals aged 18 to 70 years. Our sample ranged in age from 21.6 to 79.3 years, with 5 people with HIV over the age of 70 years. Larger samples of HIV-uninfected individuals, particularly those individuals over 70 years of age, will be collected to refine these demographic adjustments. It may also be possible to better refine the cutpoints that maximize sensitivity and specificity for impairment, using more robust regression models. That work, in various cohorts, is underway. Another limitation was that our smaller sample of people with HIV completing a lengthier cognitive battery comprised fewer males than the larger sample. This study provides the groundwork for additional studies examining the psychometric properties of BRACE. Additionally, our measurement of clinical and behavioral comorbidities from ICD-10 is not optimal, particularly, for mental health (eg, depression or anxiety) and substance use disorders, which can fluctuate with management. Electronic medical record extraction of conditions is also not always comprehensive although it can be a rich data source. Future studies will be needed to look more deeply at better measurements of comorbidities in conjunction with BRACE. Additionally, at this point, we were unable to assess important covariates in this study including polypharmacy, which has shown to be associated with increased cognitive impairment [35]. Generalizability at this point is also limited to a predominately low educated, African-American, older people with HIV seeking outpatient clinic care, which is an important understudied population. Determining the clinical utility of BRACE in other US populations and internationally is warranted.

To continue to address cognitive impairment moving forward, traditional neuropsychological assessments are necessary but are often not conducted due to feasibility of available neuropsychologists as they typically have long wait lists. Thus, many persons with milder but clinically relevant cognitive impairment go undetected and without intervention. Sensitive and rapidly obtainable metrics that are obtained continuously, ubiquitously, and proactively in real time such as BRACE (an expanded cognitive screener) are needed. Other technology-based tools that differ from BRACE (eg, length of assessment; administrator-assisted; computer, tablet, or phone-based) have also been developed or used to screen for cognitive impairment in HIV including NeuroScreen [29,39], the Computer Assessment of Mild Cognitive Impairment [40], and CogState [41]. The primary advantage of BRACE is that it was designed to be self-administered versus administrator-assisted. Rapid advancement of iPad-based technologies have increased our ability to effectively screen cognitive impairment in busy clinics where HIV providers have limited time to manage patients with multimorbidity (eg, multiple medical, psychiatric, and cognitive conditions) and polypharmacy (eg, multiple antiretroviral therapy and nonantiretroviral therapy drugs in use). In addition, ubiquitous access to the internet enables updating of norms and the real-time calculations of risks. BRACE appears to provide the field with an effective user- and clinician-friendly cognitive screener that has the potential to influence patient care for identifying cognitive impairment (eg, identify a patient that may have been missed or identified too late), tracking performance over time, and determining prediction models of cognitive impairment. The results of BRACE can also inform the neuropsychological assessments which can expand upon the initial screen. While larger, longitudinal studies across heterogeneous subgroups of people with HIV and HIV-uninfected individuals in primary care are needed, our study provides initial evidence for the utility of this tool in predominately African-American older people with HIV with low levels of education seeking outpatient clinic care.

Acknowledgments

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Conflicts of Interest

AB is a full-time employee of Digital Artefacts LLC. JC is a full-time employee of Abbvie Inc. KA is a consultant to the All of Us Research Program (National Institutes of Health) and is on the scientific advisory board of TrioHealth.

Multimedia Appendix 1
Supplementary tables.
[DOCX File , 33 KB - mental_v8i9e25660_app1.docx]

References

1. Smith CJ, Ryom L, Weber R, Morlat P, Pradier C, Reiss P, D:A:D Study Group. Trends in underlying causes of death in people with HIV from 1999 to 2011 (D:A:D): a multicohort collaboration. Lancet 2014 Jul 19;384(9939):241-248. [doi: 10.1016/S0140-6736(14)60604-8] [Medline: 25042234]
2. Weber R, Ruppik M, Rickenbach M, Spoerri A, Furrer H, Battegay M, Swiss HIV Cohort Study (SHCS). Decreasing mortality and changing patterns of causes of death in the Swiss HIV Cohort Study. HIV Med 2013 Apr;14(4):195-207 [FREE Full text] [doi: 10.1111/j.1468-1293.2012.01051.x] [Medline: 22998068]

3. Trickey A, May MT, Vehreschild J, Obel N, Gill MJ, Crane HM, et al. Survival of HIV-positive patients starting antiretroviral therapy between 1996 and 2013: a collaborative analysis of cohort studies. Lancet HIV 2017 Aug;4(8):e349-e356. [doi: 10.1016/s2352-3018(17)30066-8]
4. McGuire D. CSF biomarkers in HIV dementia: through a glass darkly. Neurology 2009 Dec 08;73(23):1942-1944. [doi: 10.1212/WNL.0b013e3181c51a92] [Medline: 19907014]
5. Althoff KN, Chandran A, Zhang J, Arevalo WM, Gange SJ, Sterling TR, North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD) of IeDEA. Life-expectancy disparities among adults with HIV in the United States and Canada: the impact of a reduction in drug- and alcohol-related deaths using the lives saved simulation model. Am J Epidemiol 2019 Dec 31;188(12):2097-2109 [FREE Full text] [doi: 10.1093/aje/kwz232] [Medline: 31602475]
6. Grant I. Neurocognitive disturbances in HIV. Int Rev Psychiatry 2008 Feb;20(1):33-47. [doi: 10.1080/09540260701877894] [Medline: 18240061]
7. Cysique LA, Heaton RK, Kamminga J, Lane T, Gates TM, Moore DM, et al. HIV-associated neurocognitive disorder in Australia: a case of a high-functioning and optimally treated cohort and implications for international neuroHIV research. J Neurovirol 2014 Jun;20(3):258-268 [FREE Full text] [doi: 10.1007/s13365-014-0242-x] [Medline: 24696363]
8. Heaton RK, Franklin DR, Ellis RJ, McCutchan JA, Letendre SL, Leblanc S, CHARTER Group, HNRC Group. HIV-associated neurocognitive disorders before and during the era of combination antiretroviral therapy: differences in rates, nature, and predictors. J Neurovirol 2011 Feb;17(1):3-16 [FREE Full text] [doi: 10.1007/s13365-010-0006-1] [Medline: 21174240]
9. Rubin LH, Maki PM, Springer G, Benning L, Anastos K, Gustafson D, Women's Interagency HIV Study. Cognitive trajectories over 4 years among HIV-infected women with optimal viral suppression. Neurology 2017 Oct 10;89(15):1594-1603 [FREE Full text] [doi: 10.1212/WNL.0000000000004491] [Medline: 28904086]
10. Sacktor NC, Wong M, Nakasujja N, Skolasky RL, Selnes OA, Musisi S, et al. The International HIV Dementia Scale: a new rapid screening test for HIV dementia. AIDS 2005 Sep 02;19(13):1367-1374. [Medline: 16103767]
11. Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. J Am Geriatr Soc 2005 Apr;53(4):695-699. [doi: 10.1111/j.1532-5415.2005.53221.x] [Medline: 15817019]
12. Power C, Selnes OA, Grim JA, McArthur JC. HIV Dementia Scale: a rapid screening test. J Acquir Immune Defic Syndr Hum Retrovirol 1995 Mar 01;8(3):273-278. [doi: 10.1097/00042560-199503010-00008] [Medline: 7859139]
13. Milanini B, Paul R, Bahemana E, Adamu Y, Kiweewa F, Langat R, AFRICOS study Team. Limitations of the International HIV Dementia Scale in the current era. AIDS 2018 Nov 13;32(17):2477-2483 [FREE Full text] [doi: 10.1097/QAD.0000000000001968] [Medline: 30134293]
14. Joska JA, Witten J, Thomas KG, Robertson C, Casson-Crook M, Roosa H, et al. A comparison of five brief screening tools for HIV-associated neurocognitive disorders in the USA and South Africa. AIDS Behav 2016 Aug;20(8):1621-1631. [doi: 10.1007/s10461-016-1316-y] [Medline: 26860536]
15. Janssen MAM, Bosch M, Koopmans PP, Kessels RPC. Validity of the Montreal Cognitive Assessment and the HIV Dementia Scale in the assessment of cognitive impairment in HIV-1 infected patients. J Neurovirol 2015 Aug;21(4):383-390 [FREE Full text] [doi: 10.1007/s13365-015-0324-4] [Medline: 25678141]
16. Kamminga J, Cysique LA, Lu G, Batchelor J, Brew BJ. Validity of cognitive screens for HIV-associated neurocognitive disorder: a systematic review and an informed screen selection guide. Curr HIV/AIDS Rep 2013 Dec;10(4):342-355 [FREE Full text] [doi: 10.1007/s11904-013-0176-6] [Medline: 24072534]
17. Zipursky AR, Gogolishvili D, Rueda S, Brunetta J, Carvalhal A, McCombe JA, et al. Evaluation of brief screening tools for neurocognitive impairment in HIV/AIDS: a systematic review of the literature. AIDS 2013 Sep 24;27(15):2385-2401 [FREE Full text] [doi: 10.1097/QAD.0b013e328363bf56] [Medline: 23751261]
18. Valcour V, Paul R, Chiao S, Wendelken LA, Miller B. Screening for cognitive impairment in human immunodeficiency virus. Clin Infect Dis 2011 Oct;53(8):836-842 [FREE Full text] [doi: 10.1093/cid/cir524] [Medline: 21921226]
19. Antinori A, Arendt G, Becker JT, Brew BJ, Byrd DA, Cherner M, et al. Updated research nosology for HIV-associated neurocognitive disorders. Neurology 2007 Oct 30;69(18):1789-1799 [FREE Full text] [doi: 10.1212/01.WNL.0000287431.88658.8b] [Medline: 17914061]
20. Kroenke K, Spitzer RL, Williams JBW. The Patient Health Questionnaire-2: validity of a two-item depression screener. Med Care 2003 Nov;41(11):1284-1292. [doi: 10.1097/01.MLR.0000093487.78664.3C] [Medline: 14583691]
21. Maki PM, Rubin LH, Springer G, Seaberg EC, Sacktor N, Miller EN, Neuropsychology Working Groups of the Women s Interagency HIV Studythe Multicenter AIDS Cohort Study. Differences in cognitive function between women and men with HIV. J Acquir Immune Defic Syndr 2018 Sep 01;79(1):101-107 [FREE Full text] [doi: 10.1097/QAI.0000000000001764] [Medline: 29847476]
22. Rubin LH, Springer G, Martin EM, Seaberg EC, Sacktor NC, Levine A, et al. Elevated depressive symptoms are a stronger predictor of executive dysfunction in HIV-infected women than in men. J Acquir Immune Defic Syndr 2019 Jul 01;81(3):274-283 [FREE Full text] [doi: 10.1097/QAI.0000000000002029] [Medline: 30893126]
23. Rubin LH, Neigh GN, Sundermann EE, Xu Y, Scully EP, Maki PM. Sex differences in neurocognitive function in adults with HIV: patterns, predictors, and mechanisms. Curr Psychiatry Rep 2019 Sep 14;21(10):94. [doi: 10.1007/s11920-019-1089-x] [Medline: 31522330]

24. Rubin LH, Maki PM. HIV, depression, and cognitive impairment in the era of effective antiretroviral therapy. Curr HIV/AIDS Rep 2019 Feb;16(1):82-95 [FREE Full text] [doi: 10.1007/s11904-019-00421-0] [Medline: 30661180]
25. Rubin LH, Maki PM. Neurocognitive complications of HIV infection in women: insights from the WIHS cohort. In: Current Topics in Behavioral Neurosciences. Berlin, Heidelberg: Springer; Aug 09, 2019.
26. Rubin LH, Gustafson D, Hawkins KL, Zhang L, Jacobson LP, Becker JT, et al. Midlife adiposity predicts cognitive decline in the prospective multicenter AIDS cohort study. Neurology 2019 Jul 16;93(3):e261-e271 [FREE Full text] [doi: 10.1212/WNL.0000000000007779] [Medline: 31201294]
27. Cysique LA, Brew BJ. Prevalence of non-confounded HIV-associated neurocognitive impairment in the context of plasma HIV RNA suppression. J Neurovirol 2011 Apr;17(2):176-183. [doi: 10.1007/s13365-011-0021-x] [Medline: 21416169]
28. Wang Z, Molsberry SA, Cheng Y, Kingsley L, Levine AJ, Martin E, Neuropsychology Working Group of the Multicenter AIDS Cohort Study. Cross-sectional analysis of cognitive function using multivariate normative comparisons in men with HIV disease. AIDS 2019 Nov 15;33(14):2115-2124. [doi: 10.1097/QAD.0000000000002312] [Medline: 31335803]
29. Robbins RN, Gouse H, Brown HG, Ehlers A, Scott TM, Leu C, et al. A mobile app to screen for neurocognitive impairment: preliminary validation of NeuroScreen among HIV-infected South African adults. JMIR Mhealth Uhealth 2018 Jan 05;6(1):e5 [FREE Full text] [doi: 10.2196/mhealth.9148] [Medline: 29305338]
30. Heaton RK, Marcotte TD, Mindt MR, Sadek J, Moore DJ, Bentley H, HNRC Group. The impact of HIV-associated neuropsychological impairment on everyday functioning. J Int Neuropsychol Soc 2004 May;10(3):317-331. [doi: 10.1017/S1355617704102130] [Medline: 15147590]
31. Huck DM, Hanna DB, Rubin LH, Maki P, Valcour V, Springer G, et al. Carotid artery stiffness and cognitive decline among women with or at risk for HIV infection. J Acquir Immune Defic Syndr 2018 Jul 01;78(3):338-347 [FREE Full text] [doi: 10.1097/QAI.0000000000001685] [Medline: 29578932]
32. Heaton RK, Marcotte TD, White DA, Ross D, Meredith K, Taylor MJ, et al. Nature and vocational significance of neuropsychological impairment associated with HIV infection. Clin Neuropsychol 1996 Jan;10(1):1-14. [doi: 10.1080/13854049608406658]
33. Scott JC, Woods SP, Vigil O, Heaton RK, Schweinsburg BC, Ellis RJ, San Diego HIV Neurobehavioral Research Center (HNRC) Group. A neuropsychological investigation of multitasking in HIV infection: implications for everyday functioning. Neuropsychology 2011 Jul;25(4):511-519 [FREE Full text] [doi: 10.1037/a0022491] [Medline: 21401259]
34. Waldrop-Valverde D, Jones DL, Gould F, Kumar M, Ownby RL. Neurocognition, health-related reading literacy, and numeracy in medication management for HIV infection. AIDS Patient Care STDS 2010 Aug;24(8):477-484 [FREE Full text] [doi: 10.1089/apc.2009.0300] [Medline: 20662594]
35. Rubin LH, Radtke KK, Eum S, Tamraz B, Kumanan KN, Springer G, et al. Cognitive burden of common non-antiretroviral medications in HIV-infected women. J Acquir Immune Defic Syndr 2018 Sep 01;79(1):83-91 [FREE Full text] [doi: 10.1097/QAI.0000000000001755] [Medline: 29781879]
36. Robertson KR, Jiang H, Kumwenda J, Supparatpinyo K, Marra CM, Berzins B, AIDS Clinical Trials Group. Human immunodeficiency virus-associated neurocognitive impairment in diverse resource-limited settings. Clin Infect Dis 2019 May 02;68(10):1733-1738 [FREE Full text] [doi: 10.1093/cid/ciy767] [Medline: 30219843]
37. Rubin LH, Saylor D, Nakigozi G, Nakasujja N, Robertson K, Kisakye A, et al. Heterogeneity in neurocognitive change trajectories among people with HIV starting antiretroviral therapy in Rakai, Uganda. J Neurovirol 2019 Dec;25(6):800-813 [FREE Full text] [doi: 10.1007/s13365-019-00768-5] [Medline: 31218522]
38. Dastgheyb RM, Sacktor N, Franklin D, Letendre S, Marcotte T, Heaton R, et al. Cognitive trajectory phenotypes in human immunodeficiency virus-infected patients. J Acquir Immune Defic Syndr 2019 Sep 01;82(1):61-70 [FREE Full text] [doi: 10.1097/QAI.0000000000002093] [Medline: 31107302]
39. Robbins RN, Brown H, Ehlers A, Joska JA, Thomas KGF, Burgess R, et al. A smartphone app to screen for HIV-related neurocognitive impairment. J Mob Technol Med 2014 Feb 01;3(1):23-26 [FREE Full text] [doi: 10.7309/jmtm.3.1.5] [Medline: 24860624]
40. Becker JT, Dew MA, Aizenstein HJ, Lopez OL, Morrow L, Saxton J. Concurrent validity of a computer-based cognitive screening tool for use in adults with HIV disease. AIDS Patient Care STDS 2011 Jun;25(6):351-357 [FREE Full text] [doi: 10.1089/apc.2011.0051] [Medline: 21545295]
41. Cysique LAJ, Maruff P, Darby D, Brew BJ. The assessment of cognitive function in advanced HIV-1 infection and AIDS dementia complex using a new computerised cognitive test battery. Arch Clin Neuropsychol 2006 Feb;21(2):185-194. [doi: 10.1016/j.acn.2005.07.011] [Medline: 16343841]

Abbreviations

AIDS: acquired immunodeficiency syndrome
BRACE: Brain Baseline Assessment of Cognition and Everyday Functioning
HIV: human immunodeficiency virus
ICD-10: International Statistical Classification of Disease, tenth revision
TMT: Trail Making Test

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Review

Virtual Reality for Supporting the Treatment of Depression and Anxiety: Scoping Review

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Abstract

Background: Mental health conditions pose a major challenge to health care providers and society at large. The World Health Organization predicts that by 2030, mental health conditions will be the leading cause of disease burden worldwide. The current need for mental health care is overwhelming. In New Zealand, 1 in 6 adults has been diagnosed with common mental disorders, such as depression and anxiety disorders, according to a national survey. Cognitive behavioral therapy (CBT) has been shown to effectively help patients overcome a wide variety of mental health conditions. Virtual reality exposure therapy (VRET) might be one of the most exciting technologies emerging in the clinical setting for the treatment of anxiety and depression.

Objective: This study aims to investigate the virtual reality (VR) technologies currently being used to help support the treatment of depression and anxiety. We also aim to investigate whether and how CBT is included as part of VRET and look at the VR technologies and interventions that have been used in recent studies on depression and anxiety.

Methods: We performed a scoping review. To identify significant studies, we decided to use already aggregated sources from the Google Scholar database. Overall, the goal of our search strategy was to limit the number of initial results related to VR in mental health to only a relevant minimum.

Results: Using our defined keywords, Google Scholar identified >17,300 articles. After applying all the inclusion and exclusion criteria, we identified a total of 369 articles for further processing. After manual evaluation, 34 articles were shortlisted; of the 34 articles, 9 (26%) reported the use of CBT with VR. All of the articles were published between 2017 and 2021. Out of the 9 studies, CBT was conducted within a VR environment in 5 (56%) studies, whereas in the remaining 4 (44%) studies, CBT was used as an addition to VRET. All 9 studies reported the use of CBT either in vivo or in a virtual environment to be effective in supporting the treatment of anxiety or depression.

Conclusions: Most studies demonstrated the use of VR to be effective for supporting the treatment of anxiety or depression in a range of settings and recommended its potential as a tool for use in a clinical environment. Even though standalone headsets are much easier to work with and more suitable for home use, the shift from tethered VR headsets to standalone headsets in the mental health environment was not observed. All studies that looked at the use of CBT either in vivo or in a virtual environment found it to be effective in supporting the treatment of anxiety or depression.

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KEYWORDS

virtual reality; mental health; depression; anxiety; CBT

Introduction

Background

Mental health conditions are a major challenge for society, health care providers, and health systems, with the recent COVID-19 pandemic only worsening these pre-existing conditions [1]. Mental health services are struggling to meet the needs of users and fail to reach large proportions of those in need of care. The World Health Organization (WHO) predicts that by 2030, mental disorders will be the leading cause of disease burden worldwide [2]. The WHO has also estimated that anxiety disorders have cost the global economy approximately US $1 trillion per year in lost productivity costs [3]. Between 75% and 85% of people with mental disorders remain untreated in low-income countries, with almost 1 million people taking their lives each year. In addition, according to the WHO, 1 in 13 people is affected by anxiety worldwide, with specific phobias, major depressive disorders, and social phobias being the most common. Barriers to effective care include a lack of resources, lack of trained health care providers, and social stigma associated with mental disorders [2].

According to a recent New Zealand health survey, 1 in 6 New Zealand adults has been diagnosed with common mental disorders such as depression and anxiety disorders. Māori and Pacific adults (indigenous population) have higher rates of being diagnosed with depression and anxiety than the rest of the population. There is also a certain level of societal stigma attached to mental health problems, preventing some people from accessing the available resources [4].

Mood disorders and anxiety disorders are closely linked, and individuals who develop depression often experience an anxiety disorder earlier in life. Indeed, individuals with depression often experience symptomology similar to that characteristic of anxiety disorders, including nervousness, irritability, disturbed sleep or appetite, and poor concentration, among other symptoms [5].

Cognitive Behavioral Therapy

Cognitive behavioral therapy (CBT) is among the therapies commonly available for treating anxiety and depression. It is supported by many guidelines as a first-line treatment for mood and anxiety disorders [6,7]. CBT is a type of psychotherapeutic treatment that helps people learn how to identify and change destructive or disturbing thought patterns that have a negative influence on behavior and emotions [8]. It is the most empirically supported therapy and has been shown to effectively help patients overcome a wide variety of mental health conditions, including anxiety and depression [8].

Exposure Therapy

Exposure therapy, a form of behavioral therapy, has become increasingly popular in recent years with both mental health consumers and treatment professionals as one of the most effective treatments for phobic anxiety disorders. Exposure therapies are usually conducted through in vivo exposure (IVE) or imaginal exposure (IE). In IVE therapy, the patient is deliberately exposed to the feared object or situation in the real world. It is often used in the treatment of phobias or anxieties [9,10]. Despite being an effective treatment, some IVE therapies may require to be conducted in public, thereby risking patient confidentiality, or are too expensive or face difficulty in replicating the feared scenarios (eg, fear of flying). To help overcome these IVE limitations, IE therapy can be an alternative approach to trigger the feared situations through imagination. However, for IE therapy to be effective, the patient must be ready and willing to spend time and effort analyzing their thoughts and feelings.

Virtual Reality and Virtual Exposure Therapy

The use of virtual reality (VR) in health care was pioneered by Hoffman et al [11,12] in the early 2000s, with a VR gaming system called SnowWorld that was able to reduce pain perception during burn wound care in both adolescent and adult patients. VR is the use of computer modeling and simulation that enables a person to interact with an artificial 3D visual environment or other sensory environments. VR systems typically comprise the following components:

- Graphics rendering units: the computer hardware to compute the virtual scene and render it to a frame buffer, ready to be sent to a display device. This is typically a high-end graphics computer.
- 3D stereo display units: it operates as the interface from the computer to the user. Visual information is often presented via large projection-based displays or head-mounted displays (HMDs).
- Tracking system: serves as the interface between the user and the computer. Modern HMDs include integrated head tracking, thereby allowing the user to move their head and change their visual perspective in the virtual environment accordingly.
- Other interfaces include joysticks or sensory gloves, which provide tactile feedback.
- Examples of recent popular VR devices include Oculus Quest 2, HTC Vive, and Sony PlayStation VR.

VR might be one of the most exciting, emerging technologies that is rapidly gaining traction in the treatment of anxiety and depression [13-15]. VR exposure therapy (VRET) is a modern type of exposure therapy that follows the same procedures as traditional exposure therapy, with the only difference being that the feared objects or situations are rendered within a virtual environment. A virtual environment provides a greater degree of control for the therapists to customize, reproduce, and tweak several treatment parameters according to the patient's needs. Such a level of customization cannot be achieved in traditional exposure therapy. Risk of privacy intrusion is reduced as everything is confined to a virtual environment. Furthermore, VRET is considered less frightening than IVE therapy according to the patients [16].

VR applications and VRETs have also been shown to be effective in the treatment of a variety of other mental health conditions, such as specific phobias (acrophobia and arachnophobia) or social anxiety disorder (SAD), autism, panic disorder, posttraumatic stress disorder, substance abuse, or addiction disorders (alcohol and gambling) [9,10,17-23]. Thus, this study presents findings from a scoping review on state-of-the-art VR therapies for supporting the treatment of anxiety and depression.

Objective

A scoping review methodology specified by Arksey and O'Malley [24] was followed in this study. In this scoping review, we aim to investigate two questions: (1) what VR technologies and interventions have recently been studied in depression and anxiety disorders and (2) whether and how CBT is included and used as part of VRET (within the VR environment or in addition to a VR intervention)?

As technology advances rapidly, it is critical to understand the current state-of-the-art technologies being used, especially in interdisciplinary fields such as VR in mental health. Thus, to answer the first question, we will study VR technology, types of interventions, participants' interactions during the intervention, and how the virtual environments were created.

It is known that CBT is an effective tool used for the treatment of several mental health problems [8]. Common VR interventions, such as VRET, may be sufficient to treat anxiety or depression; however, the combination of these interventions with CBT has been an understudied area. There is currently much less literature that specifically explores the effectiveness of CBT used in combination with common VR interventions. Thus, the second question systematically explores the use of CBT along with VRET and provides a detailed review of how CBT was used, whether it was used inside a virtual environment or in addition to VRET, and the effectiveness of this type of methodology in the treatment of anxiety or depression.

Methods

Search Strategy and Eligibility Criteria

We defined the search strategy specifically suited to find the most relevant papers that used VR to support and enhance the outcome of mental health issues, particularly focusing on anxiety and depression.

Databases Searched

We used Google Scholar as the primary source of materials included in this research. Google Scholar provides a simple and quick way to search across a variety of disciplines, databases, and journals. To limit the number of studies relevant to our research questions (RQs), we defined specific eligibility criteria and search terms. The goal of our search strategy was to limit the number of results related to our RQs to only a relevant minimum.

Search Terms

The search terms were discussed among the research team and were defined as *Anxiety*, *Depression*, and *Virtual Reality*. Sometimes, *virtual reality* can also be acronymized as *VR*; however, the full term was exclusively used during the search to avoid any potential conflicts with other terms that may use the VR acronym (eg, *voice recognition*). These defined search terms also reflect the most used keywords in the studies relevant to our RQs.

Eligibility Criteria

As information technology is evolving rapidly in terms of hardware and software related to VR, we decided to limit the year of publication to 2017 to identify state-of-the-art technologies. Therefore, the main article dates were set from 2017 to 2021. Google Scholar advance search allows the selection of articles using only a limited set of criteria. When we used the search filter criteria *anywhere in the article* with the defined search terms *Virtual reality*, *Depression*, and *Anxiety*, the Google Scholar search yielded 17,300 results. On the basis of our search strategy goal, we decided to use a combination of three search requests that were compliant with the following rules:

- All search terms must be present in the article.
- All search terms must be present in the title of the article (not only in the article body).
- The article publication year must be within a specific range from 2017 to 2021.

With these rules in place, we were able to execute three separate search requests using the following combination of search terms:

- *Virtual reality* AND *anxiety*
- *Virtual reality* AND *depression*
- *Virtual reality* AND *depression* AND *anxiety*

Some of the additional exclusion criteria were defined as follows:

- Duplicates, version updates, or written in a language other than English
- Swot analysis, thesis and citations, systematic reviews, or no significant reported results
- Anxiety or depression as a secondary aspect or induced due to an illness

A detailed explanation of the search strategy is provided in Multimedia Appendix 1.

Study Selection

The search strategy yielded 369 articles overall. The first step included the removal of duplicates, which was found to be 6.5% (24/369) of articles, thus reducing the number of articles to 345. A total of 4 authors screened the titles of the 345 articles for relevance. If a decision could not be made regarding the relevance of an article, then the abstract was taken into consideration. If the authors still lacked certainty, then the full text of the article was reviewed to reach the final decision.

In total, 15.4% (53/345) of articles were excluded because of nonrelevancy as determined by the authors upon screening, making the number of eligible articles 292. The nonrelevant articles included out-of-context studies, such as those not targeting anxiety or depression. Few nonrelevant articles targeted anxiety or depression but relied on technologies other than VR. The last screening step required articles to meet the defined eligibility criteria, which were assessed upon a full-text review. A total of 34 articles were confirmed for the scoping review that met the eligibility criteria.

This study selection process is depicted in Figure 1.

An in-depth breakdown of the study selection process is explained in Table 1.

Figure 1. Literature screening and selection flowchart following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) guidelines.

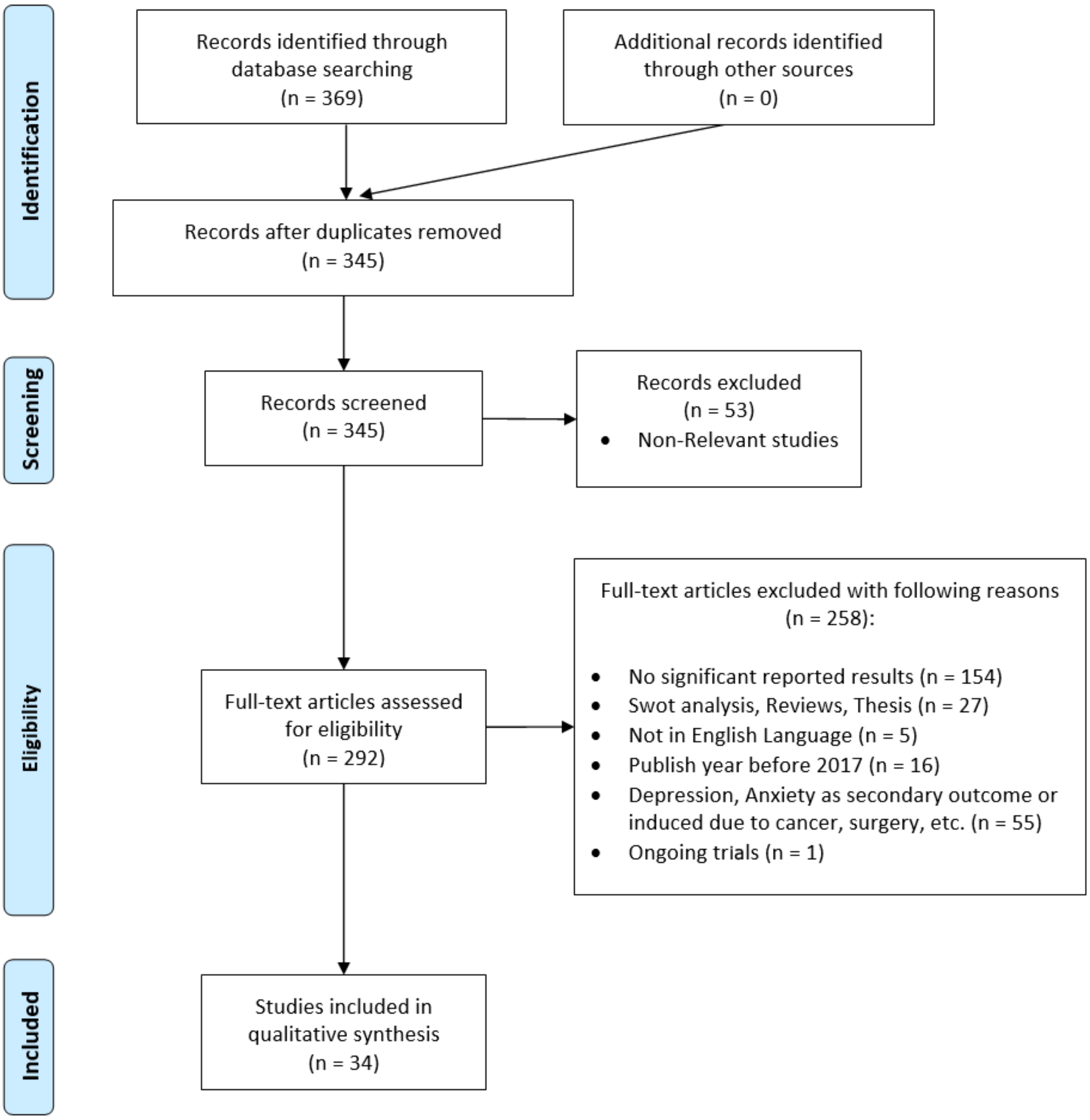


Table 1. The reasons for exclusions and the number of studies excluded and selected for final review[a].

Study ID and search terms		Articles, n (%)
Total collected		369 (100)
1	Virtual reality AND anxiety	298 (80.8)
2	Virtual reality AND depression	62 (16.8)
3	Virtual reality AND depression AND anxiety	9 (2.4)
Total excluded		335 (100)
1	Excluding nonrelevant studies	53 (15.8)
2	Excluding duplicities and version updates	24 (7.2)
3	Excluding documents with no significant reported results	154 (46)
4	Excluding swot analysis, thesis and citations, and system reviews	27 (8.1)
5	Excluding documents not in the English language	5 (1.5)
6	Excluding documents published before 2017	16 (4.8)
7	Excluding documents with anxiety or depression as a secondary aspect or anxiety or depression induced because of cancer and surgery	55 (16.4)
8	Excluding documents with ongoing trials	1 (0.3)

[a] Total selected: 100% (34/34).

Data Extraction

One of the authors performed the data extraction process, whereas the data validity and accuracy were checked by the remaining authors. All articles were downloaded as full text and maintained in a database shared among all authors. The following data were extracted:

1. Publication year and authors
2. Demographics such as sample size, age distribution, and gender ratio
3. Methodology (eg, study design, was CBT included, duration of study, and number of sessions)
4. VR hardware and software details such as type of headset, toolkit used, what was the VR scenario, and how the VR environment was designed
5. Key findings concerning the effectiveness of VR in supporting the treatment of depression and anxiety and the role and significance of CBT, if used

The extracted data allowed us to generate information related to our RQs, especially in determining the experimental setup and significance of CBT. Moreover, the data provided useful insights into the development of the statistics of the articles used in the review.

Results

Publications Statistics

A total of 34 articles were selected for this scoping review (Multimedia Appendix 2 [14,15,25-56]). Articles with no available information were discarded during the plotting.

Multimedia Appendix 3 shows most articles published in the year 2019 [25-36], comprising 35% (12/34) of the total articles. Articles published in 2018 [37-43] and 2020 [15,44-49] were of equal proportions (7/34, 21%), whereas those published in 2017 [14,50-53] were the third highest (5/34, 15%). Recent publications from early 2021 [54-56] were also selected (3/34, 9%).

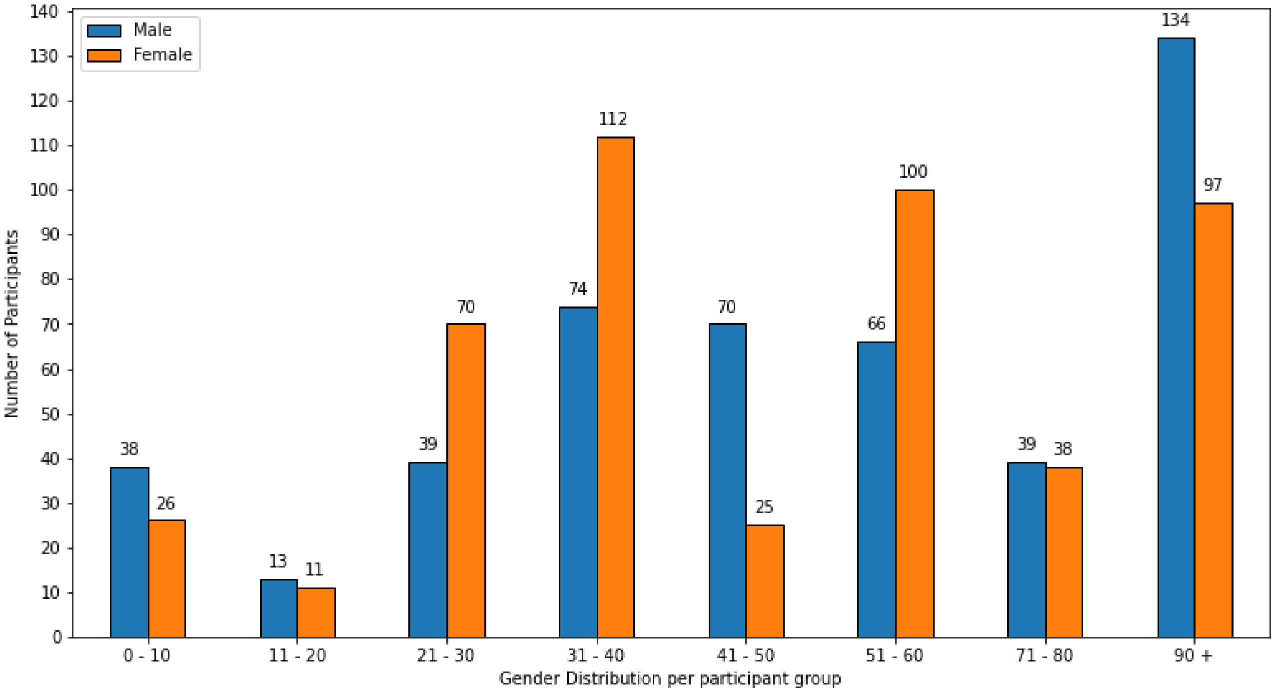
Demographics

Multimedia Appendix 4 shows the participant’s average age distribution. The age distribution is particularly dominated by the two age groups of 21-30 years and 31-40 years, comprising 67% (21/31) of the total articles. The lowest average age group was 0-10 years, whereas the highest average age group was 71-80 years, indicating that the participants across all age groups were recruited for VR support in tackling depression or anxiety.

Multimedia Appendix 5 depicts the distribution of total participants. Most of the articles (13/34, 38%) included <10 participants [26,31-34,36-38,40-42,45,55], whereas two studies had >90 participants [35,54].

Similarly, the gender distribution of the participants is shown in Figure 2. The total number of female and male participants was 479 and 473, respectively, indicating an equal gender ratio among the participants.

Figure 2. Gender distribution of participants.



Clinical Conditions

Multimedia Appendix 6 illustrates the count of clinical conditions per publication. Overall, most studies centered around one or the other type of anxiety condition (25/34, 74%) compared with depression (4/34, 12%). SAD was the most studied, with 3% (9/34) of studies focusing on using VR therapy solely for patients with SAD [29,34,37,41,47,50,52-54]. Generalized anxiety disorder (6/34, 18%) [27,28,39,42,46,49] was next, followed by public speaking anxiety (4/34, 12%) [14,31,51,56]. The rest of the studies aimed at specific clinical conditions such as paruresis [40], exam anxiety [48], driving-related [38] or car passenger anxiety [30], disruptive behavior in the classroom [45], or social anxiety in children with autism spectrum disorder [33].

Fewer studies (4/34, 12%) focused on using VR therapy exclusively for the treatment of individuals with depression [15,26,36,43]; 15% (5/34) of studies targeted multiple conditions such as stress [25,35] or posttraumatic stress disorder [44,55] or panic disorder [32], in addition to anxiety and depression.

Investigating the RQs

RQ 1: What VR Technologies and Interventions Are Currently Being Used in Studies on Depression and Anxiety?

To answer this question, we developed a robust data extraction process, which is explained in the earlier section. We reviewed the articles and extracted details such as types of VR interventions, plotted in Multimedia Appendix 7; types of VR headsets, shown in Multimedia Appendix 8; additional monitoring software and hardware, details about what the participants did during the intervention, and number of sessions, depicted in Multimedia Appendix 9; and how long the interventions lasted.

The most frequent type of VR intervention was VRET (standard VR scene), which was used in 26% (9/34) of studies [25,31,34,40,41,47,53,55,56]. Interestingly, 6% (2/34) of studies used behavior therapy in addition to VRET, using commercial simulator software in the treatment of SAD [41] and public speaking anxiety [31]. It was followed by CBT inside VR (5/34, 15%) [26,28,37,50,54] and VR application (5/34, 15%) [30,33,35,43,52] interventions. Approximately 6% (2/34) of studies demonstrated a unique use of VR applications using music therapy (where participants had to sing a song in a virtual hall) [33] and art therapy (where participants performed activities using a tilt-brush VR application) [35]. VR music therapy was used in the treatment of social anxiety in adolescents with autism spectrum disorder. Other interventions applied were VR games or exercises [15,45,46,49], CBT in addition to VR [14,27,38,39], and 360° VR videos [36,44,48,51]. Approximately 9% (3/34) of studies used different types of VR interventions, such as visuo-haptic–based multimodal feedback VR system [32], VR-based neurofeedback therapy [42], and a VR task-tracking avoidance behavior [29].

The most popular VR headset among the articles was HTC Vive (6/34, 18%), whereas Oculus Rift was the next most frequently used VR headset (4/34, 12%). Approximately 9% (3/34) of studies used Gear VR; different types of VR simulators; and Cave Automatic Virtual Environment–like systems, one used Leap Motion [32] and one used Windows Mixed Reality Headsets [36]. A regular feature among most studies was the external monitoring of additional data such as heart rate, eye movement, or electroencephalogram readings during the intervention or pre- and postintervention.

A wide range of VR environments or scenarios was observed. A workplace environment or job interview was the most common virtual environment for participants with SAD. A conference room or classroom was usually used for public speaking anxiety, whereas virtual nature exposure was a common scenario seen in studies focusing on both anxiety and depression. An interesting virtual environment of underwater world exploration was used in the treatment of state anxiety and disruptive classroom behavior, wherein the movement was controlled through participants' breathing using a VR biofeedback game intervention [45].

Multimedia Appendix 9 shows wide variability in the number of sessions that the participants underwent for VR therapy. A single session was used in most studies (8/34, 24%). Notably, one of the studies had a total of 108 trial sessions, which was an outlier as the range of sessions was observed from 1 to a maximum of 17. The session time ranged from 2-90 minutes, depending on the type of VR intervention.

A recent study by Jeong et al [54] aimed to identify the number of sessions that were sufficient for a successful VR intervention in the treatment of SAD, concluding 9-10 sessions or possibly fewer sessions (5-6) of VR-based CBT can be effective in the treatment of SAD. Increasing the number of sessions above this provided minimal additional benefits.

RQ 2: Is CBT Included as Part of VRET and, if so, How Is CBT Used (Within the VR Environment or in Addition to VR Intervention)?

To answer the second question, we systematically reviewed the articles and extracted relevant data that explored the use of CBT along with other VR interventions. We then formulated a review table (Table 2) that described the CBT methodology in terms of how CBT was used, what was the VR experiment, and the key findings.

Approximately 26% (9/34) of studies mentioned the use of CBT with other interventions. Only those studies that explicitly mentioned CBT were selected. Of the 9 studies, 3 (9%) focused on the treatment of SAD and 2 (6%) focused on generalized anxiety disorder. One study targeted both SAD and generalized anxiety disorder. One study mentioned the use of CBT for depression. CBT inside a VR environment was the most used (5/34, 15%); 12% (4/34) of studies used CBT in addition to VRET. Approximately 9% (3/34) of studies made use of commercial software to expose participants to the virtual environment [38,39,50]. Notably, there was no common hardware or software across all studies, except the use of an HMD. Total participants varied from 2 to 115.

All studies reported that the use of CBT was associated with a reduction in symptoms of anxiety or depression, with one study even reporting that conducting CBT inside a virtual environment was more effective than CBT with IVE on the primary outcome measure of anxiety symptoms in a randomized controlled trial (RCT). It was also found to be more practical by therapists than conducting CBT with IVE [50].

Table 2. Review of CBT[a] studies.

ID	Condition	CBT type	VR[b] toolkit	VR scenario and total participants	Summary of findings
Anderson et al [14]	Public speaking anxiety	CBT and VR	—[c]	Participants gave a speech in front of the increasing number group in a virtual conference room, classroom, and auditorium (n=28).	Participants showed statistically significant improvement on all self-report measures from pretreatment to follow-up.
Stamou et al [26]	Postnatal Depression	CBT inside VR	—	Participants were exposed to a series of virtual stressors, whereas at the same time, they were asked to tidy up the virtual house (n=6).	All participants reported feeling better, more relaxed and with improved mood, better self-esteem, and improved sleep and appetite.
Guitard et al [27]	Generalized anxiety disorder	CBT and VR	A 6-side CAVE[d]-like system and wireless motion tracking	Three standardized VE[e] of an emergency room (n=11), an apartment (n=15), and a student room (n=2)	The standardized VE induced significant anxiety. No difference was found between standardized VE and imagined scenario.
Geraets et al [28]	Generalized and social anxiety disorder	CBT inside VR	Head-mounted display (Sony HMZ-T1) and joystick	Virtual street, bus, cafe, and supermarket environments were available. Patients tested their beliefs and feedback was given on cognition and behavior (n=15).	Two patients dropped out of treatment. Social anxiety and quality of life improved at posttreatment. At follow-up, depressive symptoms decreased, and social anxiety was maintained.
Kovar I [37]	Social anxiety disorder	CBT inside VR	HTC Vive+ controllers	Public speaking, a telephone call from a random institution, criticism of their appearance, and a job interview or refusal (n=10)	Most significant improvement in the length of fluent speech. VRET[f] improved reaction speed by 204.8 seconds. No effect in job interview VE.
Zinzow et al [38]	Driving-related anxiety	CBT and VR	Drive Safety CDS[g]-250 driving simulator. Three 19-inch LCD[h] screen displays	Lane keeping straight, changing, and mirrors, speed control straight, pedals and stopping, functional object detection–basic, turning left and right (n=8)	Hyperarousal in driving situations declined by 69%, aggressive driving declined by 29%, and risky driving declined by 21%.
Tarrant et al [39]	Generalized anxiety disorder	CBT inside VR	SPSS software, Gear VR 19-channel EEG[i], and Brain Master[j]	A mindfulness meditation by Story Up VR (n=12)	The VR meditation significantly reduced subjectively reported anxiety.
Bouchard et al [50]	Social anxiety disorder	CBT inside VR (RCT[k])	Virtually Better, eMagin z800 head-mounted display, and InterSense InertiaCube motion tracker	Eight VEs such as a meeting room, job interview, introducing oneself, and facing criticism situations (n=59)	Conducting CBT with in virtuo exposure was effective and more practical for therapists than CBT with in vivo exposure.
Jeong et al [54]	Social anxiety	CBT inside VR	Desktop or mobile version with monitor of eye movement, speaking time, and heart rate	Some VEs were classroom, auditorium, job interview, train, and cafe (n=115)	Short-term VR-based individual CBT of 9-10 sessions may be effective. Minimal benefit if extended.

[a] CBT: cognitive behavioral therapy.

[b] VR: virtual reality.

[c] Not applicable.

[d] CAVE: cave automatic virtual environment.

[e] VE: virtual environment.

[f] VRET: virtual reality exposure therapy.

[g] CDS: Clinical Driving Simulator.

[h] LCD: liquid crystal display.

[i] EEG: electroencephalogram.

[j] BrainMaster Technologies, Inc.

[k] RCT: randomized controlled trial.

Discussion

Principal Findings

VR therapy has been used widely for treating a variety of mental health conditions. This scoping review covered 34 articles, which used VR for the treatment of various syndromes of anxiety and depression. It was observed that most studies demonstrated a reduction in symptoms of anxiety or depression with the use of VR. Furthermore, most studies had a follow-up session post intervention to record the effects of the therapy on whether the anxiety or depression improvements were maintained in the participants. Most suggest effectiveness and acceptability in a range of clinical settings.

To gain a deeper understanding of the participants, we performed an exploratory data analysis that visualized the participants' demographics such as their average age groups (Multimedia Appendix 4), gender ratio (Figure 2), or the total number of participants (Multimedia Appendix 5) involved in the studies. The exploratory data analysis revealed that the two most common average age groups among participants were the young to middle-aged adults of 21-30 years and 31-40 years. The data as depicted in Multimedia Appendix 5 show that there is a lack of research on the older as well as the younger population, with only a handful of studies covering these age groups. Moreover, visualizing the gender distribution in Figure 2 showed that there was almost no gender bias present across the studies as the gender ratio of males (473) to females (479) was almost the same. Interestingly, Multimedia Appendix 5 shows that the most frequent sample size consisted of only 1-10 total participants, suggesting that there is a need to cover a larger sample size for conclusive proof of the presented results.

Although standalone VR headsets are becoming more affordable to obtain, easier to work with, and more suitable for home use, the shift from tethered VR headsets to standalone headsets in mental health studies has not yet been observed. Manufacturers such as Sony, Samsung, Google, HTC, and Microsoft have heavily invested in their own VR products; however, based on our study, HTC Vive and Oculus Rift were the most frequently used headsets. In terms of software assets, studies generally used Unity 3D, and none of the studies used its major rival Unreal Engine for developing the VR scenes. It was also interesting to see that more recent studies did not invest in creating their own virtual environment but instead used off-the-shelf products. For those who did develop their own VR environment, the 3ds Max studio was the primary modeling tool.

Limitations

The following limitations should be considered when interpreting the results of this review. The developed search strategy was limited to using Google Scholar for efficient and accurate search results. This may have excluded qualified articles from additional databases. In searching for studies, the terms *anxiety* and *depression* exclude studies using terms such as major depressive disorder or phobia. Moreover, because of the large number of articles reviewed, there is a possibility of overlooking valid publications that might have met the inclusion criteria. Non-English articles were not included in this review.

Conclusions and Future Work

Most studies we reviewed demonstrated the use of VR to be effective for supporting the treatment of anxiety or depression in a range of settings and recommended its potential as a tool for use in a clinical environment. As standalone headsets are much easier to work with and more suitable for home use, the shift from tethered VR headsets to standalone headsets in the mental health environment was not observed. Nine studies explicitly mentioned the use of CBT. Out of the 9 studies, CBT was conducted within a VR environment in 5 (56%) studies, whereas in the remaining 4 (44%) studies, CBT was used as an addition to VRET. All 9 studies reported the use of CBT either in vivo or inside a virtual environment to be effective in supporting the treatment of anxiety or depression.

Although a considerable number of studies (n=34) were included in this review, some areas are still under research, thereby lowering the percentage of such studies to be included. Specifically, we found a lot of studies dedicated to one or the other form of anxiety, whereas a limited number of studies were found to concentrate on depression (4/34, 12%). Supporting people with depression in VR settings could be an interesting area to explore for health and technology researchers in the future.

Few studies conducted an RCT, as shown in Multimedia Appendix 2. Future research could use the VR scenarios and technologies outlined in this review to conduct RCTs to test the effectiveness and cost or benefits of using VR in the treatment of depression and anxiety.

Out of the 34 reviewed articles, only 9 (26%) studies explicitly mentioned the use of CBT in combination with or in addition to VRET. All 9 studies reported improvement in participants' anxiety or depressive symptoms via CBT in addition to VRET or CBT within a virtual environment. As there is little literature on the combination of CBT and VRET, the comprehensive review produced by this study is effective in offering new insights and allows for further research on the use of CBT and VRET for a variety of mental health conditions in the future.

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Conflicts of Interest

RP used computer software provided by SBT-Pro at no cost for research purposes. RP also received support for travel to educational meetings from Servier and Lundbeck.

Multimedia Appendix 1
Search strategies.
[DOCX File , 480 KB - mental_v8i9e29681_app1.docx]

Multimedia Appendix 2
A summary of reviewed articles.
[DOCX File , 28 KB - mental_v8i9e29681_app2.docx]

Multimedia Appendix 3
Number of publications per year.
[PNG File , 16 KB - mental_v8i9e29681_app3.png]

Multimedia Appendix 4
Average age group distribution.
[PNG File , 16 KB - mental_v8i9e29681_app4.png]

Multimedia Appendix 5
Distribution of total participants across studies.
[PNG File , 15 KB - mental_v8i9e29681_app5.png]

Multimedia Appendix 6
Number of publications per clinical conditions.
[PNG File , 22 KB - mental_v8i9e29681_app6.png]

Multimedia Appendix 7
Types of virtual reality interventions.
[PNG File , 16 KB - mental_v8i9e29681_app7.png]

Multimedia Appendix 8
Types of virtual reality headsets.
[PNG File , 20 KB - mental_v8i9e29681_app8.png]

Multimedia Appendix 9
Number of virtual reality sessions.
[PNG File , 12 KB - mental_v8i9e29681_app9.png]

References

1. Thomas L. COVID-19 pandemic has worsened pre-existing mental health conditions. News-Medical.Net. 2020. URL: https://www.news-medical.net/news/20200601/COVID-19-pandemic-has-worsened-pre-existing-mental-health-conditions.aspx [accessed 2021-03-02]
2. Depression. World Health Organization. 2020. URL: https://www.who.int/news-room/fact-sheets/detail/depression [accessed 2021-03-02]
3. Bach N. Illness in the workplace is more common than you might think. Fortune. 2017. URL: https://fortune.com/2017/10/10/world-mental-health-day-2017-workplace-depression-anxiety/ [accessed 2021-02-27]
4. Mental health and illness. Community & Public Health. 2018. URL: https://www.cph.co.nz/your-health/mental-illness/ [accessed 2021-03-05]
5. Anxiety and Depression Association of America. 2017. URL: https://adaa.org/understanding-anxiety/facts-statistics [accessed 2021-03-02]
6. Malhi GS, Bell E, Bassett D, Boyce P, Bryant R, Hazell P, et al. The 2020 Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for mood disorders. Aust N Z J Psychiatry 2021 Jan 22;55(1):7-117. [doi: 10.1177/0004867420979353] [Medline: 33353391]
7. Andrews G, Bell C, Boyce P, Gale C, Lampe L, Marwat O, et al. Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of panic disorder, social anxiety disorder and generalised anxiety disorder. Aust N Z J Psychiatry 2018 Nov 30;52(12):1109-1172. [doi: 10.1177/0004867418799453]
8. Hofmann S, Asnaani A, Vonk IJ, Sawyer AT, Fang A. The efficacy of cognitive behavioral therapy: a review of meta-analyses. Cognit Ther Res 2012 Oct 01;36(5):427-440 [FREE Full text] [doi: 10.1007/s10608-012-9476-1] [Medline: 23459093]
9. Rothbaum B, Hodges L, Smith S, Lee J, Price L. A controlled study of virtual reality exposure therapy for the fear of flying. J Consult Clin Psychol 2000 Dec;68(6):1020-1026 [FREE Full text] [doi: 10.1037/0022-006x.68.6.1020]

10. Gutiérrez-Maldonado J, Wiederhold B, Riva G. Future directions: how virtual reality can further improve the assessment and treatment of eating disorders and obesity. Cyberpsychol Behav Soc Netw 2016 Feb;19(2):148-153. [doi: 10.1089/cyber.2015.0412] [Medline: 26378982]
11. Hoffman H, Doctor J. Virtual reality as an adjunctive pain control during burn wound care in adolescent patients. Pain 2000:305-309 [FREE Full text] [doi: 10.1016/s0304-3959(99)00275-4]
12. Hoffman H, Patterson D, Carrougher GJ. Use of virtual reality for adjunctive treatment of adult burn pain during physical therapy: a controlled study. Clin J Pain 2000 Sep;16(3):244-250 [FREE Full text] [doi: 10.1097/00002508-200009000-00010] [Medline: 11014398]
13. Otkhmezuri B, Boffo M, Siriaraya P, Matsangidou M, Wiers RW, Mackintosh B, et al. Believing is seeing: a proof-of-concept semiexperimental study on using mobile virtual reality to boost the effects of interpretation bias modification for anxiety. JMIR Ment Health 2019 Feb 21;6(2):e11517 [FREE Full text] [doi: 10.2196/11517] [Medline: 30789353]
14. Anderson P, Edwards S, Goodnight JR. Virtual reality and exposure group therapy for social anxiety disorder: results from a 4–6 year follow-up. Cogn Ther Res 2016 Nov 15;41(2):230-236 [FREE Full text] [doi: 10.1007/s10608-016-9820-y]
15. Lin A, Cheng F, Chen C. Use of virtual reality games in people with depression and anxiety. In: Proceedings of the 5th International Conference on Multimedia and Image Processing. 2020 Presented at: ICMIP 2020: 2020 5th International Conference on Multimedia and Image Processing; January 10 - 12, 2020; Nanjing China p. 169-174. [doi: 10.1145/3381271.3381299]
16. Garcia-Palacios A, Botella C, Hoffman H, Fabregat S. Comparing acceptance and refusal rates of virtual reality exposure vs. in vivo exposure by patients with specific phobias. Cyberpsychol Behav 2007 Oct;10(5):722-724 [FREE Full text] [doi: 10.1089/cpb.2007.9962] [Medline: 17927544]
17. Botella C, Serrano B, baños R, García-Palacios A. Virtual reality exposure-based therapy for the treatment of post-traumatic stress disorder: a review of its efficacy, the adequacy of the treatment protocol, and its acceptability. Neuropsychiat Diseas Treat 2015 Oct:2533 [FREE Full text] [doi: 10.2147/ndt.s89542]
18. Maples-Keller J, Bunnell B, Kim S, Rothbaum B. The use of virtual reality technology in the treatment of anxiety and other psychiatric disorders. Harv Rev Psychiatry 2017;25(3):103-113 [FREE Full text] [doi: 10.1097/hrp.0000000000000138]
19. Metcalf M, Rossie K, Stokes K, Tallman C, Tanner BAJ. Virtual reality cue refusal video game for alcohol and cigarette recovery support: summative study. JMIR Serious Games 2018 Apr 16;6(2):e7 [FREE Full text] [doi: 10.2196/games.9231] [Medline: 29661748]
20. Powers M, Rothbaum BO. Recent advances in virtual reality therapy for anxiety and related disorders: Introduction to the special issue. J Anxiety Disord 2019 Jan;61:1-2 [FREE Full text] [doi: 10.1016/j.janxdis.2018.08.007] [Medline: 30181011]
21. Oing T, Prescott J. Implementations of virtual reality for anxiety-related disorders: systematic review. JMIR Serious Games 2018 Nov 07;6(4):e10965 [FREE Full text] [doi: 10.2196/10965] [Medline: 30404770]
22. Didehbani N, Allen T, Kandalaft M, Krawczyk D, Chapman S. Virtual Reality Social Cognition Training for children with high functioning autism. Comput Hum Behav 2016 Sep;62:703-711 [FREE Full text] [doi: 10.1016/j.chb.2016.04.033]
23. Llobera J, González-Franco M, Perez-Marcos D, Valls-Solé J, Slater M, Sanchez-Vives MV. Virtual reality for assessment of patients suffering chronic pain: a case study. Exp Brain Res 2013 Mar;225(1):105-117 [FREE Full text] [doi: 10.1007/s00221-012-3352-9] [Medline: 23223781]
24. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005 Feb;8(1):19-32 [FREE Full text] [doi: 10.1080/1364557032000119616]
25. Šalkevicius J, Damaševičius R, Maskeliunas R, Laukienė I. International journal of social research methodologyanxiety level recognition for virtual reality therapy system using physiological signals. Electronics 2019 Sep 16;8(9):1039 [FREE Full text] [doi: 10.3390/electronics8091039]
26. Stamou G, Garcia-Palacios A, Botella C. The combination of cognitive-behavioural therapy with virtual reality for the treatment of post-natal depression. In: Proceedings of the 31st Australian Conference on Human-Computer-Interaction. 2019 Presented at: OZCHI'19: 31st Australian Conference on Human-Computer-Interaction; December 2 - 5, 2019; Fremantle WA Australia p. 599-603. [doi: 10.1145/3369457.3369541]
27. Guitard T, Bouchard S, Bélanger C, Berthiaume M. Exposure to a standardized catastrophic scenario in virtual reality or a personalized scenario in imagination for generalized anxiety disorder. J Clin Med 2019 Mar 05;8(3):309 [FREE Full text] [doi: 10.3390/jcm8030309] [Medline: 30841509]
28. Geraets C, Veling W, Witlox M, Staring A, Matthijssen SJ, Cath D. Virtual reality-based cognitive behavioural therapy for patients with generalized social anxiety disorder: a pilot study. Behav Cogn Psychother 2019 Mar 27;47(6):745-750 [FREE Full text] [doi: 10.1017/s1352465819000225]
29. Lange B, Pauli P. Social anxiety changes the way we move-A social approach-avoidance task in a virtual reality CAVE system. PLoS One 2019;14(12):e0226805 [FREE Full text] [doi: 10.1371/journal.pone.0226805] [Medline: 31869406]
30. Koilias A, Mousas C, Rekabdar B. The effects of driving habits on virtual reality car passenger anxiety. In: Bourdot P, Interrante V, Nedel L, Magnenat-Thalmann N, Zachmann G, editors. Virtual Reality and Augmented Reality. Cham: Springer; 2019:263-281.
31. Zacarin M, Borloti E, Haydu VB. Behavioral therapy and virtual reality exposure for public speaking anxiety. Temas Psicol 2019;27(2):491-507 [FREE Full text] [doi: 10.9788/tp2019.2-14]

32. Kim Y, Jung S, Min S, Seol E, Seo S, Hur JW, et al. Visuo-haptic-based multimodal feedback virtual reality solution to improve anxiety symptoms: a proof-of-concept study. Psychiatry Investig 2019 Mar;16(2):167-171 [FREE Full text] [doi: 10.30773/pi.2018.12.25.1] [Medline: 30808124]
33. Adjorlu A, Barriga N, Serafin S. Virtual reality music intervention to reduce social anxiety in adolescents diagnosed with autism spectrum disorder. In: Proceedings of the 16th Sound and Music Computing Conferences. 2019 Presented at: 16th Sound and Music Computing Conferences; May 28-31, 2019; Malaga, Spain p. 261-268 URL: https://vbn.aau.dk/en/publications/virtual-reality-music-intervention-to-reduce-social-anxiety-in-ad
34. Hartanto D. Computer-based social anxiety regulation in virtual reality expos. In: Thesis. Netherlands: Delft University of Technology; 2019.
35. Schaaf A. Tilt Brush: The Utilization of a virtual intervention for evaluating self-reported anxiety. Thesis, University of Cincinnati. 2019. URL: https://scholar.uc.edu/concern/articles/pz50gx41c [accessed 2021-02-10]
36. Suwanjatuporn A, Chintakovid T. Using a virtual reality system to improve quality of life of the elderly people with depression. In: Proceedings of the IEEE International Conference on Consumer Electronics - Asia, ICCE-Asia. 2019 Presented at: IEEE International Conference on Consumer Electronics - Asia, ICCE-Asia; June 12-14, 2019; Bangkok, Thailand p. 153-156 URL: https://doi.org/10.1109/ICCE-Asia46551.2019.8941607 [doi: 10.1109/icce-asia46551.2019.8941607]
37. Kovar, I. Virtual reality as support of cognitive behavioral therapy in social anxiety disorder. Int J Adv Sci, Eng Inf Technol 2018:1343-1349 [FREE Full text] [doi: 10.18517/ijaseit.8.4.5904]
38. Zinzow H, Brooks J, Rosopa PJ, Jeffirs S, Jenkins C, Seeanner J, et al. Virtual reality and cognitive-behavioral therapy for driving anxiety and aggression in veterans: a pilot study. Cogn Behav Pract 2018 May;25(2):296-309 [FREE Full text] [doi: 10.1016/j.cbpra.2017.09.002]
39. Tarrant J, Viczko J, Cope H. Virtual reality for anxiety reduction demonstrated by quantitative EEG: a pilot study. Front Psychol 2018;9:1280 [FREE Full text] [doi: 10.3389/fpsyg.2018.01280] [Medline: 30087642]
40. Lewis J, Paul A, Brown D. An exploratory investigation into the potential of mobile virtual reality for the treatment of paruresis - a social anxiety disorder. In: Proceedings of the 12th International Conference on Disability, Virtual Reality and Associated Technologies. 2018 Presented at: 12th International Conference on Disability, Virtual Reality and Associated Technologies; September 4-6, 2018; Nottingham, UK URL: https://www.researchgate.net/publication/327052844_An_Exploratory_Investigation_into_the_Potential_of_Mobile_Virtual_Reality_for_the_Treatment_of_Paruresis-a_Social_Anxiety_Disorder
41. Perandré Y, Haydu VB. A treatment program for social anxiety disorder by using virtual reality. Temas Psicol 2018;26(2):867-882 [FREE Full text] [doi: 10.9788/tp2018.2-12en]
42. Khosravi N, Mahmoodi G. Effect of neurofeedback therapy based on virtual reality technology on anxiety in patients with anxiety disorder 4?83. Soc Determ Health 2018:78-83 [FREE Full text] [doi: 10.14264/aa253ef]
43. Dehn L, Kater L, Piefke M, Botsch M, Driessen M, Beblo T. Training in a comprehensive everyday-like virtual reality environment compared to computerized cognitive training for patients with depression. Comput Hum Behav 2018 Feb;79:40-52 [FREE Full text] [doi: 10.1016/j.chb.2017.10.019]
44. Nason E, Trahan M, Smith S, Metsis V, Selber K. Virtual treatment for veteran social anxiety disorder: A comparison of 360° video and 3D virtual reality. J Technol Hum Serv 2019 Nov 28;38(3):288-308 [FREE Full text] [doi: 10.1080/15228835.2019.1692760]
45. Bossenbroek R, Wols A, Weerdmeester J, Lichtwarck-Aschoff A, Granic I, van Rooij MM. Efficacy of a virtual reality biofeedback game (DEEP) to reduce anxiety and disruptive classroom behavior: single-case study. JMIR Ment Health 2020 Mar 24;7(3):e16066 [FREE Full text] [doi: 10.2196/16066] [Medline: 32207697]
46. Pallavicini F, Pepe A. Virtual reality games and the role of body involvement in enhancing positive emotions and decreasing anxiety: within-subjects pilot study. JMIR Serious Games 2020 Jun 17;8(2):e15635 [FREE Full text] [doi: 10.2196/15635] [Medline: 32554371]
47. Kim H, Lee S, Jung D, Hur JW, Lee HJ, Lee S, et al. Effectiveness of a participatory and interactive virtual reality intervention in patients with social anxiety disorder: longitudinal questionnaire study. J Med Internet Res 2020 Oct 06;22(10):e23024 [FREE Full text] [doi: 10.2196/23024] [Medline: 33021481]
48. O'Meara A, Cassarino M, Bolger A, Setti A. Virtual reality nature exposure and test anxiety. Multimod Technol Interact 2020 Oct 22;4(4):75 [FREE Full text] [doi: 10.3390/mti4040075]
49. Wang TC, Sit CH, Tang TW, Tsai CL. Psychological and physiological responses in patients with generalized anxiety disorder: the use of acute exercise and virtual reality environment. Int J Environ Res Public Health 2020 Jul 06;17(13):4855 [FREE Full text] [doi: 10.3390/ijerph17134855] [Medline: 32640554]
50. Bouchard S, Dumoulin S, Robillard G, Guitard T, Klinger É, Forget H, et al. Virtual reality compared with exposure in the treatment of social anxiety disorder: a three-arm randomised controlled trial. Br J Psychiatry 2017 Apr;210(4):276-283 [FREE Full text] [doi: 10.1192/bjp.bp.116.184234] [Medline: 27979818]
51. Stupar-Rutenfrans S, Ketelaars L, van Gisbergen MS. Beat the fear of public speaking: mobile 360° video virtual reality exposure training in home environment reduces public speaking anxiety. Cyberpsychol Behav Soc Netw 2017 Oct;20(10):624-633 [FREE Full text] [doi: 10.1089/cyber.2017.0174] [Medline: 29039704]

52. Kim H, Hong Y, Kim M, Jung Y, Kyeong S, Kim J. Effectiveness of self-training using the mobile-based virtual reality program in patients with social anxiety disorder. Comp Hum Behav 2017 Aug;73:614-619 [FREE Full text] [doi: 10.1016/j.chb.2017.04.017]
53. Dechant M, Trimpl S, Wolff C, Mühlberger A, Shiban Y. Potential of virtual reality as a diagnostic tool for social anxiety: A pilot study. Comput Hum Behav 2017 Nov;76:128-134 [FREE Full text] [doi: 10.1016/j.chb.2017.07.005]
54. Jeong H, Lee J, Kim H, Kim J. Appropriate number of treatment sessions in virtual reality-based individual cognitive behavioral therapy for social anxiety disorder. J Clin Med 2021 Mar 26;10(5):915 [FREE Full text] [doi: 10.3390/jcm10050915] [Medline: 33652739]
55. Trahan MH, Morley RH, Nason EE, Rodrigues N, Huerta L, Metsis V. Virtual reality exposure simulation for student veteran social anxiety and PSTD: a case study. Clin Soc Work J 2021 Jan 19:1-11 [FREE Full text] [doi: 10.1007/s10615-020-00784-7] [Medline: 33487778]
56. Lindner P, Dagöö J, Hamilton W, Miloff A, Andersson G, Schill A, et al. Virtual Reality exposure therapy for public speaking anxiety in routine care: a single-subject effectiveness trial. Cogn Behav Ther 2021 Jan;50(1):67-87 [FREE Full text] [doi: 10.1080/16506073.2020.1795240] [Medline: 32870126]

Abbreviations

CBT: cognitive behavioral therapy
HMD: head-mounted display
IE: imaginal exposure
IVE: in vivo exposure
RCT: randomized controlled trial
RQ: research question
SAD: social anxiety disorder
VR: virtual reality
VRET: virtual reality exposure therapy
WHO: World Health Organization

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Original Paper

Testing the Differential Impact of an Internet-Based Mental Health Intervention on Outcomes of Well-being and Psychological Distress During COVID-19: Uncontrolled Intervention Study

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Abstract

Background: During COVID-19, the psychological distress and well-being of the general population has been precarious, increasing the need to determine the impact of complementary internet-based psychological interventions on both positive mental health as well as distress states. Psychological distress and mental well-being represent distinct dimensions of our mental health, and congruent changes in outcomes of distress and well-being do not necessarily co-occur within individuals. When testing intervention impact, it is therefore important to assess change in both outcomes at the individual level, rather than solely testing group differences in average scores at the group level.

Objective: This study set out to investigate the differential impact of an internet-based group mental health intervention on outcomes of positive mental health (ie, well-being, life satisfaction, resilience) and indicators of psychological distress (ie, depression, anxiety, stress).

Methods: A 5-week mental health intervention was delivered to 89 participants using the Zoom platform during 2020. Impact on outcomes of distress, well-being, and resilience was assessed at the start and end of the program with multiple analysis of variance (MANOVA) and reliable change indices (RCIs) being used to determine program impact at the group and individual levels, respectively.

Results: The intervention significantly improved all mental health outcomes measured, ($F_{6,83}$=5.60, P<.001; Wilks Λ=.71; partial η^2=.29) showing small to moderate effect sizes on individual outcomes. The largest effect sizes were observed for life satisfaction and overall well-being (η^2=.22 and η^2=.2, respectively). Larger effect sizes were noted for those with problematic mental health scores at baseline. A total of 92% (82/89) of participants demonstrated reliable change in at least one mental health outcome. Differential response patterns using RCI revealed that more than one-half of the participants showed improvement in both mental well-being and psychological distress, over one-quarter in outcomes of well-being only, and almost one-fifth in distress only.

Conclusions: The results provide evidence for the significant impact of an internet-based mental health intervention during COVID-19 and indicate the importance of assessing dimensions of both well-being and distress when determining mental health intervention effectiveness.

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KEYWORDS

COVID-19; internet-based interventions; mental health; well-being; intervention; study; impact; internet; online intervention; distress; resilience; depression; anxiety; stress

Introduction

Mental Well-being and Psychological Distress as Dual Dimensions of Mental Health

A commonly cited definition of mental health is the one postulated by the World Health Organization: “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” [1]. Despite this definition — and numerous other readily used mental health definitions — incorporating positive facets of mental health, mental health care, and the research that underpins it is overwhelmingly focused on understanding and solving problems related to mental disorders [2]. The same applies for mental health intervention research, where historically, efforts have centered around treating or intervening in mental disorders, invariably focusing on “mental health conditions” or “mental illnesses” that significantly affect cognition, emotion, and behavior that may lead to dysfunction or disability [3,4]. Concurrently, research into mental health has focused on the related outcome of psychological distress [5], a state of emotional suffering that is typically characterized by symptoms of depression and anxiety [6].

Although a predominant emphasis on addressing psychological distress and mental disorder still persists, the COVID-19 pandemic has made the need to focus beyond mental disorders in clinical populations more salient. The far-reaching societal consequences of the pandemic increased the need to investigate how the general population can maintain positive and adaptive states of mental health and how these positive and adaptive states can be utilized to buffer against developing more complex problems [7,8]. Although the pandemic brought promotion of positive mental health, or alternatively, states of “mental well-being,” more front-of-mind, these outcomes have for decades already been advocated to be an important standalone mental health outcome and therapeutic avenue, in contrast to the “traditional” focus on merely reducing pathology [9,10]. Mental well-being specifically refers to a state where people generally feel good (ie, experience more positive than negative emotions, feel a sense of life satisfaction) and feel that they can function fully (eg, are able to self-actualize, self-realize, and have a sense of meaning) [11]. In other words, they perceive enjoyment and fulfilment with one’s life as a whole [12]. Decades of research by well-being pioneers such as Diener [13], Ryff [14], and Keyes [15], followed by researchers operating in the field of positive psychology [16], broached the important role of promoting mental well-being in the general population. A now large and established body of research clearly links the presence of mental well-being to a range of desirable physical health (eg, longevity and healthy aging, reduced hospital use) and mental health (eg, lower rates of suicide ideation, more healthy coping) outcomes [17-23].

Psychological distress and mental well-being do not merely occupy opposite ends of a single continuum, and further research is required to understand the complex relationship between the constructs, particularly in intervention research [24,25]. For example, high well-being indicators do not simply equate to being mentally healthy, as both well-being *and* the absence of distress or disorder are required to be mentally healthy [24,26]. Similarly, mental well-being is not simply the opposite of mental disorder, but rather is an outcome that can co-occur and be juxtaposed to the presence of mental disorder and psychological distress. A scoping review conducted in 2020 identified over 80 scientific publications providing supportive evidence that well-being and disorder/distress are considered to be negatively related but independent outcomes, with both aspects associated with good mental health [27]. First, empirical studies have shown the importance of maintaining and improving the mental state of well-being for the *prevention* of potential mental disorder [28-30]. Second, studies have shown that improving states of mental well-being in people with current mental disorders can impact rates of recovery [31,32].

The Need for Scalable Interventions Designed to Address Both Well-being and Distress

While definitive research on the long-term impact of COVID-19 on mental health outcomes across the general population is heterogeneous and not clearly established, with more research needed to determine which population groups are most affected, academic research published since the outbreak of the pandemic generally points to a negative immediate consequence [33-39]. These adverse mental health consequences are often the result of societal restrictions and policies, rather than infection with (or fear thereof) the virus itself [40-42]. This is particularly the case for countries where COVID-19 caseloads have been comparatively low such as Australia. As of July 10, 2021, Australia had a total of 31,017 confirmed cases of COVID-19, resulting in 910 deaths (2.93% death rate) [43]. This death rate, 3.6 per 100,000, is very low compared with other countries such as the United States (184.9 per 100,000) and the United Kingdom (192.5 per 100,000) [44]. Despite this attenuated impact, various studies point to an immediate impact on outcomes of well-being and distress in Australia, particularly in at-risk population groups [45-48]. For instance, Batterham et al [49] found that participants in Australia who had financial distress, social impairment, and work impairment were most impacted. Similarly, Li et al [50] found that young people, who due to their age are already at higher risk of mental health problems, showed elevated mental health problems. University students, who generally display high rates of mental health problems and lower well-being [51], similarly demonstrated mental health problems immediately after the pandemic began [52].

As a result of the observed and anticipated consequences, there have been widespread calls to proactively intervene in mental health by targeting distress and the well-being of the general population [8]. The importance of addressing states of well-being and distress conjointly is advocated by proponents of dual-factor models [24,53], well-being therapy [54], the recovery movement [10], positive (clinical) psychology [2], and positive psychiatry [55]. These distinct streams in mental health care propose that, by taking both well-being and distress into account, the way we deliver mental health care across the spectrum of mental health, ranging from self-help options to treatment of recurrent lifetime disorders, can be improved. For example, mental health interventions incorporating a focus on well-being have the potential to prevent more severe mental disorder, can augment treatment, or can be used as early intervention for subclinical issues. In other words, such interventions can be used as a target to promote mental health in the general population using psychological interventions, addressing prodromal symptoms [26].

A range of behavioral and psychological interventions exist that have proven to positively impact mental well-being in nonclinical settings [56-58]. The most renowned of these psychological interventions stems from the work of positive psychology [59], but various distinct psychological interventions will have a significant impact, depending on a range of moderators including target population and delivery format [58]. One viable delivery format that has been shown to be able to have a sustainable impact in the general population is the use of internet-based solutions, which can be deployed at a larger scale and can be used irrespective of the presence of physical restrictions (eg, lockdowns) [60,61]. This is particularly the case for mental health interventions that target lower-intensity problems or issues related to well-being and mental health promotion, where support by mental health professionals is less warranted [62]. A rapid review by Rauschenberg et al [63] found good evidence for the short-term impact of online mental health interventions during COVID-19 for mental disorder, with evidence for mental health promotion interventions still being sparse.

A by-product of utilizing internet-based interventions with a stronger focus on well-being is that it can also help improve the current gap in service delivery for those experiencing symptoms of mental disorder, as it may help to address various challenges of the mental health system in clinical populations, including access issues, stigma, or “treatment resistance” to name a few [64,65]. For instance, providing complementary or integrated well-being intervention programs may reach clients and community members who do not respond to traditional treatment or do not access these due to associated stigma [66]. Adopting a strong emphasis on well-being also diminishes the reliance on using outcomes of distress and illness as the only indicators of treatment effectiveness. For instance, a poor response to psychological interventions is not uncommon, with nonresponder estimates of 30%-40% being documented [67]. Nonresponse in outcomes of distress is often seen as a lack of treatment impact, particularly in treatment models where the main focus is elimination of symptoms. As mental well-being is related to both prevention of mental disorder and recovery from illness, it plays a fundamental role in personal and functional recovery, which may be considered to be a proxy for future treatment impact [18,27].

The Need to Look Beyond Group Averages

In order to determine the merit of psychological interventions on improving mental health outcomes, scholars increasingly stress the importance of measuring both states of distress and well-being to best evaluate mental health intervention impact, a recommendation that comes with an often-overlooked nuance [68]. The impact of an intervention is often determined by comparing an average shift in scores of a cohort of participants using specific outcome measures [69]. For instance, an intervention targeting distress is thought to be beneficial if it can demonstrate an average significant and meaningful change in average scores [70] using, for example, a validated depression outcome measure such as the Depression Anxiety and Stress Scale (DASS-21) [71]. While average improvements are an important way to assess the potential impact of interventions on *groups*, it does not indicate whether interventions are efficacious or even suitable on an individual level [72].

Comparison of average changes furthermore obscure any possible *differential* impact of interventions on outcomes of mental well-being or distress within individuals [73]. Average improvements in mental well-being and mental disorder outcome measures at a group level do not necessarily mean that each individual demonstrates equal changes in both measures after receiving an intervention. These types of analyses leave intra- and even interindividual responses unclear and limited in their ability to detect how different individuals may respond in relation to different mental health outcomes. Thus, these generic approaches obscure important results that provide information as to what interventions work, on what dimensions they apply, and who specifically benefits from them. Subsequently, these studies provide limited guidance for practitioners and other stakeholders who wish to understand the nuances of how different interventions affect outcomes within (as opposed to between) individuals and then applying this knowledge to the way they provide mental health care [73].

Scientific studies investigating mental health interventions have not readily reported analyses of intraindividual change across both dimensions of mental health. A notable recent exception is a study by Trompetter et al [68], who investigated the impact of a self-help Acceptance and Commitment Therapy (ACT) intervention for people with clinical depression or anxiety. The authors utilized reliable change indices (RCIs) [74,75] to determine whether individuals demonstrated a meaningful change in their mental health outcomes. The researchers found that improvements in mental health or mental disorder did not necessarily co-occur. While 31% of participants improved across both dimensions, only 12% improved in aspects of positive mental health, and 57% improved in symptoms of distress. Additionally, results further differed for participants with depression and anxiety, showing how outcomes of well-being can interact differently with different outcomes of illness. Thus, analysis of the results using RCI not just enabled assessment of the overall effectiveness of the intervention for these 2 clinical populations but also gave better insight about for whom the intervention showed the most effect.

Additionally, approaches such as those taken by Trompetter et al [68] enable the assessment of change while taking baseline scores into consideration. Baseline scores have a clear impact on the summary of change that is potentially possible for each individual [76]. Positive reliable change cannot be expected if participants start at a baseline level that is not conducive to further improvement. Studies that focus on a reduction in pathology, both mental and physical, therefore typically use severity classifications to inform participant criteria for potential participant recruitment. For example, researchers might only include participants who meet the mild depression cutoff on measures such as the DASS-21 or Hamilton Anxiety and Depression Scales to ensure that participants actually show signs of current distress [77,78]. In contrast, studies that investigate the impact of interventions on mental well-being typically do not consider cutoffs as an important starting factor, neglecting the critical impact of baseline scores; this is an important relation to assess considering the precarious situation of mental health and mental health care and the calls for mental health promotion interventions for the general population during the COVID-19 pandemic [8,48,62].

This study aimed to advance the literature in a number of ways. First, it aimed to determine the impact of an internet-based psychological intervention on mental health outcomes during COVID-19 in Australia. It aimed to add to the currently lacking evidence [63] on the benefit of (internet-based) interventions to promote mental health and well-being, as opposed to targeting clinical symptoms in clinical populations. Second, it aimed to investigate whether the findings reported by Trompetter et al [68] can be replicated in a nonclinical, general population sample; the study aimed to determine differences in reliable change in outcomes of both mental well-being and psychological distress. Rather than using an intervention based on a clinical treatment approach (ACT in the case of the study by Trompetter et al [68]), our study aimed to show this differential impact of a universal, group-based, mental health intervention designed to promote mental health in the general nonclinical population. Finally, the study aimed to examine the effect of baseline differences in well-being and psychological distress on the effectiveness of the intervention.

Methods

Study Design

This study was designed to establish whether a range of mental health outcomes would increase due to exposure to an internet-based psychological intervention and to test whether individuals would display improvements differentially across these outcomes using reliable change analysis. The study was an uncontrolled intervention study comparing data collected using an internet-based measurement tool at the beginning of the intervention compared to data by the end of the intervention. The study was approved by the Flinders University Human Research Ethics Committee (PN 2163).

Participants

Participants for this study were from 2 cohorts. The first consisted of adults (18 years or older) from the general population, while the second cohort consisted of adult university students. Participants from the general population signed up via an online website, which was promoted via local print media and radio, an email newsletter for the South Australian Health and Medical Research Institute (SAHMRI), and social media posts on Facebook and Twitter. The second cohort consisted of students who were recruited through one of the major universities in South Australia. No specific inclusion or exclusion criteria applied other than the requirement to be adult, understand the English language, and have access to an internet-enabled device with Zoom [79]. There was no face-to-face contact with any of the participants.

Recruitment

Recruitment was conducted over 6 months from March 2020 until July 2020. Recruitment procedures for the general population and the student population differed slightly. At the university, the study was advertised as a tailored, free, online program to improve mental health and well-being developed by SAHMRI and Flinders University. Promotional information for students was distributed via university emails, student associations, and social media including details about the program, facilitators, and the delivery format. Recruitment material highlighted the importance of well-being and mental health, and importantly, this period coincided with the ongoing impact of COVID-19. Recruitment material provided information about the development and individual components of the program. Interested participants provided their email address, name, and college and were sent an invitation to complete a measurement about their mental health and well-being 1 week before starting the first online session. Measurement was to be completed prior to commencing the intervention. Participants were not obliged to participate in the research study in order to attend the individual sessions. Within the general population, participants could enroll via a website with detailed information about the program or were recruited via partner organizations who were interested in promoting a well-being program to their staff.

Participants were sent an invitation to complete a measurement about their mental health and well-being before starting the initial online session. All participants were invited to attend 5 2-hour weekly sessions hosted online. While initially the study was planned to be conducted in person, COVID-19 restrictions in Australia required online delivery of the program via Zoom [79]. By the final session, participants were invited to complete a second measurement, which was used to determine the post-intervention score outcomes. This was emailed to participants 1 week before the final session, to be completed prior to attending the final session so that participants could track any changes observed since the original measure.

Intervention

The “Be Well Plan” is a 5-week, group-based psychological program that helps participants create a personalized mental health and well-being plan by experimenting with a variety of resources and evidence-based activities to improve mental health and well-being. The program can be delivered in person in small- to medium-sized group settings (ranging between 10 and 40 participants) or alternatively online via platforms such as Zoom [79], the format utilized for this study.

Program facilitators for the training do not need to be trained mental health professionals, but rather are upskilled to be able to facilitate the training in an engaging and safe way, thereby improving the scalability of the program without further constraining existing health care resourcing. The trained trainers are required to participate in a minimum of 26 hours of face-to-face training. For this study, 6 trained trainers were involved in the delivery of the intervention with a variety of professional backgrounds including well-being research, counselling, workplace development training, and clinical psychology. Facilitators were either staff involved in the development in the intervention (n=4) or colleagues who have a professional training background and were involved in early testing rounds of the intervention (n=2).

The program was designed using a rigorous intervention development process called intervention mapping and among other techniques, relied on the use of co-design with end users and stakeholders [80]. The program aims to impact both outcomes of well-being and outcomes of distress by incorporating evidence-based activities aimed at promoting mental health. Included activities were derived from a large systematic review on distinct psychological interventions aimed at improving outcomes of well-being conducted by members of the research team [58]. A particular strength is that the program is tailored to participants' unique mental health needs and interests of individual participants. A detailed description of the program and its development will be published in a separate manuscript. A general overview of the intervention can be found in Table 1.

Table 1. Summary of the 5 sessions of the Be Well Plan.

Session	Description
Session 1: Getting on the same page	Participants explore reasons for participating in the program, including their personal drivers. They also acquire basic knowledge of mental health and its malleability. This aims to stimulate a mindset for change. They continue by exploring the evidence for different psychological interventions and start creating their first Be Well Plan. They do this by choosing one of many formats of practicing mindfulness and setting a goal on how to practice it during the week. They get introduced to the formation of tiny habits and implementation intentions as a technique to improve the chance of goal attainment.
Session 2: Using your mental health profile	Participants reflect on session 1. They are introduced to the concept of self-compassion (as opposed to self-criticism) and how it can be used to learn from failure and shape our thinking patterns. They practice a self-compassion activity. They subsequently use their own measurement result stemming from the integrated assessment to focus on an outcome they want to work on (well-being, resilience, mood, anxiety, stress, health) and are introduced to activity finders: flow charts that map evidence-based activities to each of the activities. They pick one activity from the activity bank to add to their Be Well Plan and set new goals for the week. They will be introduced to the use of prompts and reminders as another method to increase goal attainment.
Session 3: Your resources and challenges	Participants reflect on week 2. They work with (and are reminded of) existing resources to their own mental health via 2 practical activities. In the first one, participants choose pictures that display sources of meaning in their life; in the second one, participants identify core values that can be used to guide goals. They then use a simple questionnaire to identify a key resource or challenge they want to work on. They are introduced to a second activity finder that maps evidence-based activities to various challenges and resources. They pick a new activity from the activity bank to add to their Be Well Plan. They finish the session by adjusting their Be Well Plan.
Session 4: Stress, coping, and resilience	Participants reflect on week 3. This session focuses on stressful times and effective ways to cope (avoidance-focused coping versus more helpful ways, such as problem-focused coping). They are then walked through various ways of coping using psychological techniques and theories, including identification of cognitive traps and the use of thought defusion. They are asked to identify social supporters for challenging times and are reminded of various professional services. They then choose 1 new activity specifically focusing on stress and resilience. They are actively asked to reach out to a social supporter as part of their weekly activities.
Session 5: Future-proofing your Be Well Plan	Participants reflect on the past 4 weeks. They are asked to complete a new measurement and investigate how their outcomes have changed over the 4 weeks. The facilitators introduce the concept of realistic optimism, growth, and the fact that progress comes with ups and downs. Participants work on practicing positive reframing as a way to deal with mistakes and setbacks. They then build their final Be Well Plan, which aims to summarize key learnings from the previous weeks into a standalone plan. They summarize what their best possible mental health looks like, highlight their unique drivers and motivators, and existing resources and challenges in their life. They set a longer-term goal and choose the activities they wish to add to their Be Well Plan. They identify their key supporters and reflect on what support services they need in case of emergency.

Measures

Outcomes measured in this study included positive mental health and psychological distress, which are mental health outcomes that are most relevant to nonclinical populations.

Mental Well-being

Mental well-being was captured using the Mental Health Continuum Short-Form (MHC-SF) [81], which allows the calculation of a generic well-being score as well as subscores for emotional (hedonic), psychological (eudaimonic), and social well-being. The scale showed high internal reliability, with a Cronbach α of 0.94. Furthermore, the Satisfaction With Life Scale (SWLS) [82] was used to provide an alternative measure of general well-being, which similarly showed good internal reliability: α=0.89.

Psychological Distress

Psychological distress was captured with the DASS-21, which offers clear cutoff points for the level of severity of symptoms. This facilitates grouping of scores into "normal," "mild," "moderate," "severe," and "extremely severe" symptoms of psychological distress for the domains of depression (α=0.91), anxiety (α=0.82), and stress (α=0.86).

Resilience

An additional outcome of interest was resilience, or the perceived ability to withstand stress, a relevant outcome considering the impact of COVID-19 on stress levels. Resilience was assessed using the Brief Resilience Scale [83], which looks at whether respondents feel they are able to deal with stressful situations. This tool also comes with cutoffs for low, normal, and high resilience. Internal consistency was high: α=0.89.

Statistical Analysis

Evaluating the Impact of the Intervention

Data analysis was conducted in RStudio and SPSS version 27. To determine the average change between baseline and the final session, a repeated measures multiple analysis of variance (MANOVA) was completed. A MANOVA was chosen in order to account for the considerable overlap between selected mental health outcome measures. Where needed, data were transformed to deal with the presence of nonnormality; as results did not change between analyses on transformed and untransformed data, the untransformed results were used in this article. One univariate outlier was excluded from the analysis as it significantly impacted the results. Multivariate outliers did not affect the results and were therefore left unchanged. Multicollinearity was assessed using bivariate correlations, revealing that the majority of outcomes showed a positive or negative correlation between .40 and .65. Partial eta squared was used as a measure of effect size, where 0.02 equals a small effect, 0.13 a medium effect, and 0.26 or higher a large effect [84].

Analysis of Within-Individual Changes Post-Intervention

Within-individual changes in outcomes were assessed by calculating an RCI using the traditional method for assessment of reliable change as suggested by Jacobson and Truax [75]. The RCI was calculated by subtracting an individual's post-intervention score from their baseline score and subsequently dividing this difference score by the standard error of the difference for the measurements used. The standard error of the difference was calculated using the following formula:

$$\text{SEdiff} = \text{SD}_x * \sqrt{}(1\text{-}r_{xx}),$$

where SD_x refers to the SD of the difference scores and R_{xx} refers to the correlation between scores on the pre and post measurements. Any change larger than 1.96 (2 SDs) was considered a reliable change.

Assessment of Baseline Differences in Intervention Outcomes

The impact of baseline well-being and psychological distress on outcome impact was assessed with independent samples *t* tests. Where distributions were nonparametric, both normal and parametric tests (ie, Mann-Whitney U-tests) were run. As the results for parametric and nonparametric tests returned similar results, results presented report the parametric results (ie, results for the *t* tests). Participants were grouped into "high" vs "low" well-being according to the cutoffs on the MHC-SF [81] as well as "high" vs "low" life satisfaction according to a cutoff on the SWLS [82]. Furthermore, participants were also grouped into "distressed" vs "no distress" if they met any of the cutoffs for "mild distress" on one of the DASS-21 subscales [71].

Results

A total of 240 participants took part in the training, of which 140 participants provided consent to be studied. Of these 140, a total of 90 participants provided data at both timepoints. A total of 89 participants were included in the analysis, after excluding a severe outlier.

Participant Characteristics

The average participant age was 38.67 (SD 13.06) years. A total of 59 participants (59/89, 66%) were female, who had an average age of 40.05 (SD 14.07) years. Of the participants, 19 (19/89, 21%) were male, with an average age of 37.37 (SD 10.43) years. "Prefer not to say" was answered by 11 participants (11/89, 12%). Most participants were employed (69/89, 77%; average age: 40.71, SD 13.26 years) and not studying (57/89, 64%; average age: 43.25, SD 12.40 years). When comparing students (32/89, 36%; average age: 30.53, SD 9.98 years) to participants from the general population, it was noted that mental health baseline values were significantly worse for students for all outcomes: $F_{6,82}$=3.94, P=.002; Wilks Λ=.78; partial η^2=.22.

Evaluating the Impact of the Intervention

Comparison of pre- and post-intervention scores showed a significant change in mental health variables across time: $F_{6,83}$=5.60, P<.001; Wilks Λ=.71; partial η^2=.29. Table 2 displays the positive changes in all individual domains and the relevant test statistics, showing a significant positive change in all outcomes measured. Effect sizes for significant outcomes ranged between small and moderate, with the largest significant improvement noted in life satisfaction and the smallest improvements in anxiety.

Table 2. Pre- and postintervention scores for outcomes of mental well-being, psychological distress, and resilience in the total sample (n=89).

Outcomes	Preintervention		Postintervention		Statistics		
	Score, mean (SD)	Participants with problematic scores[a], n (%)	Score, mean (SD)	Participants with problematic scores, n (%)	*F* (*df*)	*P*	η^2
Overall well-being	45.81 (11.18)	51 (57)	49.39 (12.19)	41 (46)	22.43 (1)	<.001	.20
Life satisfaction	22.01 (5.93)	26 (29)	24.46 (6.48)	21 (24)	25.29 (1)	<.001	.22
Distress due to mood	10.00 (8.91)	42 (47)	7.91 (7.37)	32 (36)	9.44 (1)	.003	.10
Distress due to anxiety	6.54 (6.77)	34 (38)	5.33 (5.71)	26 (29)	5.45 (1)	.02	.06
Distress due to stress	13.03 (8.18)	32 (36)	10.67 (7.94)	25 (28)	11.86 (1)	<.001	.12
Resilience	3.27 (0.76)	26 (29)	3.45 (0.75)	21 (24)	10.84 (1)	.001	.110

[a] Problematic scores refer to scores where participants did not meet the cut-off for high well-being, normal resilience, or no presence of distress.

Analysis of Within-Individual Changes Post-Intervention

Analysis of reliable change indicated that a total of 92% (82/89) of the participants demonstrated improvement in at least one of the domains of the outcomes measured. Of these 83 participants, 51% (42/82) showed both improvements in well-being and indicators of distress, whereas 29% (24/82) only showed improvement in well-being and 20% (17/82) only showed improvements in distress. Further, response patterns differed for the various distress categories.

Those who met the threshold for mild depressive symptoms and displayed a reliable improvement largely showed reliable change in both well-being and distress (25/35, 71%), with additional proportions demonstrating improvement in either well-being (5/35, 14%) or distress (5/35, 14%). Those participants who met the threshold for anxiety demonstrated reliable improvement in both anxiety and well-being (15/29, 52%) or well-being alone (13/29, 45%); only one participant (1/29, 3%) demonstrated reliable change in anxiety scores only. The majority of those who met the threshold for stress showed reliable change in well-being outcomes only (19/31, 61%), with 7 participants (7/31, 23%) showing a reliable change in both distress and well-being and 5 participants (5/31, 16%) showing reliable change in distress only.

Assessment of Baseline Differences in Intervention Outcomes

Change in mental health outcomes significantly differed for those with "low" baseline values compared with those with "high" baseline scores before the intervention. As expected, significant changes were found for life satisfaction and distress across all categories, with those reporting lower baseline scores experiencing significantly lower change in outcome scores (see Table 3). Despite students showing significantly worse baseline mental health problems, no significant interaction effect was noted ($F_{6,82}$=1.70, *P*=.132; Wilks Λ=.89; partial η^2=.11), showing that the change in the mental health outcome was not significantly different for students versus nonstudents.

Table 3. Comparison of the outcomes of mental well-being, psychological distress, and resilience in the total sample of participants between participants with and without problematic scores at baseline.

Outcomes	Participants with problematic scores[a] at baseline			Participants with healthy scores at baseline			Statistics		
	Pre-intervention, mean (SD)	Post-intervention, mean (SD)	N	Pre-intervention, mean (SD)	Post-intervention, mean (SD)	N	*t* (*df*)	*P*	*d*
Well-being	38.18 (7.61)	42.47 (10.62)	51	56.05 (5.56)	58.68 (6.78)	38	1.02 (86)	.31	0.21
Life satisfaction	14.62 (3.20)	18.77 (6.56)	26	25.06 (3.65)	26.81 (4.80)	63	2.14 (87)	.04	0.50
Mood problems	17.76 (6.69)	13.05 (7.10)	42	3.06 (2.79)	3.32 (3.64)	47	3.79 (55)	<.001	0.84
Anxiety problems	13.35 (6.06)	8.53 (6.41)	34	2.33 (2.24)	3.35 (4.20)	55	6.23 (55)	<.001	1.46
Stress problems	22.06 (5.39)	16.44 (8.09)	32	7.96 (4.04)	7.44 (5.77)	57	3.37 (44)	.002	0.85
Resilience	2.29 (0.40)	2.69 (0.70)	25	3.66 (0.45)	3.74 (0.53)	64	2.86 (87)	.005	0.68

[a] Problematic scores refer to scores where participants did not meet the cut-off for high well-being, normal resilience, or no presence of distress.

Discussion

This study demonstrated that an internet-based mental health program could elicit differential change in outcomes of mental well-being and psychological distress in a nonclinical population during COVID-19. Results demonstrated that mental health outcomes in the sample improved from the beginning to the end of the intervention and that participants with poorer baseline scores had a significantly better response compared to those with greater average baseline scores. Furthermore, the results highlighted that reliable change in outcomes of mental well-being and psychological distress could occur independently, with type of distress (depression, anxiety, stress) resulting in differential response patterns.

The results here bolster the evidence that internet-based interventions can play a significant role in dealing with the mental health consequences of the pandemic [60,61,85,86]. This intervention was delivered over internet-based teleconferencing software using trained professionals outside of a clinical setting. The training, which focuses on promoting mental health, not the specific treatment of mental illness, was designed to be able to be delivered without the reliance on clinical staff. This approach of upskilling nonclinical staff to deliver mental health training has successfully been utilized by our team before and facilitates scalability and reach of the solution [87,88]. Mental health systems are typically under-resourced, which has further deteriorated during COVID-19, fueling calls for innovative solutions as the one presented in this article, particularly those that safeguard ethical principles [85,89]. Finding positive results for interventions that aim to promote mental health in both outcomes of well-being and distress in a general population under duress makes for promising standalone first-line interventions or as solutions to deal with existing system issues (eg, waitlists) [18].

While the significant impact of the intervention in a general nonclinical population was promising, the use of the term “nonclinical” warrants attention. This term mainly reflects the inclusion criteria rather than an actual lack of clinical symptoms among participants. As may be expected, the majority of participants did in fact show mild symptoms of distress (53/89, 60%). This proportion, at first glance, may appear higher than typically reported in the general population, such as the frequently cited “one in five who are struggling with symptoms of a common mental disorder” [90]. This increased rate may partly be attributed to the result of the pandemic but may also be explained by the fact that our sample stemmed from 2 different population pools: the general adult population and tertiary university students. Previous studies have demonstrated that mental health outcomes in students are worse across many domains than in the general population [51,91,92], which was supported in our study. These findings first elicit the need to thoroughly investigate and improve the mental health of, demands on, and lifestyle of our tertiary students [93], but second, highlights an area that requires the attention of researchers who may use student cohorts for their mental health research and wish to compare their findings to a sample of the general population.

The findings support previous research indicating that improvements in distress do not automatically result in improvements in well-being and vice versa. Similar to the findings by Trompetter et al [68], this study showed that, while participation in the intervention led to overall improved mental well-being and reduced psychological distress, not every individual improved in both domains. These results provide an additional piece of evidence that supports the independence of outcomes for mental well-being and mental disorder [27]. As research by dual-factor model scholars such as Keyes [24] and Greenspoon and Saklofske [53] proposes, the ultimate end goal of our mental health care system ought to strive for “complete” states of mental health, that is states of high well-being and no distress or symptoms of mental disorder in as many people as possible. This indeed would be the expectation if we were to deliver mental health care that lived up to and met the contemporary definitions of mental health such as the one posited by the World Health Organization [1]. Results here show though, that in order to meet this aspirational international standard, it is critical to systematically measure both outcomes of well-being as well as psychological distress when assessing the impact of psychological interventions in research and practice [27].

The difference in intra-individual responses between psychological distress types furthermore points to the complex relationship between states of well-being and distress and their outcome measures [25]. Most participants who showed changes in depression had simultaneous improvements in well-being outcomes, which was not the case for anxiety or stress. A possible explanation for these patterns of change points to the inherent similarity between the construct of depression and happiness [29]. For instance, evidence for dual-factor models is less convincing for people with severe depression [94], and these models do not work as well when outcome measures specifically take advantage of the emotion of “happiness” or other affective states of hedonic well-being. In the data presented here, even the moderate correlation (r=.5) between the measure of life satisfaction (SWLS) and general well-being (MHC-SF), which captures the factors of hedonic, eudemonic, and social well-being, shows that these 2 well-being measures vary substantially. Therefore, it is essential to carefully consider the most appropriate measure when assessing the impact of interventions or treatment modalities, as this decision has consequences for the perceived impact of the intervention in both types of outcomes [95].

Our finding that effect sizes were higher for people meeting the threshold of psychological distress or low well-being is encouraging. In addition to providing insight into the impact of interventions for individuals with different states of mental health, promoting the importance of baseline mental health on interventions has practical implications for treatment models. There is an ever-increasing burden of mental health problems, with mental health systems around the globe feeling the strain [96,97]. Advocates of change have long been calling for new solutions to help support the provision of complementary services and group-based mental health interventions that can be delivered online and in person. The Be Well Plan program offers a solution that can be implemented to ameliorate current system pressures, complementing other accessible solutions such as low-intensity cognitive behavioral therapy [98,99]. Consequently, it is important to determine an effective model of universal programs that have the greatest impact on mental health outcomes, while reducing the burden of disease. While more research is needed to understand the particular effectiveness of each program component on different mental health outcomes [73], our findings support the need to improve and innovate lower tiers in evidence-based, stepped-care models or stimulate a stronger focus on well-being within integrated care models [100,101].

This research has limitations requiring comment. First, the results stem from an uncontrolled study, which means that the evidence is not conclusive in supporting the efficacy of the intervention. The intervention was delivered in response to the immediate mental health demands in the community during the pandemic; therefore, the team made a conscious call to deliver the intervention to anyone who signed on immediately, rather than randomize them into waitlists. This design limitation, however, does not impact the validity of the findings, as a core aim of the study was to explore a within-subject change design. That said, it is important to compare and verify reliable change between an active intervention and a comparable control condition in future studies. Uncontrolled studies, for example, do not account for various confounding factors (eg, the impact of extraneous events and lifestyle factors). In this case, the study was conducted while the COVID-19 pandemic was ongoing, which could have had a significant impact on mental health outcomes during this extraordinary period [45] and therefore would have impacted the results one way or the other.

Second, the results presented only refer to short-term outcomes, clearly warranting the need to examine long-term changes. For instance, improvement in well-being has been shown to be associated with long-term recovery of mental disorder in observational studies [31]. It is hypothesized that well-being may therefore be a therapeutic focus for long-term (symptom) recovery [18], but a rigorous body of research intervention studies is yet to be established [27].

Third, the current results apply to a general population cohort; extrapolation to clinical populations should be used with caution. Although the sample did include participants that showed higher distress levels, the presence of psychological symptoms does not equal the presence of disorder, which requires assessment using different outcome measures [5]. The results presented by Trompetter and colleagues [68], however, did apply to clinical populations and therefore pose a reference point for those working in the clinical area.

A fourth and similar limitation lies in the specificity of our outcome measures. This study used a general measure of distress implying that the results should not be generalized to determining the impact on explicit symptoms of mental disorder [102]. The current results only refer to the differential changes in well-being and distress, demonstrating that changes in outcomes of mental well-being and psychological distress do not automatically go hand in hand after participation in a mental health intervention. Both outcomes should be considered and assessed when investigating the impact of psychological interventions and changes in mental health outcomes.

Finally, the study did not collect in-depth data on intervention usage, which means the study is limited in being able to talk to the fidelity of the training or its short- or long-term use by the participants. This will be an important focus area for future studies on the Be Well Plan.

To conclude, this study provides evidence for the impact of an internet-based mental health intervention during a period of significant community need. The intervention resulted in improvements in both participant mental well-being and psychological distress. After analyzing within-individual effects of the program, a differential response pattern was observed, indicating that improvement in mental well-being and reduction in psychological distress were not necessarily congruent. This indicates the importance of assessing dimensions of both well-being and distress when determining intervention effectiveness, which in the case of the Be Well Plan, added evidence to the impact that internet-based mental health promotion interventions can have generally and during times of societal distress such as pandemics.

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Conflicts of Interest

The South Australian Health and Medical Research Institute, which employs JvA and MI, receives financial compensation from providing the Be Well Plan to organizations and the community.

References

1. Mental health: strengthening our response. World Health Organization. 2018 Mar 30. URL: https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response [accessed 2020-11-10]
2. Wood AM, Tarrier N. Positive Clinical Psychology: a new vision and strategy for integrated research and practice. Clin Psychol Rev 2010 Nov;30(7):819-829. [doi: 10.1016/j.cpr.2010.06.003] [Medline: 20655136]
3. Manderscheid R, Ryff C, Freeman E, McKnight-Eily L, Dhingra S, Strine T. Evolving definitions of mental illness and wellness. Prev Chronic Dis 2010 Jan;7(1):A19 [FREE Full text] [Medline: 20040234]
4. Telles-Correia D, Saraiva S, Gonçalves J. Mental Disorder-The Need for an Accurate Definition. Front Psychiatry 2018 Mar 12;9:64 [FREE Full text] [doi: 10.3389/fpsyt.2018.00064] [Medline: 29593578]
5. Payton AR. Mental health, mental illness, and psychological distress: same continuum or distinct phenomena? J Health Soc Behav 2009 Jun 01;50(2):213-227. [doi: 10.1177/002214650905000207] [Medline: 19537461]
6. Drapeau A, Marchand A, Beaulieu-Prévost D. Epidemiology of psychological distress. In: Mental illnesses-understanding, prediction and control. London, England: InTechOpen Limited; 2012:105-134.

7. Waters L, Algoe SB, Dutton J, Emmons R, Fredrickson BL, Heaphy E, et al. Positive psychology in a pandemic: buffering, bolstering, and building mental health. The Journal of Positive Psychology 2021 Feb 09:1-21. [doi: 10.1080/17439760.2021.1871945]
8. Campion J, Javed A, Sartorius N, Marmot M. Addressing the public mental health challenge of COVID-19. The Lancet Psychiatry 2020 Aug;7(8):657-659. [doi: 10.1016/s2215-0366(20)30240-6]
9. Fava GA, Ruini C. Development and characteristics of a well-being enhancing psychotherapeutic strategy: well-being therapy. Journal of Behavior Therapy and Experimental Psychiatry 2003 Mar;34(1):45-63. [doi: 10.1016/s0005-7916(03)00019-3]
10. Leamy M, Bird V, Le Boutillier C, Williams J, Slade M. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. Br J Psychiatry 2011 Dec 02;199(6):445-452. [doi: 10.1192/bjp.bp.110.083733] [Medline: 22130746]
11. Huppert FA. The state of wellbeing science: Concepts, measures, interventions, and policies. In: Huppert FA, Cooper CL, editors. Wellbeing: A complete reference guide. Hoboken, NJ: John Wiley & Sons, Ltd; 2014.
12. Disabato D, Goodman F, Kashdan TB. A hierarchical framework for the measurement of well-being. PsyArXiv. 2019 Dec 31. URL: https://psyarxiv.com/5rhqj/ [accessed 2021-08-24]
13. Diener E. The Science of Well-Being: The Collected Works of Ed Diener. Switzerland: Springer Nature; 2009.
14. Ryff CD. Psychological well-being revisited: advances in the science and practice of eudaimonia. Psychother Psychosom 2014;83(1):10-28 [FREE Full text] [doi: 10.1159/000353263] [Medline: 24281296]
15. Keyes CLM. Social Well-Being. Social Psychology Quarterly 1998 Jun;61(2):121. [doi: 10.2307/2787065]
16. Gable SL, Haidt J. What (and Why) is Positive Psychology? Review of General Psychology 2005 Jun 01;9(2):103-110. [doi: 10.1037/1089-2680.9.2.103]
17. Cross MP, Hofschneider L, Grimm M, Pressman SD. Subjective well-being and physical health. In: Diener E, Oishi S, Tay L, editors. Handbook of Well-Being. Salt Lake City, UT: DEF Publishers; 2018.
18. Slade M. Mental illness and well-being: the central importance of positive psychology and recovery approaches. BMC Health Serv Res 2010 Jan 26;10(1):26 [FREE Full text] [doi: 10.1186/1472-6963-10-26] [Medline: 20102609]
19. Steptoe A, Deaton A, Stone AA. Subjective wellbeing, health, and ageing. The Lancet 2015 Feb;385(9968):640-648. [doi: 10.1016/s0140-6736(13)61489-0]
20. DuBois CM, Lopez OV, Beale EE, Healy BC, Boehm JK, Huffman JC. Relationships between positive psychological constructs and health outcomes in patients with cardiovascular disease: A systematic review. Int J Cardiol 2015 Sep 15;195:265-280 [FREE Full text] [doi: 10.1016/j.ijcard.2015.05.121] [Medline: 26048390]
21. Diener E, Pressman SD, Hunter J, Delgadillo-Chase D. If, Why, and When Subjective Well-Being Influences Health, and Future Needed Research. Appl Psychol Health Well Being 2017 Jul 14;9(2):133-167. [doi: 10.1111/aphw.12090] [Medline: 28707767]
22. Pressman SD, Jenkins BN, Moskowitz JT. Positive Affect and Health: What Do We Know and Where Next Should We Go? Annu Rev Psychol 2019 Jan 04;70(1):627-650. [doi: 10.1146/annurev-psych-010418-102955] [Medline: 30260746]
23. Dubois CM, Beach SR, Kashdan TB, Nyer MB, Park ER, Celano CM, et al. Positive psychological attributes and cardiac outcomes: associations, mechanisms, and interventions. Psychosomatics 2012 Jul;53(4):303-318. [doi: 10.1016/j.psym.2012.04.004] [Medline: 22748749]
24. Keyes CLM. Mental Illness and/or Mental Health? Investigating Axioms of the Complete State Model of Health. Journal of Consulting and Clinical Psychology 2005 Jun;73(3):539-548. [doi: 10.1037/0022-006x.73.3.539]
25. van Agteren J, Iasiello M. Advancing our understanding of mental wellbeing and mental health: The call to embrace complexity over simplification. Australian Psychologist 2021 Mar 11;55(4):307-316. [doi: 10.1111/ap.12440]
26. Keyes CLM. Promoting and protecting mental health as flourishing: A complementary strategy for improving national mental health. American Psychologist 2007;62(2):95-108. [doi: 10.1037/0003-066x.62.2.95]
27. Iasiello M, van Agteren J, Muir-Cochrane E. Mental Health and/or Mental Illness: A Scoping Review of the Evidence and Implications of the Dual-Continua Model of Mental Health. Evidence Base 2020;2020(1):1-45. [doi: 10.21307/eb-2020-001]
28. Keyes CLM, Dhingra SS, Simoes EJ. Change in Level of Positive Mental Health as a Predictor of Future Risk of Mental Illness. Am J Public Health 2010 Dec;100(12):2366-2371. [doi: 10.2105/ajph.2010.192245]
29. Wood AM, Joseph S. The absence of positive psychological (eudemonic) well-being as a risk factor for depression: a ten year cohort study. J Affect Disord 2010 May;122(3):213-217. [doi: 10.1016/j.jad.2009.06.032] [Medline: 19706357]
30. Keyes CLM, Yao J, Hybels CF, Milstein G, Proeschold-Bell RJ. Are changes in positive mental health associated with increased likelihood of depression over a two year period? A test of the mental health promotion and protection hypotheses. J Affect Disord 2020 Jun 01;270:136-142. [doi: 10.1016/j.jad.2020.03.056] [Medline: 32339105]
31. Iasiello M, van Agteren J, Keyes CL, Cochrane EM. Positive mental health as a predictor of recovery from mental illness. J Affect Disord 2019 May 15;251:227-230 [FREE Full text] [doi: 10.1016/j.jad.2019.03.065] [Medline: 30927584]
32. Schotanus-Dijkstra M, Keyes CL, de Graaf R, Ten Have M. Recovery from mood and anxiety disorders: The influence of positive mental health. J Affect Disord 2019 Jun 01;252:107-113. [doi: 10.1016/j.jad.2019.04.051] [Medline: 30981053]

33. Xiong J, Lipsitz O, Nasri F, Lui LM, Gill H, Phan L, et al. Impact of COVID-19 pandemic on mental health in the general population: A systematic review. J Affect Disord 2020 Dec 01;277:55-64 [FREE Full text] [doi: 10.1016/j.jad.2020.08.001] [Medline: 32799105]
34. Nearchou F, Flinn C, Niland R, Subramaniam SS, Hennessy E. Exploring the Impact of COVID-19 on Mental Health Outcomes in Children and Adolescents: A Systematic Review. Int J Environ Res Public Health 2020 Nov 16;17(22):8479 [FREE Full text] [doi: 10.3390/ijerph17228479] [Medline: 33207689]
35. Robinson E, Sutin AR, Daly M, Jones A. A systematic review and meta-analysis of longitudinal cohort studies comparing mental health before versus during the COVID-19 pandemic. medRxiv. 2021 Mar 08. URL: https://www.medrxiv.org/content/10.1101/2021.03.04.21252921v1 [accessed 2021-08-24]
36. Kola L, Kohrt BA, Hanlon C, Naslund JA, Sikander S, Balaji M, et al. COVID-19 mental health impact and responses in low-income and middle-income countries: reimagining global mental health. The Lancet Psychiatry 2021 Jun;8(6):535-550. [doi: 10.1016/s2215-0366(21)00025-0]
37. Chiesa V, Antony G, Wismar M, Rechel B. COVID-19 pandemic: health impact of staying at home, social distancing and 'lockdown' measures-a systematic review of systematic reviews. J Public Health (Oxf) 2021 Apr 13:2021 [FREE Full text] [doi: 10.1093/pubmed/fdab102] [Medline: 33855434]
38. Moreno C, Wykes T, Galderisi S, Nordentoft M, Crossley N, Jones N, et al. How mental health care should change as a consequence of the COVID-19 pandemic. The Lancet Psychiatry 2020 Sep;7(9):813-824. [doi: 10.1016/s2215-0366(20)30307-2]
39. Singh S, Roy D, Sinha K, Parveen S, Sharma G, Joshi G. Impact of COVID-19 and lockdown on mental health of children and adolescents: A narrative review with recommendations. Psychiatry Res 2020 Nov;293:113429 [FREE Full text] [doi: 10.1016/j.psychres.2020.113429] [Medline: 32882598]
40. Ganesan B, Al-Jumaily A, Fong KNK, Prasad P, Meena SK, Tong RK. Impact of Coronavirus Disease 2019 (COVID-19) Outbreak Quarantine, Isolation, and Lockdown Policies on Mental Health and Suicide. Front Psychiatry 2021 Apr 16;12:565190 [FREE Full text] [doi: 10.3389/fpsyt.2021.565190] [Medline: 33935817]
41. Henssler J, Stock F, van Bohemen J, Walter H, Heinz A, Brandt L. Mental health effects of infection containment strategies: quarantine and isolation-a systematic review and meta-analysis. Eur Arch Psychiatry Clin Neurosci 2021 Mar 06;271(2):223-234 [FREE Full text] [doi: 10.1007/s00406-020-01196-x] [Medline: 33025099]
42. Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Greenberg N, et al. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. The Lancet 2020 Mar;395(10227):912-920. [doi: 10.1016/s0140-6736(20)30460-8]
43. Coronavirus (COVID-19) case numbers and statistics. Australia Government Department of Health. URL: https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/coronavirus-covid-19-current-situation-and-case-numbers [accessed 2021-08-24]
44. WHO Coronavirus (COVID-19) Dashboard. World Health Organization. URL: https://covid19.who.int/ [accessed 2021-08-24]
45. Fisher JR, Tran TD, Hammarberg K, Sastry J, Nguyen H, Rowe H, et al. Mental health of people in Australia in the first month of COVID-19 restrictions: a national survey. Med J Aust 2020 Nov 26;213(10):458-464 [FREE Full text] [doi: 10.5694/mja2.50831] [Medline: 33107063]
46. Newby JM, O'Moore K, Tang S, Christensen H, Faasse K. Acute mental health responses during the COVID-19 pandemic in Australia. PLoS One 2020 Jul 28;15(7):e0236562 [FREE Full text] [doi: 10.1371/journal.pone.0236562] [Medline: 32722711]
47. Rossell SL, Neill E, Phillipou A, Tan EJ, Toh WL, Van Rheenen TE, et al. An overview of current mental health in the general population of Australia during the COVID-19 pandemic: Results from the COLLATE project. Psychiatry Res 2021 Feb;296:113660 [FREE Full text] [doi: 10.1016/j.psychres.2020.113660] [Medline: 33373808]
48. van Agteren J, Bartholomaeus J, Fassnacht DB, Iasiello M, Ali K, Lo L, et al. Using Internet-Based Psychological Measurement to Capture the Deteriorating Community Mental Health Profile During COVID-19: Observational Study. JMIR Ment Health 2020 Jun 11;7(6):e20696 [FREE Full text] [doi: 10.2196/20696] [Medline: 32490845]
49. Batterham PJ, Calear AL, McCallum SM, Morse AR, Banfield M, Farrer LM, et al. Trajectories of depression and anxiety symptoms during the COVID-19 pandemic in a representative Australian adult cohort. Med J Aust 2021 Jun 26;214(10):462-468 [FREE Full text] [doi: 10.5694/mja2.51043] [Medline: 33899939]
50. Li SH, Beames JR, Newby JM, Maston K, Christensen H, Werner-Seidler A. The impact of COVID-19 on the lives and mental health of Australian adolescents. Eur Child Adolesc Psychiatry 2021 Apr 28:1 [FREE Full text] [doi: 10.1007/s00787-021-01790-x] [Medline: 33913036]
51. Van Agteren J, Woodyatt L, Iasiello M, Rayner J, Kyrios M. Make it Measurable: Assessing Psychological Distress, Wellbeing and Resilience at Scale in Higher Education. SUCCESS 2019 Dec 11;10(3):1-13. [doi: 10.5204/ssj.v10i3.1411]
52. Dodd RH, Dadaczynski K, Okan O, McCaffery KJ, Pickles K. Psychological Wellbeing and Academic Experience of University Students in Australia during COVID-19. Int J Environ Res Public Health 2021 Jan 20;18(3):866 [FREE Full text] [doi: 10.3390/ijerph18030866] [Medline: 33498376]
53. Greenspoon PJ, Saklofske DH. Toward an integration of subjective well-being and psychopathology. Social Indicators Research 2001;54(1):81-108. [doi: 10.1023/A:1007219227883]

54. Ruini C, Fava GA. Role of well-being therapy in achieving a balanced and individualized path to optimal functioning. Clin Psychol Psychother 2012 May 09;19(4):291-304. [doi: 10.1002/cpp.1796] [Medline: 22570318]
55. Jeste DV, Palmer BW, Rettew DC, Boardman S. Positive Psychiatry. J. Clin. Psychiatry 2015 May 12;76(06):675-683. [doi: 10.4088/jcp.14nr09599]
56. Carr A, Cullen K, Keeney C, Canning C, Mooney O, Chinseallaigh E, et al. Effectiveness of positive psychology interventions: a systematic review and meta-analysis. The Journal of Positive Psychology 2020 Sep 10:1-21. [doi: 10.1080/17439760.2020.1818807]
57. Weiss LA, Westerhof GJ, Bohlmeijer ET. Can We Increase Psychological Well-Being? The Effects of Interventions on Psychological Well-Being: A Meta-Analysis of Randomized Controlled Trials. PLoS One 2016 Jun 21;11(6):e0158092 [FREE Full text] [doi: 10.1371/journal.pone.0158092] [Medline: 27328124]
58. van Agteren J, Iasiello M, Lo L, Bartholomaeus J, Kopsaftis Z, Carey M, et al. A systematic review and meta-analysis of psychological interventions to improve mental wellbeing. Nat Hum Behav 2021 May 19;5(5):631-652. [doi: 10.1038/s41562-021-01093-w] [Medline: 33875837]
59. Seligman M, Csikszentmihalyi M. Positive Psychology: An Introduction. In: Csikszentmihalyi M, editor. Flow and the Foundations of Positive Psychology: The Collected Works of Mihaly Csikszentmihalyi. Dordrecht, Netherlands: Springer Netherlands; 2014:279-298.
60. Wind TR, Rijkeboer M, Andersson G, Riper H. The COVID-19 pandemic: The 'black swan' for mental health care and a turning point for e-health. Internet Interv 2020 Apr;20:100317 [FREE Full text] [doi: 10.1016/j.invent.2020.100317] [Medline: 32289019]
61. Torous J, Jän Myrick K, Rauseo-Ricupero N, Firth J. Digital Mental Health and COVID-19: Using Technology Today to Accelerate the Curve on Access and Quality Tomorrow. JMIR Ment Health 2020 Mar 26;7(3):e18848 [FREE Full text] [doi: 10.2196/18848] [Medline: 32213476]
62. Amsalem D, Dixon L, Neria Y. The Coronavirus Disease 2019 (COVID-19) Outbreak and Mental Health: Current Risks and Recommended Actions. JAMA Psychiatry 2021 Jan 01;78(1):9-10. [doi: 10.1001/jamapsychiatry.2020.1730] [Medline: 32579160]
63. Rauschenberg C, Schick A, Hirjak D, Seidler A, Paetzold I, Apfelbacher C, et al. Evidence Synthesis of Digital Interventions to Mitigate the Negative Impact of the COVID-19 Pandemic on Public Mental Health: Rapid Meta-review. J Med Internet Res 2021 Mar 10;23(3):e23365 [FREE Full text] [doi: 10.2196/23365] [Medline: 33606657]
64. Chakhssi F, Kraiss JT, Sommers-Spijkerman M, Bohlmeijer ET. The effect of positive psychology interventions on well-being and distress in clinical samples with psychiatric or somatic disorders: a systematic review and meta-analysis. BMC Psychiatry 2018 Jun 27;18(1):211 [FREE Full text] [doi: 10.1186/s12888-018-1739-2] [Medline: 29945603]
65. Demyttenaere K. What is treatment resistance in psychiatry? A "difficult to treat" concept. World Psychiatry 2019 Oct 09;18(3):354-355 [FREE Full text] [doi: 10.1002/wps.20677] [Medline: 31496099]
66. Schnyder N, Panczak R, Groth N, Schultze-Lutter F. Association between mental health-related stigma and active help-seeking: systematic review and meta-analysis. Br J Psychiatry 2017 Apr 02;210(4):261-268. [doi: 10.1192/bjp.bp.116.189464] [Medline: 28153928]
67. Gloster AT, Rinner MT, Ioannou M, Villanueva J, Block VJ, Ferrari G, et al. Treating treatment non-responders: A meta-analysis of randomized controlled psychotherapy trials. Clin Psychol Rev 2020 Feb;75:101810. [doi: 10.1016/j.cpr.2019.101810] [Medline: 31884147]
68. Trompetter H, Lamers S, Westerhof G, Fledderus M, Bohlmeijer E. Both positive mental health and psychopathology should be monitored in psychotherapy: Confirmation for the dual-factor model in acceptance and commitment therapy. Behav Res Ther 2017 Apr;91:58-63. [doi: 10.1016/j.brat.2017.01.008] [Medline: 28160719]
69. Fu R, Holmer HK. Change Score or Followup Score?: An Empirical Evaluation of the Impact of Choice of Mean Difference Estimates. In: AHRQ Methods for Effective Health Care: Report No.: 15-EHC016-EF. Rockville, MD: Agency for Healthcare Research and Quality; 2015.
70. Ellis PD. The essential guide to effect sizes: statistical power, meta-analysis, and the interpretation of research results. Cambridge, United Kingdom: Cambridge University Press; 2010:1139488155.
71. Osman A, Wong JL, Bagge CL, Freedenthal S, Gutierrez PM, Lozano G. The Depression Anxiety Stress Scales-21 (DASS-21): further examination of dimensions, scale reliability, and correlates. J Clin Psychol 2012 Dec 28;68(12):1322-1338. [doi: 10.1002/jclp.21908] [Medline: 22930477]
72. Bauer S, Lambert MJ, Nielsen SL. Clinical significance methods: a comparison of statistical techniques. J Pers Assess 2004 Feb;82(1):60-70. [doi: 10.1207/s15327752jpa8201_11] [Medline: 14979835]
73. Hofmann SG, Hayes SC. The Future of Intervention Science: Process-Based Therapy. Clin Psychol Sci 2019 Jan 29;7(1):37-50 [FREE Full text] [doi: 10.1177/2167702618772296] [Medline: 30713811]
74. Wise EA. Methods for analyzing psychotherapy outcomes: a review of clinical significance, reliable change, and recommendations for future directions. J Pers Assess 2004 Feb;82(1):50-59. [doi: 10.1207/s15327752jpa8201_10] [Medline: 14979834]
75. Jacobson N, Truax P. Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. J Consult Clin Psychol 1991 Feb;59(1):12-19. [doi: 10.1037//0022-006x.59.1.12] [Medline: 2002127]

76. Clifton L, Clifton DA. The correlation between baseline score and post-intervention score, and its implications for statistical analysis. Trials 2019 Jan 11;20(1):43 [FREE Full text] [doi: 10.1186/s13063-018-3108-3] [Medline: 30635021]
77. Zimmerman M, Martinez JH, Young D, Chelminski I, Dalrymple K. Severity classification on the Hamilton Depression Rating Scale. J Affect Disord 2013 Sep 05;150(2):384-388. [doi: 10.1016/j.jad.2013.04.028] [Medline: 23759278]
78. Matza LS, Morlock R, Sexton C, Malley K, Feltner D. Identifying HAM-A cutoffs for mild, moderate, and severe generalized anxiety disorder. Int J Methods Psychiatr Res 2010 Dec 18;19(4):223-232 [FREE Full text] [doi: 10.1002/mpr.323] [Medline: 20718076]
79. Zoom Video Communications, Inc. URL: https://zoom.us/ [accessed 2021-08-24]
80. Eldridge LKB, Markham CM, Ruiter RAC, Fernandez ME, Kok G, Parcel GS. Planning Health Promotion Programs: An Intervention Mapping Approach, 4th Edition. San Francisco, CA: Jossey-Bass; 2016.
81. Lamers SM, Westerhof GJ, Bohlmeijer ET, ten Klooster PM, Keyes CL. Evaluating the psychometric properties of the Mental Health Continuum-Short Form (MHC-SF). J Clin Psychol 2011 Jan 22;67(1):99-110. [doi: 10.1002/jclp.20741] [Medline: 20973032]
82. Pavot W, Diener E. Review of the satisfaction with life scale. In: Diener E, editor. Assessing well-being. Dordrecht, Netherlands: Springer; 2009:101-117.
83. Smith BW, Dalen J, Wiggins K, Tooley E, Christopher P, Bernard J. The brief resilience scale: assessing the ability to bounce back. Int J Behav Med 2008 Sep;15(3):194-200. [doi: 10.1080/10705500802222972] [Medline: 18696313]
84. Richardson JT. Eta squared and partial eta squared as measures of effect size in educational research. Educational Research Review 2011 Jan;6(2):135-147. [doi: 10.1016/j.edurev.2010.12.001]
85. Holmes EA, O'Connor RC, Perry VH, Tracey I, Wessely S, Arseneault L, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. The Lancet Psychiatry 2020 Jun;7(6):547-560. [doi: 10.1016/s2215-0366(20)30168-1]
86. Willems SH, Rao J, Bhambere S, Patel D, Biggins Y, Guite JW. Digital Solutions to Alleviate the Burden on Health Systems During a Public Health Care Crisis: COVID-19 as an Opportunity. JMIR Mhealth Uhealth 2021 Jun 11;9(6):e25021 [FREE Full text] [doi: 10.2196/25021] [Medline: 34033575]
87. van Agteren J, Iasiello M, Lo L. Improving the wellbeing and resilience of health services staff via psychological skills training. BMC Res Notes 2018 Dec 22;11(1):924 [FREE Full text] [doi: 10.1186/s13104-018-4034-x] [Medline: 30577884]
88. Bartholomaeus JD, Van Agteren JEM, Iasiello MP, Jarden A, Kelly D. Positive Aging: The Impact of a Community Wellbeing and Resilience Program. Clin Gerontol 2019 Jan 18;42(4):377-386. [doi: 10.1080/07317115.2018.1561582] [Medline: 30654716]
89. Martinez-Martin N, Dasgupta I, Carter A, Chandler JA, Kellmeyer P, Kreitmair K, et al. Ethics of Digital Mental Health During COVID-19: Crisis and Opportunities. JMIR Ment Health 2020 Dec 22;7(12):e23776 [FREE Full text] [doi: 10.2196/23776] [Medline: 33156811]
90. Steel Z, Marnane C, Iranpour C, Chey T, Jackson J, Patel V, et al. The global prevalence of common mental disorders: a systematic review and meta-analysis 1980-2013. Int J Epidemiol 2014 Apr;43(2):476-493 [FREE Full text] [doi: 10.1093/ije/dyu038] [Medline: 24648481]
91. Stallman HM. Psychological distress in university students: A comparison with general population data. Australian Psychologist 2010 Nov 06;45(4):249-257. [doi: 10.1080/00050067.2010.482109]
92. Farrer LM, Gulliver A, Bennett K, Fassnacht DB, Griffiths KM. Demographic and psychosocial predictors of major depression and generalised anxiety disorder in Australian university students. BMC Psychiatry 2016 Jul 15;16(1):241 [FREE Full text] [doi: 10.1186/s12888-016-0961-z] [Medline: 27422284]
93. Brown JSL. Student mental health: some answers and more questions. J Ment Health 2018 Jun;27(3):193-196. [doi: 10.1080/09638237.2018.1470319] [Medline: 29768071]
94. van Erp Taalman Kip RM, Hutschemaekers GJM. Health, well-being, and psychopathology in a clinical population: Structure and discriminant validity of Mental Health Continuum Short Form (MHC-SF). J Clin Psychol 2018 Oct 30;74(10):1719-1729. [doi: 10.1002/jclp.22621] [Medline: 29603212]
95. Linton M, Dieppe P, Medina-Lara A. Review of 99 self-report measures for assessing well-being in adults: exploring dimensions of well-being and developments over time. BMJ Open 2016 Jul 07;6(7):e010641 [FREE Full text] [doi: 10.1136/bmjopen-2015-010641] [Medline: 27388349]
96. Richter D, Wall A, Bruen A, Whittington R. Is the global prevalence rate of adult mental illness increasing? Systematic review and meta-analysis. Acta Psychiatr Scand 2019 Nov 03;140(5):393-407. [doi: 10.1111/acps.13083] [Medline: 31393996]
97. Kilbourne AM, Beck K, Spaeth-Rublee B, Ramanuj P, O'Brien RW, Tomoyasu N, et al. Measuring and improving the quality of mental health care: a global perspective. World Psychiatry 2018 Feb 19;17(1):30-38 [FREE Full text] [doi: 10.1002/wps.20482] [Medline: 29352529]
98. Patel V, Saxena S, Lund C, Thornicroft G, Baingana F, Bolton P, et al. The Lancet Commission on global mental health and sustainable development. The Lancet 2018 Oct;392(10157):1553-1598. [doi: 10.1016/s0140-6736(18)31612-x]
99. Shafran R, Myles-Hooton P, Bennett S, Öst LG. The concept and definition of low intensity cognitive behaviour therapy. Behav Res Ther 2021 Mar;138:103803. [doi: 10.1016/j.brat.2021.103803] [Medline: 33540242]

100. Perkins D. Stepped Care, System Architecture and Mental Health Services in Australia. Int J Integr Care 2016 Sep 14;16(3):16 [FREE Full text] [doi: 10.5334/ijic.2505] [Medline: 28435424]
101. Cross S, Hickie I. Transdiagnostic stepped care in mental health. Public Health Res Pract 2017 Apr 27;27(2):e2721712 [FREE Full text] [doi: 10.17061/phrp2721712] [Medline: 28474049]
102. Pilgrim D. 'Recovery' and current mental health policy. Chronic Illn 2008 Dec 01;4(4):295-304. [doi: 10.1177/1742395308097863] [Medline: 19091938]

Abbreviations

ACT: Acceptance and Commitment Therapy
DASS: Depression Anxiety and Stress Scale
MANOVA: multivariate analysis of variance
MHC-SF: Mental Health Continuum Short-Form
RCI: reliable change index
SAHMRI: South Australian Health and Medical Research Institute
SWLS: Satisfaction With Life Scale

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Original Paper

Shift in Social Media App Usage During COVID-19 Lockdown and Clinical Anxiety Symptoms: Machine Learning–Based Ecological Momentary Assessment Study

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Abstract

Background: Anxiety symptoms during public health crises are associated with adverse psychiatric outcomes and impaired health decision-making. The interaction between real-time social media use patterns and clinical anxiety during infectious disease outbreaks is underexplored.

Objective: We aimed to evaluate the usage pattern of 2 types of social media apps (communication and social networking) among patients in outpatient psychiatric treatment during the COVID-19 surge and lockdown in Madrid, Spain and their short-term anxiety symptoms (7-item General Anxiety Disorder scale) at clinical follow-up.

Methods: The individual-level shifts in median social media usage behavior from February 1 through May 3, 2020 were summarized using repeated measures analysis of variance that accounted for the fixed effects of the lockdown (prelockdown versus postlockdown), group (clinical anxiety group versus nonclinical anxiety group), the interaction of lockdown and group, and random effects of users. A machine learning–based approach that combined a hidden Markov model and logistic regression was applied to predict clinical anxiety (n=44) and nonclinical anxiety (n=51), based on longitudinal time-series data that comprised communication and social networking app usage (in seconds) as well as anxiety-associated clinical survey variables, including the presence of an essential worker in the household, worries about life instability, changes in social interaction frequency during the lockdown, cohabitation status, and health status.

Results: Individual-level analysis of daily social media usage showed that the increase in communication app usage from prelockdown to lockdown period was significantly smaller in the clinical anxiety group than that in the nonclinical anxiety group ($F_{1,72}$=3.84, *P*=.05). The machine learning model achieved a mean accuracy of 62.30% (SD 16%) and area under the receiver operating curve 0.70 (SD 0.19) in 10-fold cross-validation in identifying the clinical anxiety group.

Conclusions: Patients who reported severe anxiety symptoms were less active in communication apps after the mandated lockdown and more engaged in social networking apps in the overall period, which suggested that there was a different pattern of digital social behavior for adapting to the crisis. Predictive modeling using digital biomarkers—passive-sensing of shifts in category-based social media app usage during the lockdown—can identify individuals at risk for psychiatric sequelae.

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KEYWORDS

anxiety disorder; COVID-19; social media; public health; digital phenotype; ecological momentary assessment; smartphone; machine learning; hidden Markov model

Introduction

During the early peaks of casualties from the first wave of the COVID-19 pandemic, government lockdown measures in urban centers drastically diminished in-person communication and forced individuals to turn to the digital world to connect with others [1]. Physical isolation has been linked with suicidal ideation, depression, and posttraumatic stress disorder during infectious disease outbreaks [2-5]; it can increase the intensity and perception of threat, especially with the inherent uncertainty of a high-mortality novel virus outbreak [6,7]. Anxiety further causes maladaptive coping behavior, such as substance use, which can, in turn, lead to adverse mental health outcomes in a negative feedback loop [8]. Anxiety can also compromise effective social decision-making, which was evident in panic buying, hoarding, and excessive internet searching for information during the COVID-19 pandemic [9,10].

In contrast, positive public health outcomes are driven by individuals' sound health decisions made based on accurate perceptions of the costs and benefits to self and society [11]. Therefore, remotely identifying the severity of short-term anxiety symptoms in the population during lockdown measures is an important public health agenda. It may lead to early detection of those who are at risk for impaired decision-making, maladaptive coping, and psychiatric sequelae [8].

In recent years, passive smartphone sensor data have been utilized in empirical studies to identify various psychiatric presentations and mental health-related behaviors, including social anxiety severity [12,13]. Current literature on social media and its impact on mental health outcomes provides conflicting perspectives about the role of social media use in the development of anxiety during crises [14,15]. For example, excessive time spent searching for news on social media has been linked with higher anxiety during COVID-19 and Ebola outbreaks [16-18]. In contrast, ready exposure to public health information through social media during the Middle East respiratory syndrome–related coronavirus outbreak was positively related to the formation of appropriate risk perceptions in the population [19]. A previous report [20] from our group suggested that increased usage of social media predicts increased physical activity, possibly promoting healthy behavior during COVID-19–related lockdown. In other words, identifying fine-grained frameworks to describe user behavior on social media platforms, as opposed to simply verifying social media usage, appears to be relevant to gathering important public health information in real time.

In this study, we focused on analyzing daily time spent on apps in 2 social media categories (communication and social networking) in a sample of psychiatric outpatients in Madrid, Spain, before and during the mandatory COVID-19 lockdown. Communication apps allow direct messaging activity, and social networking apps enable interactions on social networking sites in heterogeneous forms. We hypothesized that differential forms of social media app activity can represent the distinct user behaviors that interplay with the manifestation of anxiety. Specifically, we aimed to employ a machine learning model and individual app usage patterns during this period to predict who would report clinical anxiety symptoms at follow-up.

Methods

Study Participants

Data were drawn from 2 ongoing studies [21,22] of psychiatric outpatients (n=142) in Madrid, Spain, that involve remote smartphone monitoring. Both studies received approval from the Institutional Review Board at the Psychiatry Department of *Fundación Jimenez Diaz* Hospital, and all participants provided written informed consent. Participants were required to be aged 18 years or older, fluent in Spanish, and possess a smartphone with internet access.

Data

Sociodemographic and clinical information were collected from all participants at baseline before the onset of the pandemic via an electronic health tool (MEmind [21,23]). Sociodemographic data included age, gender, household composition, marital status, and employment status. Clinical data entailed International Classification of Diseases, tenth revision, psychiatric diagnoses grouped into the following categories: (1) anxiety, stress, and trauma-related disorders; (2) unipolar or bipolar mood disorders; (3) personality disorders; (4) substance use disorders; (5) psychotic disorders, and (6) other disorders.

From February 1 through May 3, 2020, passive smartphone usage data were collected using eB2 Mindcare [24-26], a clinically validated eHealth platform. On March 14, a country-wide state of emergency was declared due to rising mortality rates from the coronavirus pandemic, and the government mandated a lockdown of all individuals who were not essential workers (ie, they were restricted to their residences, except when purchasing food and medicines or attending emergencies). On May 4, Madrid entered the first step in a de-escalation of the lockdown, which allowed the reopening of small businesses and walking outside within set time slots [27]. Daily time (in seconds) automatically logged on communication apps and social networking apps were extracted and analyzed in the prelockdown (ie, February 1 through March 13) and the lockdown periods (ie, March 14 through May 3). Social media app categories—communication and social networking—were based on the labels designated in the Google App store. Communication apps included messaging, chat/IM, dialer, and browser apps such as WhatsApp, Telegram, Facebook Messenger, and Gmail; social networking apps were primarily those for sites such as Instagram, Twitter, and TikTok [28].

A clinical psychologist collected short-term mental health outcomes, including self-reported intensity of psychosocial stressors during the lockdown and Generalized Anxiety Disorder 7-item scale (GAD-7), by phone follow-up between May 12 and June 3 after the initial lockdown measures had been lifted. Clinical anxiety was defined as a GAD-7 score of 10 or greater, given its diagnostic value in screening for severe GAD, panic disorder, and social phobia [29,30]. COVID-19 exposures, risk perception, and social behaviors during the lockdown period were also assessed during the phone call.

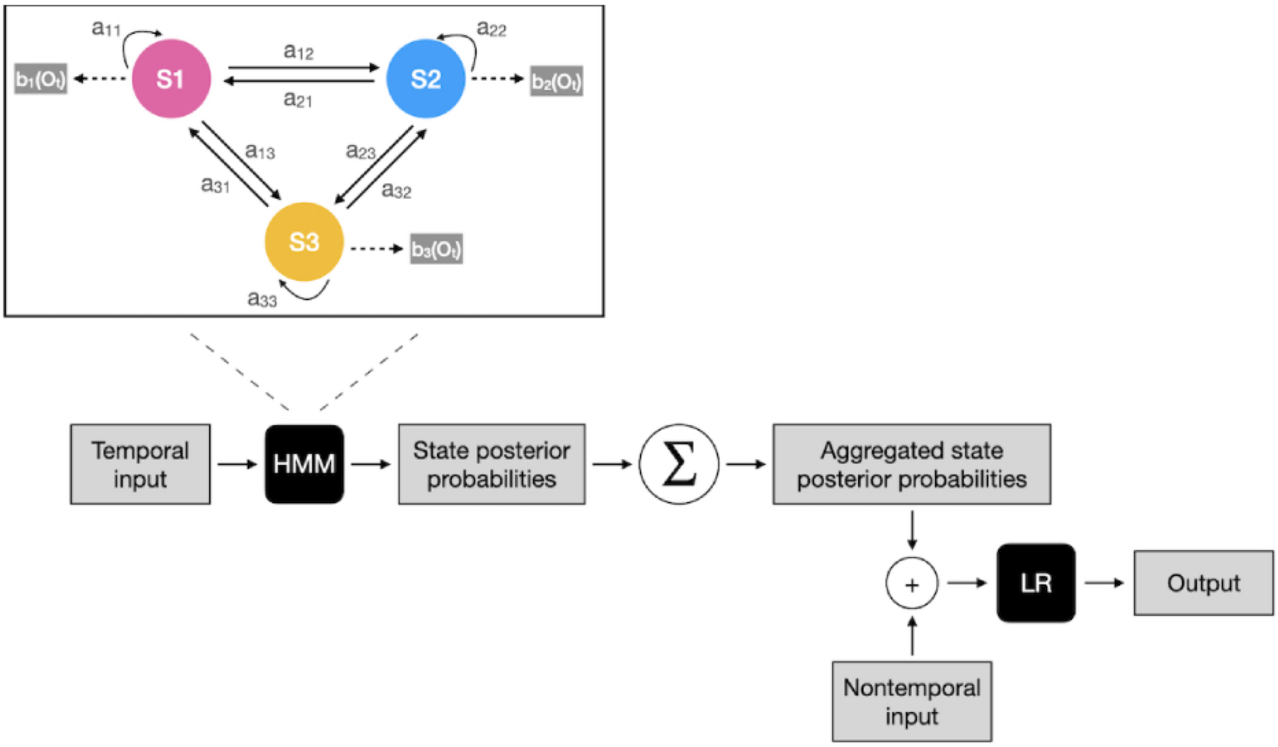
Statistical Analysis

Group-level differences were evaluated using the 2-sided *z* score, for sample proportions (ICD-10 diagnosis, gender, cohabitation status, coronavirus exposure risk items); the chi-square test, for categorical clinical variables (family, employment, physical health status, worries about life instability, modes of contact and social interaction frequency during the lockdown); or the 2-sided *t* test, for continuous variables (age, GAD-7), with a type I error of 5%. After logarithmically transforming usage data (seconds) spent on communication and social networking apps to normal distributions, individual-level differences in median social media usage during the prelockdown and lockdown periods were summarized using repeated measures analysis of variance that accounted for the fixed effects of the lockdown (prelockdown versus postlockdown), group (clinical anxiety group versus nonclinical anxiety group), the interaction of lockdown and group, and random effects of users. The median was chosen as the estimate of central tendency (instead of the mean) because the distribution of app usage was such that the mean was sensitive to extremely low values and significantly correlated with the number of logged days, which varied among users. To ensure stability when using the point estimate representing the time series variables in prelockdown vs. lockdown, analyses were restricted to the patients whose total logged days in both communication and social networking apps was more than half the total days in the lockdown (≥26 out of 51 days) and prelockdown period (≥22 out of 42 days), and whose median usage was within 2.5 SD of all available users' data in each period. This filtering resulted in 74 communication app users and 42 social networking app users available for analysis. Missing users were separately analyzed. To investigate the dose-related association of social media app usage with the intensity of anxiety symptoms later reported, Pearson correlations, of GAD-7 scores with median app usage time in the prelockdown and lockdown period, were calculated; we controlled for age given its significant correlation with social media app usage. Differences in the dependent correlations between prelockdown and lockdown periods were analyzed using the Steiger *Z* test [31].

Machine Learning Models

We designed a 2-step approach that combined a probabilistic generative model, namely a hidden Markov model (HMM) [32] for temporal data processing and aggregation, with logistic regression to predict the binary outcome (clinical anxiety versus nonclinical anxiety) by dichotomized GAD-7. Nonclinical anxiety outcome (n=51) was encoded as the negative label and clinical anxiety outcome (n=44) was encoded as the positive label. The class imbalance problem was insignificant. Continuous longitudinal daily communication and social networking app usage in seconds were chosen as independent variables, with anxiety-associated clinical variables as additional predictors (Figure 1).

Figure 1. The proposed anxiety prediction pipeline. LR: logistic regression; HMM; hidden Markov model; S1, S2, S3; the 3 states of the hidden Markov model.



HMMs are commonly used for time-series analysis. HMMs model generative sequences, which are characterized by a set of observable sequences. A first-order Markov chain process generates the states of the HMM. The following components specify an HMM: $S=s_1s_2...s_N$, a set of N states; $A=a_{11}...a_{NN}$, a transition probability matrix; $O=o_1o_2...o_T$, a sequence of T observations; $B=b_1(o_t)$, emission probabilities, expressing the probability of an observation o_t being generated from state i; and $\pi=\pi_1... \pi_N$, an initial probability distribution over states.

The state space of the applied HMM is discrete, while the observations can be discrete or continuous. In this study, communication and social networking app usage are treated as continuous variables from a Gaussian distribution. The parameters of an HMM can be trained with the Baum-Welch algorithm, a variation of the expectation-maximization algorithm. The model can deal with missing data using marginalization without requiring imputation before training. To select the optimal number of hidden states, we computed the Akaike information criterion and the Bayesian information criterion [33] after training HMMs with 2-19 numbers of states.

Once the optimal HMM was selected for each sequence, we computed the state posterior probabilities $P(s_i = k \mid x)$ (the probability of being in state k at position i of the sequence x) for each time point and aggregated them by summing over time for each patient. This feature vector of length N was then concatenated with nontemporal clinical features of length N_{clinical} to form the feature vector of length $N + N_{\text{clinical}}$. Hence the data set of size for the logistic regression was $N_{\text{patients}} \times (N + N_{\text{clinical}})$. Age, gender, self-reported worries about life instability during the lockdown, health status, presence of an essential worker in the household, changes in the frequency of social interactions during quarantine, and current employment status were chosen as nontemporal features for the model training. These features were selected because of the differences between the clinical anxiety and nonclinical anxiety groups and correlations with GAD-7 (Figure S3 in Multimedia Appendix 1). Given the clinical association between social isolation and anxiety disorder in the literature [34] and the impact of the lockdown differently impacting the social media app usage for those living alone in our sample (Table S1 in Multimedia Appendix 1), we additionally included cohabitation status.

The evaluation was performed using k-fold cross-validation [34,35], due to the limited data sample. 10 train-test splits were created from the dataset. Similarly, 10 logistic regression models were created and trained for evaluation. Since we had 95 patients, this means that in the first 5 splits, we trained the model on data from 85 patients and tested the model on data from 10 patients, while in the last 5 splits trained the model on 86 patients and tested the model on 9 patients. The results are summarized with a mean and standard deviation of the model accuracy, and area under the receiver operating curve (AUROC) scores.

Finally, we performed feature importance analysis by computing Shapley additive explanations (SHAP) values [36], which provide an overview of important features in the machine learning models by designating the weight of predictability of each feature positively or negatively to the target variable. We averaged the SHAP values over the 10-fold cross-validation for every feature for each patient.

Results

Study Participants

Of 142 participants (Table 1) 99 (70%) were female, and the mean age was 45 years (SD 14). The most commonly represented psychiatric diagnostic category was anxiety, trauma, or stress-related disorder, followed by unipolar or bipolar mood disorder. At the postlockdown phone follow-up, the mean anxiety symptom score (GAD-7) was 9.6 (range 0-21, SD 5.5). Of the 142 patients, 1 (1%) tested positive for SARS-CoV-2 (with a polymerase chain reaction test), 16 (11%) were living with people with COVID-19 infections, 6 (4%) were living with the older adults, 43 (30%) lived with essential workers, and 43 (30%) personally knew individuals who died of COVID-19. On a group level, the clinical anxiety group had an 18% higher likelihood of having an essential worker in the household (z=2.3, P=.02; 95% CI 0.03-0.34) and reported higher intensity of worries about life instability ($\chi_4{}^2$=12, P=.01), more negative self-ratings of health status ($\chi_2{}^2$=6.4, P=.04), and lower frequency of social interactions ($\chi_2{}^2$=6.8, P=.03) than those reported by the nonclinical anxiety group.

Table 1. Demographic and clinical information.

Variable	All (n=142)	Clinical anxiety[a] (n=66)	Nonclinical anxiety[b] (n=76)	*z* score, *t* test statistic (*df*)[c], or chi-square (*df*)[d]	*P* value
Baseline sociodemographic and clinical information					
Age (years), mean (SD)	45 (14.2)	43 (13.6)	47 (14.6)	–1.8 (139)[c]	.07
Gender, n (%)				0.36	.72
Male	43 (30)	19 (29)	24 (32)		
Female	99 (70)	47 (71)	52 (68)		
Cohabitating, n (%)				0.83	.40
No	21 (15)	8 (12)	13 (17)		
Yes	121 (85)	58 (88)	63 (83)		
Family status, n (%)				3.5 (3)[d]	.32
Single	46 (32)	21 (32)	25 (33)		
Separated	26 (18)	11 (17)	15 (20)		
Widowed	6 (4)	5 (8)	1 (1)		
Married or cohabitating for >6 months	64 (45)	29 (44)	35 (46)		
Employment status, n (%)				7.5 (5)[d]	.18
Employed, student or homemaker	51 (36)	23 (35)	28 (37)		
Unemployed without subsidy	28 (20)	9 (14)	19 (25)		
Unemployed with subsidy	17 (12)	8 (12)	9 (12)		
Long-term disability	11 (8)	7 (11)	4 (5)		
Temporarily incapacitated	26 (18)	16 (25)	10 (13)		
Retired	8 (6)	2 (3)	6 (8)		
Anxiety, stress, or trauma disorder[e], n (%)	79 (58)	41 (63)	38 (54)	1.1	.26
Mood disorder[e], n (%)	50 (37)	28 (43)	22 (31)	1.5	.14
Personality disorder[e], n (%)	30 (22)	14 (22)	16 (23)	–0.14	.89
Substance use disorder[e], n (%)	8 (6)	5 (8)	3 (4)	0.86	.39
Psychotic disorder[e], n (%)	3 (2)	2 (3)	1 (1)	0.66	.51
Other psychiatric disorder[e], n (%)	21 (15)	10 (15)	11 (15)	–0.02	.99
Risk perception and social behaviors during the pandemic lockdown					
Worries about life instability during lockdown, n (%)				12 (4)[d]	.01
Not at all	21 (15)	8 (12)	13 (18)		
Slightly	32 (23)	9 (14)	23 (31)		
Moderately	37 (26)	19 (29)	18 (24)		
A lot	35 (25)	18 (27)	17 (23)		
Extremely	15 (11)	12 (18)	3 (4)		
Self-ratings of physical health, n (%)				6.4 (2)[d]	.04
Positive	66 (46)	23 (35)	43 (57)		
Regular	56 (40)	32 (49)	24 (32)		
Negative	19 (13)	10 (15)	9 (12)		
Modes of contact with outside, n (%)				3.2 (2)[d]	.21

Variable	All (n=142)	Clinical anxiety[a] (n=66)	Nonclinical anxiety[b] (n=76)	z score, t test statistic (df)[c], or chi-square (df)[d]	P value
Phone calls	66 (46)	34 (52)	32 (43)		
Video calls	45 (32)	16 (24)	29 (39)		
Messengers (WhatsApp, Telegram, etc)	29 (20)	15 (23)	14 (19)		
Changes in frequency of social interactions during lockdown, n (%)				6.8 (2)[d]	.03
Less frequent than prepandemic	63 (44)	36 (55)	63 (36)		
More or less the same	48 (34)	21 (32)	48 (36)		
More frequent than prepandemic	31 (22)	9 (14)	31 (29)		
Tested positive on SARS-CoV-2 PCR[f] test, n (%)	1(1)	0 (0)	1 (1)	–0.94	.34
Living with people with COVID-19, n (%)	16 (11)	9 (14)	7 (10)	0.75	.45
Living with older adult, n (%)	6 (4)	3 (5)	3 (4)	0.20	.84
Essential workers in household, n (%)	43 (30)	27 (41)	16 (23)	2.3	.02
Knew people who died of COVID-19, n (%)	43 (30)	25 (38)	18 (24)	1.7	.08
Generalized Anxiety Disorder-7 score postlockdown (mean, SD)	9.6 (5.5)	14.6 (3.1)	5.2 (2.8)	19 (133)[c]	<.001

[a] Generalized Anxiety Disorder-7 score ≥10.

[b] Generalized Anxiety Disorder-7 score <10.

[c] A 2-sided t test was used.

[d] A chi-square independence test was used.

[e] Psychiatric diagnosis categories are not mutually exclusive.

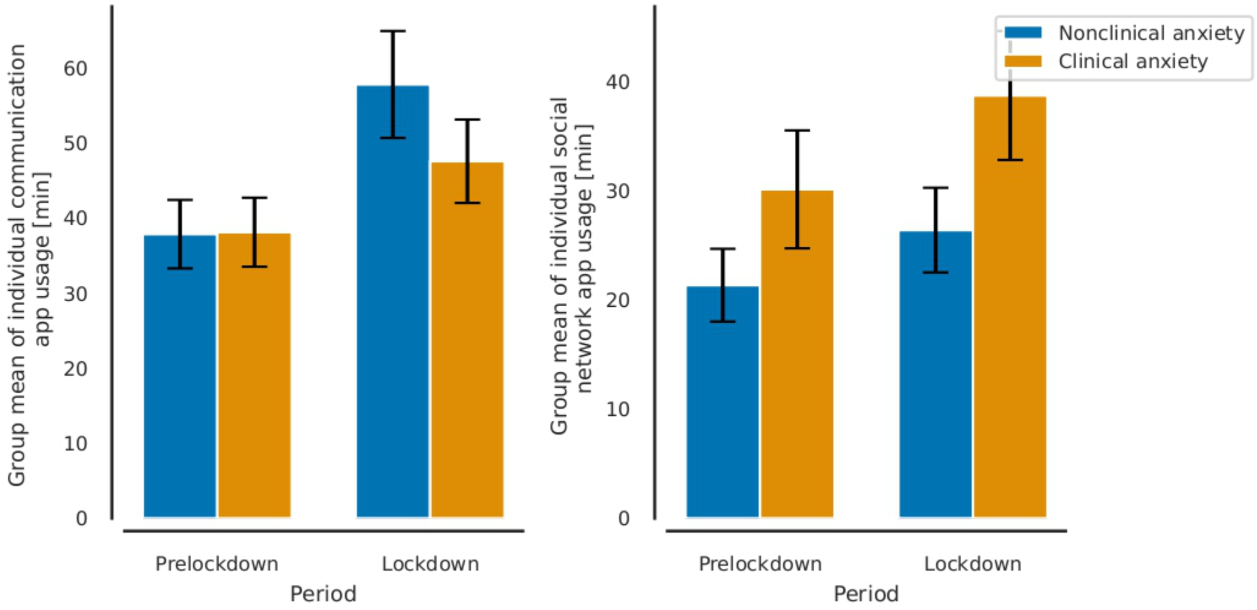
[f] PCR: polymerase chain reaction.

Active users (n=42; Table S1 in Multimedia Appendix 1) of social networking apps whose usage was consistent during the analysis period had 21% higher likelihood of carrying anxiety, stress, or trauma-related disorder diagnoses (z=2.2, P=.03; 95% CI 0.03-0.37); were approximately 8 years younger (t_{73}=–3.2, P=.002; 95% CI 3.0-14); had 14% higher likelihood of cohabitation (z=–2.2, P=.03; 95% CI 0.04-0.24); and had a higher likelihood of being employed, students, or homemakers (χ_2^2=13, P=.02), than missing or inconsistent users (n=100). However, there was no significant difference in GAD-7 (t_{88}=0.75, P=.46), which was our primary outcome for labeling the clinical anxiety group in the prediction model. Missing or inconsistent users (n=68; Table S1 in Multimedia Appendix 1) in the communication apps were not significantly different from the active users (n=74) in anxiety, stress, or trauma-related disorder diagnoses (P=.50), age (P=.41), cohabitation status (P=.36), employment status (P=.29), or GAD-7 (P=.34).

Statistical Analysis of Social Media Use Across Anxiety Groups and Periods

From prelockdown to lockdown period, the mean of individual median usage on communication app (in both anxiety groups) increased from 29 minutes (95% CI 25-35) to 41 minutes (95% CI 35-49; $F_{1,72}$=26; P<.001), and usage on social networking app increased from 19 minutes (95% CI 14-25) to 25 minutes (95% CI 20-32; $F_{1,40}$=13; P<.001) (Figure 2; Table S2 in Multimedia Appendix 1). There was a significant interaction of group and lockdown period, such that communication app usage was not significantly different between groups prelockdown but increased significantly more in the nonclinical anxiety group during the lockdown (from 29 minutes to 46 minutes, 95% CI 37-57) than that in the clinical anxiety group (from 30 minutes to 37 minutes; 95% CI 29-46; $F_{1,72}$=3.8; P=.05). There was no main effect of group on communication app usage in the entire period. There was a trend in the main effect of group on social networking app in the entire period such that the clinical anxiety group had higher median usage at 27 minutes (95% CI 22-33) than that of the nonclinical anxiety group at 17 minutes (95% CI 13-23), but it was not significant ($F_{1,40}$=3.4; P=.07).

Figure 2. The effect of lockdown on the increase in communication app usage was lower in the clinical anxiety group. Error bars indicate 95% standard error of the mean.



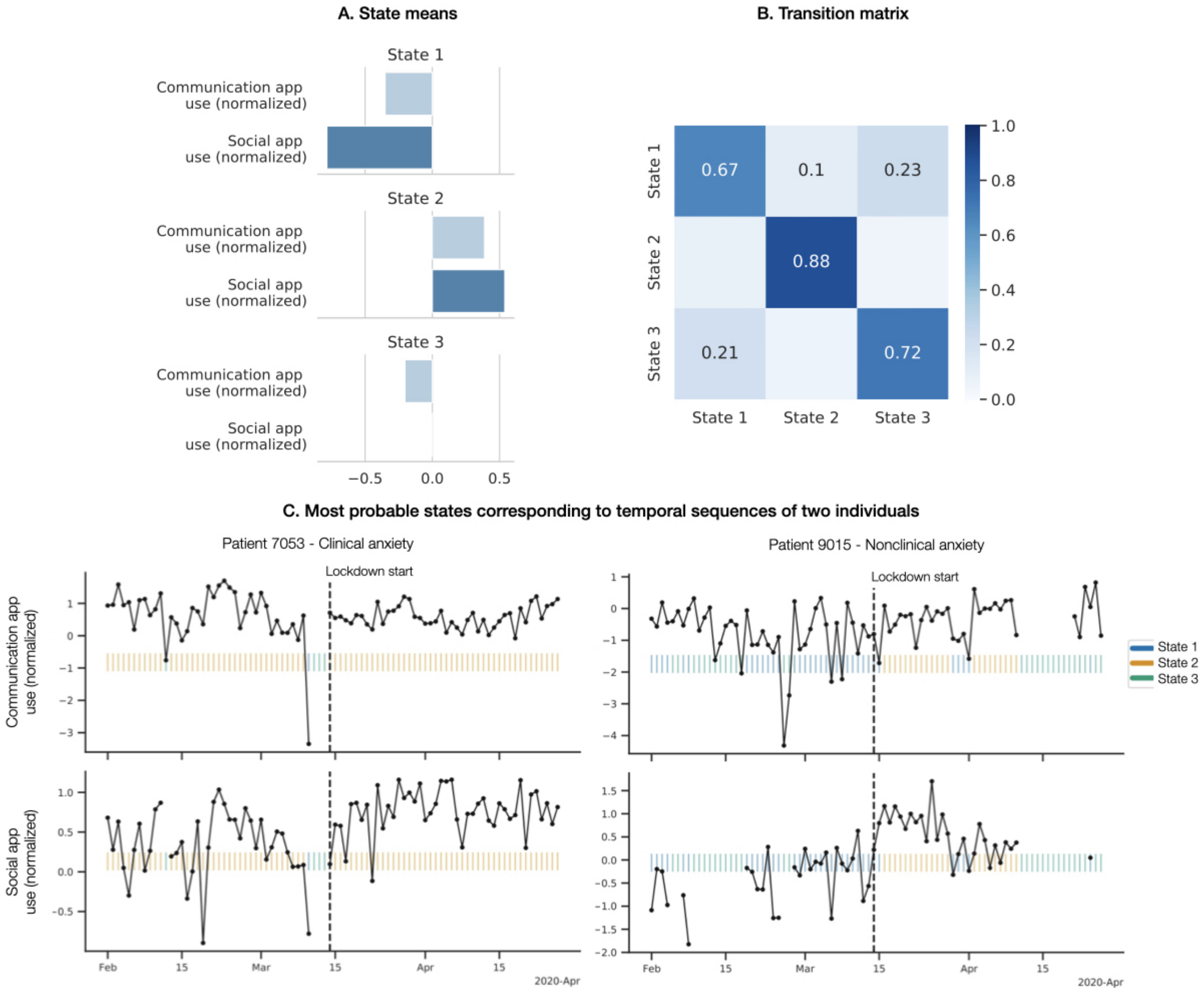
No significant correlations were found between GAD-7 and median communication or social networking app usage during prelockdown (communication: *P*=.59; social networking: *P*=.24), lockdown (communication: *P*=.14; social networking: *P*=.11), and the entire period (communication: *P*=.27; social networking: *P*=.14) (Figure S4 and Table S3 in Multimedia Appendix 1). There was no statistically significant impact of the period on dependent correlations in the patients (Table S3 in Multimedia Appendix 1, Steiger *Z* test; *P*=.25 in communication app; *P*=.47 in social networking app).

Machine Learning Pipeline for Predicting Clinical Anxiety Group

Only the patients with communication and social networking app usage data during both the prelockdown (≥1 out of 42 days) and lockdown period (≥1 out of 51 days) were considered for the model training. This resulted in 95 patients in the model with varying sequences of individual app usage data. In these sequences, 8.76% (655/7476) of the communication app and 30.26% (2262/7476) of the social networking app usage data were missing in the data set. Figure S4 in Multimedia Appendix 1 shows the overall data distribution grouped by the anxiety type.

An HMM with 3 hidden states (Figure 3A and Figure 3B) proved to capture the underlying data patterns the best according to the Akaike information criterion and Bayesian information criterion analysis and also led to the most interpretable states. State 2 was the most stable (self-transition probability of 0.88), while transitioning between states 1 and 3 was more likely. State 3 captured days with relatively low communication app usage and average social networking usage in the sample, while states 1 and 2 captured days with lower and higher app usage, respectively. When applied to individual observation sequences, state 3 preferentially represented the missing observations (ie, days the apps were not consistently used). State 2 preferentially represented the days of active and consistent social media usage, and state 1 preferentially represented the days of still active (but less so) and volatile usage (Figure 3C). For example, for patient 7053 with clinical anxiety, most days were in state 2, punctuated with 3 missing/inactive days (state 3), and after the lockdown social networking app usage increased. In the case of patient 9105 with nonclinical anxiety, days after the lockdown were marked with increased communication app usage (state 2), but during the overall period social networking app usage was less, capturing missing (state 3) and inactive or volatile (state 1) days.

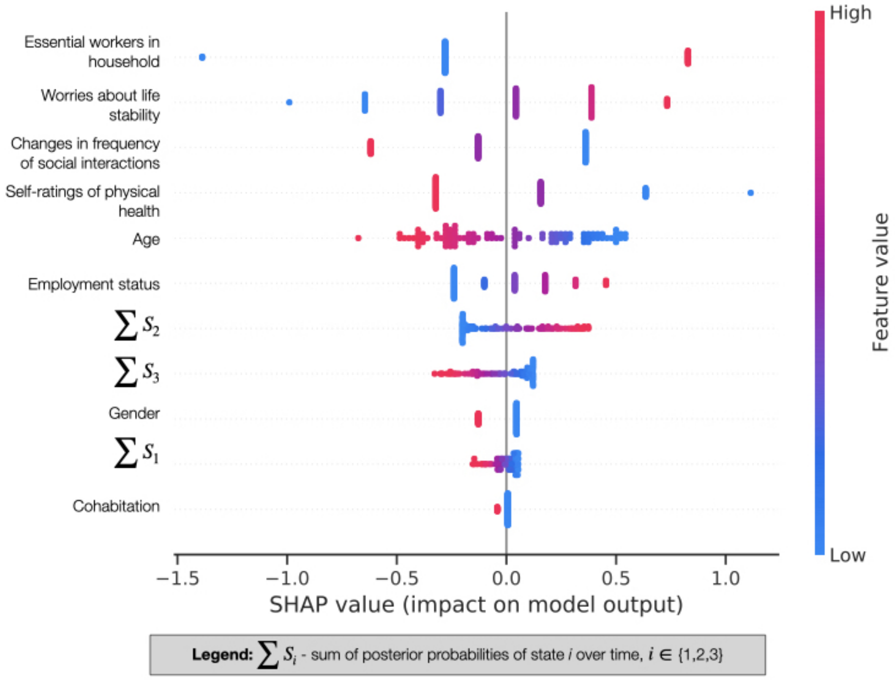
Figure 3. The 3-state hidden Markov model parameters used for temporal data modeling and most probable hidden Markov model states applied to daily communication and social media app usage of example individuals with clinical and nonclinical anxiety. Temporal variables were normalized before model training, providing the negative means. Large state transition probabilities suggest that the states were relatively stable.



Our model achieved a mean accuracy of 62.30% (SD 16%) and an AUROC of 0.70 (SD 0.19) in predicting the clinical anxiety group on the test sets (Table S4 in Multimedia Appendix 1). Performance metrics show that the model performs well on the majority of the splits; however, it underperforms on splits 6, 7, and 10, due in part to the nonrepresentative demographic features for the clinical anxiety group (Figure S5 in Multimedia Appendix 1). For example, in split 10, which had the lowest predictability with an AUROC of 0.40, clinical anxiety individuals had atypical risk perception (only 1 individual reported the presence of essential workers in the household) or self-report patterns (reported clinical anxiety despite having relatively good health and few worries about life instability during the lockdown) (Figure S6 in Multimedia Appendix 1).

The majority of nontemporal features, led by the presence of essential workers in the household, outweighed the aggregated representation of the temporal features in importance. Among temporal features, the aggregated posterior probability of state 2 (higher social networking app use) was the most important predictor of the clinical anxiety group (Figure 4), consistent with our missing user analysis, where active social networking app users had a higher burden of anxiety-related diagnoses (Table S1 in Multimedia Appendix 1). Despite their lower feature importance, states 1 and 3 still provided important insight into users' longitudinal behavior such that inactive and/or volatile social media usage patterns, specifically in lower communication app usage, predicted the clinical anxiety group. This is also consistent with our finding that clinical anxiety group communication app use was significantly lower during the lockdown period (*P*=.05; Figure 2).

Figure 4. Feature importance (Shapley additive explanation [SHAP] value) for the logistic regression model trained for the anxiety prediction task in the order of descending importance (colored by value, from low to high). Each point is for a feature and an instance, and overlapping points are jittered in the y-axis direction. SHAP values encode the feature's predictability for classifying the participant (positive, in the clinical anxiety group; negative, in the nonclinical anxiety group). For explanation of the encoded feature values see Table S5 in Multimedia Appendix 1.



Discussion

Principal Findings

Our findings demonstrate that among active social media users, those who reported clinical levels of anxiety symptoms after the mandatory lockdown spent less time on communication apps during the lockdown. Active social-networking app users, biased toward younger patients, additionally had a higher likelihood of having an anxiety disorder diagnosis. Our machine learning–based model, trained on the temporal series of communication and social networking app usage and clinically important features of self-report and demographic variables, accurately predicted which individuals were in the clinical anxiety group from higher social networking app usage and lower communication app usage. Our machine learning–based model results suggest that passive tracking of decreased communication app usage and increased social networking app usage through the lockdown period can predict users reporting clinical anxiety symptoms, at risk for impaired decision-making, maladaptive coping, and psychiatric sequelae during public health crises and lockdown periods [8]. Early remote detection of at-risk individuals would allow limited mental health resources to be allocated to serve those with the highest need and prevent or reduce negative mental health outcomes.

We interpret the findings from the perspective that patients who reported fewer anxiety symptoms proactively harnessed their digital social environment by using communication apps (eg, WhatsApp and Telegram) to initiate contact or respond to others' direct messages during this highly anxiogenic period (ie, during the COVID-19 pandemic and related lockdown). Our analysis is consistent with the clinical anxiety group's self-reports that they had less frequent social interactions with others during the lockdown. Social support systems, either in-person or online, are well-known protective factors against physiological and psychological stressors and can mitigate the impact of loneliness in times of uncertainty, including during infectious disease outbreaks [37-41]. Decreased social support has been associated with a higher mental health burden in COVID-19 literature [42,43]. Especially during mandated quarantine, when in-person contact is significantly limited, social media engagement can be viewed as a potentially healthy adaptive mechanism to regulate negative affect [44,45].

Conversely, users in our sample who were highly active on social networking apps were more likely to be diagnosed with anxiety disorder and report clinical anxiety symptoms. Social networking apps, such as Facebook, Twitter, TikTok, and Instagram, are examples of web 2.0 technology apps that have shifted the recent web-based environment of health communications, from traditionally one-way communication to interactive and iterative, characterized by passive sharing, active collaboration, and amplification of information [46,47]. However, public digital space can expose users to unfiltered or anonymous information that promotes fear during a health crisis [48] and has been linked, as a source of COVID-19 conspiracy theories and a sign of complex social and medical needs among patients, with a number of high emergency room visits [49,50]. Our analysis suggests that active engagement on social networking apps is a marker of anxiety that may be associated with individual behavioral traits, perhaps activated by increasing risk perceptions of the virus and psychosocial stressors of the lockdown period.

Our passively sensed user-driven data were prospectively collected within users' natural environment and under no influence of perceived experimental manipulation. They also contained clearly divided timeframes, followed by timely clinical surveys, which allowed our model of human behavior during the national lockdown to have high interpretability, which is critical for translating digital phenotyping research to real-life application [51]. User-driven passive data collection also reduced sampling bias and web-based activity measurement bias, particularly in self-reported scales [52]. The machine learning model utilized a data-driven algorithm to predict the clinical anxiety group, addressing missing observations and changes in social media usage after the lockdown. Although social networking app users were younger and had a higher burden of anxiety disorder diagnosis, there was no sampling bias of clinical or demographic variables in the communication app users. Our sample overall was a diverse cohort of psychiatric patients with varying ages, diagnoses, health, employment, and marital status. Therefore, our data are highly generalizable to populations of psychiatry outpatients and provide clinical utility by elucidating the link between digital behavior and public mental health outcomes in the real world [53].

Limitations

Our analysis was based on observing a small number of patients and should be interpreted with the following limitations. First, the data cannot explain the causal link between app usage and the severity of anxiety. For example, we do not know if decreased engagement in communication apps contributed to the reporting of higher anxiety symptoms, or if the former was a characteristic of the group that developed short-term clinical anxiety symptoms during the crisis (ie, a smaller volume of social support for communication to begin with). Second, besides *general worries about life instability during the lockdown*, there were no other independent variables that may reflect the evolution of subjective emotions included in the model to predict the anxiety states at clinical follow-up. Study participants had a daily mood self-reporting option on their smartphones, but such reporting was entirely voluntary, and mood data were largely missing during the lockdown. We acknowledge that our study participants were in an unprecedented and anxiogenic natural circumstance at the time. The lockdown likely increased the anxiety and stress levels of all users (mean GAD-7 was 9.6, with a clinical cut-off of 10), and we had not collected their baseline GAD-7 before the lockdown, in order to make a comparison. Therefore, the utility of our model is limited to detecting those with clinical severity anxiety symptoms (ie, GAD-7≥10). We suggest that future data-based anxiety prediction research should include self-reports of anxiety at multiple time points to improve model accuracy. Third, our assumption of user behavior was limited to the descriptive nature of the app category (communication apps require direct messaging activity and are generally used within a known social circle; social networking apps allow simple browsing of the others’ contents and provides ready exposure to anonymous content). However, the extent of the complex interplay between social media behavior and user intention is unlikely to be captured via passive sensing of total time spent on app categories. For example, although our study participants confirmed at the clinical interview that they used communication apps such as WhatsApp to stay in touch with others during the lockdown, there are reported benefits of actively using social networking sites, such as Instagram and TikTok to keep in touch or even to promote mental health awareness [54]. Further quantitative and qualitative analyses are needed to understand the mental health implications of these 2 app categories. We believe that analyzing multimedia input and output by emotional valence of content, types (text, audio, and video messages), the direction of messaging (is the user initiating or receiving social media activity), and the audience (is the user interacting with one person or multiple anonymous) will be relevant to test our behavioral hypothesis of the anxiety-relieving and anxiety-promoting effects of social media use. The privacy and patient confidentiality terms in our research protocol and data sharing protocol by third app parties prohibited collecting such information in this study.

Conclusions

To the best of our knowledge, our empirical data are the first to suggest that category-based passive sensing of a shift in smartphone usage patterns can be markers of clinical anxiety symptoms. Further studies, to digitally phenotype short-term reports of anxiety using granular behaviors on social media, are necessary for public health research when in-person psychiatric evaluations are limited during mandated physical isolation.

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Authors' Contributions

JR conceived the work, analyzed data, and wrote the manuscript. ES analyzed data, developed the machine learning models, and wrote the manuscript. AN, SL, EB, MMP-R, and AA contributed to the critical review of the draft for important intellectual content. JC acquired and interpreted data for the work. MMP-R mentored JR through the conception of the study, supervised data analysis and interpretation of results, and ensured that questions related to any part of the work’s accuracy or integrity were appropriately investigated and resolved.

Conflicts of Interest

AA and JC are cofounders of eB2. MMP-R has received research grant funding from Neurocrine Biosciences, Millennium Pharmaceuticals, Takeda, Merck, and AI Cure; she is an Advisory Board member for Neurocrine Biosciences Inc and a consultant on an American Foundation for Suicide Prevention (grant LSRG-1-005-16, principal investigator: EB-G).

Multimedia Appendix 1
Supplementary tables and figures for statistical data analysis and the 10-fold cross-validation of our hidden Markov + logistic regression model.
[PDF File (Adobe PDF File), 2967 KB - mental_v8i9e30833_app1.pdf]

References

1. Koeze E, Popper N. The virus changed the way we internet. The New York Times. 2020 Apr 07. URL: https://www.nytimes.com/interactive/2020/04/07/technology/coronavirus-internet-use.html [accessed 2021-08-03]
2. Henley J. Lockdown living: how Europeans are avoiding going stir crazy. The Guardian. 2020 Mar 28. URL: http://www.theguardian.com/world/2020/mar/28/lockdown-living-europe-activities-coronavirus-isolation [accessed 2021-08-03]
3. Styra R, Hawryluck L, Gold W. SARS control and psychological effects of quarantine, Toronto, Canada. Emerg Infect Dis 2005 Feb;11(2):354-355 [FREE Full text] [doi: 10.3201/eid1102.040978] [Medline: 15759346]
4. Reynolds DL, Garay JR, Deamond SL, Moran MK, Gold W, Styra R. Understanding, compliance and psychological impact of the SARS quarantine experience. Epidemiol Infect 2008 Jul;136(7):997-1007. [doi: 10.1017/S0950268807009156] [Medline: 17662167]
5. Xin M, Luo S, She R, Yu Y, Li L, Wang S, et al. Negative cognitive and psychological correlates of mandatory quarantine during the initial COVID-19 outbreak in China. Am Psychol 2020;75(5):607-617. [doi: 10.1037/amp0000692] [Medline: 32673008]
6. Gangemi A, Tenore K, Mancini F. Two reasoning strategies in patients with psychological illnesses. Front Psychol 2019;10:2335 [FREE Full text] [doi: 10.3389/fpsyg.2019.02335] [Medline: 31695641]
7. Reuman L, Jacoby RJ, Fabricant LE, Herring B, Abramowitz JS. Uncertainty as an anxiety cue at high and low levels of threat. J Behav Ther Exp Psychiatry 2015 Jun;47:111-119. [doi: 10.1016/j.jbtep.2014.12.002] [Medline: 25562749]
8. Rogers AH, Shepherd JM, Garey L, Zvolensky MJ. Psychological factors associated with substance use initiation during the COVID-19 pandemic. Psychiatry Res 2020 Nov;293:113407 [FREE Full text] [doi: 10.1016/j.psychres.2020.113407] [Medline: 32827993]
9. Jungmann SM, Witthöft M. Health anxiety, cyberchondria, and coping in the current COVID-19 pandemic: which factors are related to coronavirus anxiety? J Anxiety Disord 2020 Jun;73:102239 [FREE Full text] [doi: 10.1016/j.janxdis.2020.102239] [Medline: 32502806]
10. Yuen KF, Wang X, Ma F, Li KX. The psychological causes of panic buying following a health crisis. Int J Environ Res Public Health 2020 May 18;17(10):3513 [FREE Full text] [doi: 10.3390/ijerph17103513] [Medline: 32443427]
11. Bavel JJV, Baicker K, Boggio PS, Capraro V, Cichocka A, Cikara M, et al. Using social and behavioural science to support COVID-19 pandemic response. Nat Hum Behav 2020 Apr 30;4:460-471. [doi: 10.1038/s41562-020-0884-z] [Medline: 32355299]
12. Gillan CM, Rutledge RB. Smartphones and the neuroscience of mental health. Annu Rev Neurosci 2021 Jul 08;44:129-151. [doi: 10.1146/annurev-neuro-101220-014053] [Medline: 33556250]
13. Jacobson NC, Summers B, Wilhelm S. Digital biomarkers of social anxiety severity: digital phenotyping using passive smartphone sensors. J Med Internet Res 2020 May 29;22(5):e16875 [FREE Full text] [doi: 10.2196/16875] [Medline: 32348284]
14. Vannucci A, Flannery KM, Ohannessian CM. Social media use and anxiety in emerging adults. J Affect Disord 2017 Jan 01;207:163-166. [doi: 10.1016/j.jad.2016.08.040] [Medline: 27723539]
15. Kross E, Verduyn P, Sheppes G, Costello CK, Jonides J, Ybarra O. Social media and well-being: pitfalls, progress, and next steps. Trends Cogn Sci 2021 Jan;25(1):55-66 [FREE Full text] [doi: 10.1016/j.tics.2020.10.005] [Medline: 33187873]
16. Ni MY, Yang L, Leung CMC, Li N, Yao XI, Wang Y, et al. Mental health, risk factors, and social media use during the COVID-19 epidemic and cordon sanitaire among the community and health professionals in Wuhan, China: cross-sectional survey. JMIR Ment Health 2020 May 12;7(5):e19009 [FREE Full text] [doi: 10.2196/19009] [Medline: 32365044]
17. Gao J, Zheng P, Jia Y, Chen H, Mao Y, Chen S, et al. Mental health problems and social media exposure during COVID-19 outbreak. PLoS One 2020;15(4):e0231924 [FREE Full text] [doi: 10.1371/journal.pone.0231924] [Medline: 32298385]
18. Fung IC, Tse ZTH, Cheung C, Miu AS, Fu K. Ebola and the social media. Lancet 2014 Dec;384(9961):2207. [doi: 10.1016/s0140-6736(14)62418-1]
19. Choi D, Yoo W, Noh G, Park K. The impact of social media on risk perceptions during the MERS outbreak in South Korea. Comput Human Behav 2017 Jul;72:422-431 [FREE Full text] [doi: 10.1016/j.chb.2017.03.004] [Medline: 32288176]

20. Norbury A, Liu SH, Campaña-Montes JJ, Romero-Medrano L, Barrigón ML, Smith E, MEmind Study Group, et al. Social media and smartphone app use predicts maintenance of physical activity during Covid-19 enforced isolation in psychiatric outpatients. Mol Psychiatry 2020 Dec 14:1-11 [FREE Full text] [doi: 10.1038/s41380-020-00963-5] [Medline: 33318619]
21. Barrigón ML, Berrouiguet S, Carballo JJ, Bonal-Giménez C, Fernández-Navarro P, Pfang B, MEmind study group. User profiles of an electronic mental health tool for ecological momentary assessment: MEmind. Int J Methods Psychiatr Res 2017 Mar;26(1):e1554. [doi: 10.1002/mpr.1554] [Medline: 28276176]
22. Berrouiguet S, Ramírez D, Barrigón ML, Moreno-Muñoz P, Carmona Camacho R, Baca-García E, et al. Combining continuous smartphone native sensors data capture and unsupervised data mining techniques for behavioral changes detection: a case series of the evidence-based behavior (eB2) study. JMIR Mhealth Uhealth 2018 Dec 10;6(12):e197 [FREE Full text] [doi: 10.2196/mhealth.9472] [Medline: 30530465]
23. Muñoz-Navarro R, Cano-Vindel A, Moriana JA, Medrano LA, Ruiz-Rodríguez P, Agüero-Gento L, et al. Screening for generalized anxiety disorder in Spanish primary care centers with the GAD-7. Psychiatry Res 2017 Oct;256:312-317. [doi: 10.1016/j.psychres.2017.06.023] [Medline: 28666201]
24. Home page. eB2. URL: https://eb2.tech/?lang=en [accessed 2021-08-03]
25. Bonilla-Escribano P, Ramirez D, Sedano-Capdevila A, Campana-Montes JJ, Baca-Garcia E, Courtet P, et al. Assessment of e-social activity in psychiatric patients. IEEE J Biomed Health Inform 2019 Nov;23(6):2247-2256. [doi: 10.1109/JBHI.2019.2918687] [Medline: 31135374]
26. Carretero P, Campana-Montes JJ, Artes-Rodriguez A. Ecological momentary assessment for monitoring risk of suicide behavior. Curr Top Behav Neurosci 2020;46:229-245. [doi: 10.1007/7854_2020_170] [Medline: 32797403]
27. Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med 2006 May 22;166(10):1092-1097. [doi: 10.1001/archinte.166.10.1092] [Medline: 16717171]
28. Kroenke K, Spitzer RL, Williams JBW, Monahan PO, Löwe B. Anxiety disorders in primary care: prevalence, impairment, comorbidity, and detection. Ann Intern Med 2007 Mar 06;146(5):317-325. [doi: 10.7326/0003-4819-146-5-200703060-00004] [Medline: 17339617]
29. Dolan C. Lifting of lockdown in Spain - full details of all phases for all regions. Spain in English. 2020. URL: https://www.spainenglish.com/2020/06/18/lifting-lockdown-spain-full-details-phases/ [accessed 2021-08-03]
30. Choose a category and tags for your app or game. Google Support. URL: https://support.google.com/googleplay/android-developer/answer/9859673?hl=en&visit_id=637404551129521641-377005271&rd=1 [accessed 2021-08-03]
31. Steiger JH. Tests for comparing elements of a correlation matrix. Psychol Bull 1980;87(2):245-251. [doi: 10.1037/0033-2909.87.2.245]
32. Rabiner L. A tutorial on hidden Markov models and selected applications in speech recognition. In: Waibel A, Lee KF, editors. Readings in Speech Recognition. San Mateo, California: Morgan Kaufmann Publishers; 1990:267-296.
33. Pohle J, Langrock R, van Beest FM, Schmidt NM. Selecting the number of states in hidden Markov models: pragmatic solutions illustrated using animal movement. J Agric Biol Environ Stat 2017 Jun 5;22(3):270-293. [doi: 10.1007/s13253-017-0283-8]
34. Teo AR, Lerrigo R, Rogers MAM. The role of social isolation in social anxiety disorder: a systematic review and meta-analysis. J Anxiety Disord 2013 May;27(4):353-364. [doi: 10.1016/j.janxdis.2013.03.010] [Medline: 23746493]
35. Trevor H, Robert T, Jerome F. The Elements of Statistical Learning: Data Mining, Inference, and Prediction. New York, New York: Springer-Verlag; Apr 21, 2017.
36. Scott L, Su-In L. A unified approach to interpreting model predictions. arXiv. Preprint posted online on Nov 22, 2017 2021 [FREE Full text]
37. Chen FS, Kumsta R, von Dawans B, Monakhov M, Ebstein RP, Heinrichs M. Common oxytocin receptor gene (OXTR) polymorphism and social support interact to reduce stress in humans. Proc Natl Acad Sci U S A 2011 Dec 13;108(50):19937-19942 [FREE Full text] [doi: 10.1073/pnas.1113079108] [Medline: 22123970]
38. Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Greenberg N, et al. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. Lancet 2020 Mar 14;395(10227):912-920. [doi: 10.1016/S0140-6736(20)30460-8] [Medline: 32112714]
39. Uchino BN. Social support and health: a review of physiological processes potentially underlying links to disease outcomes. J Behav Med 2006 Aug;29(4):377-387 [FREE Full text] [doi: 10.1007/s10865-006-9056-5] [Medline: 16758315]
40. Lin S, Faust L, Robles-Granda P, Kajdanowicz T, Chawla NV. Social network structure is predictive of health and wellness. PLoS One 2019;14(6):e0217264 [FREE Full text] [doi: 10.1371/journal.pone.0217264] [Medline: 31170181]
41. Blackman D, Falkner AL. Balancing anxiety and social desire. Nat Neurosci 2021 Apr;24(4):453-454. [doi: 10.1038/s41593-021-00812-w] [Medline: 33674751]
42. Benke C, Autenrieth LK, Asselmann E, Pané-Farré CA. Lockdown, quarantine measures, and social distancing: associations with depression, anxiety and distress at the beginning of the COVID-19 pandemic among adults from Germany. Psychiatry Res 2020 Nov;293:113462 [FREE Full text] [doi: 10.1016/j.psychres.2020.113462] [Medline: 32987222]
43. Wathelet M, Duhem S, Vaiva G, Baubet T, Habran E, Veerapa E, et al. Factors associated with mental health disorders among university students in france confined during the COVID-19 pandemic. JAMA Netw Open 2020 Oct 01;3(10):e2025591 [FREE Full text] [doi: 10.1001/jamanetworkopen.2020.25591] [Medline: 33095252]

44. Orben A, Przybylski AK. The association between adolescent well-being and digital technology use. Nat Hum Behav 2019 Feb 14;3(2):173-182. [doi: 10.1038/s41562-018-0506-1] [Medline: 30944443]
45. Zhao X, Fan J, Basnyat I, Hu B. Online health information seeking using "#COVID-19 patient seeking help" on Weibo in Wuhan, China: Descriptive Study. J Med Internet Res 2020 Oct 15;22(10):e22910 [FREE Full text] [doi: 10.2196/22910] [Medline: 33001838]
46. Yoo W, Choi D, Park K. The effects of SNS communication: how expressing and receiving information predict MERS-preventive behavioral intentions in South Korea. Comput Human Behav 2016 Sep;62:34-43 [FREE Full text] [doi: 10.1016/j.chb.2016.03.058] [Medline: 32288174]
47. Andrejevic M. Public service media utilities: rethinking search engines and social networking as public goods. Media Int Aus 2013 Feb 01;146(1):123-132. [doi: 10.1177/1329878x1314600116]
48. MERS for one month: SNS's mention declines. SBS News. 2015 Jun 19. URL: https://news.sbs.co.kr/news/endPage.do?news_id=N1003033638 [accessed 2021-08-03]
49. Ahmed W, Vidal-Alaball J, Downing J, López Seguí F. COVID-19 and the 5G conspiracy theory: social network analysis of Twitter data. J Med Internet Res 2020 May 06;22(5):e19458 [FREE Full text] [doi: 10.2196/19458] [Medline: 32352383]
50. Guntuku SC, Klinger EV, McCalpin HJ, Ungar LH, Asch DA, Merchant RM. Social media language of healthcare super-utilizers. NPJ Digit Med 2021 Mar 25;4(1):55 [FREE Full text] [doi: 10.1038/s41746-021-00419-2] [Medline: 33767336]
51. Onnela J. Opportunities and challenges in the collection and analysis of digital phenotyping data. Neuropsychopharmacology 2021 Jan;46(1):45-54. [doi: 10.1038/s41386-020-0771-3] [Medline: 32679583]
52. Pierce M, McManus S, Jessop C, John A, Hotopf M, Ford T, et al. Says who? the significance of sampling in mental health surveys during COVID-19. Lancet Psychiatry 2020 Jul;7(7):567-568 [FREE Full text] [doi: 10.1016/S2215-0366(20)30237-6] [Medline: 32502467]
53. H Birk R, Samuel G. Can digital data diagnose mental health problems? a sociological exploration of 'digital phenotyping'. Sociol Health Illn 2020 Nov;42(8):1873-1887. [doi: 10.1111/1467-9566.13175] [Medline: 32914445]
54. Latha K, Meena KS, Pravitha MR, Dasgupta M, Chaturvedi SK. Effective use of social media platforms for promotion of mental health awareness. J Educ Health Promot 2020;9:124 [FREE Full text] [doi: 10.4103/jehp.jehp_90_20] [Medline: 32642480]

Abbreviations

AUROC: area under the receiver operating characteristics curve
GAD-7: Generalized Anxiety Disorder scale
HMM: hidden Markov model
SHAP: Shapley additive explanation

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Original Paper

Trends in Stress Throughout Pregnancy and Postpartum Period During the COVID-19 Pandemic: Longitudinal Study Using Ecological Momentary Assessment and Data From the Postpartum Mothers Mobile Study

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Abstract

Background: Stress is associated with adverse birth and postpartum health outcomes. Few studies have longitudinally explored racial differences in maternal stress in a birthing population in the United States during the ongoing COVID-19 pandemic.

Objective: This study aimed to do the following: (1) assess changes in reported stress before, during, and after initial emergency declarations (eg, stay-at-home orders) were in place due to the COVID-19 pandemic, and (2) assess Black-White differences in reported stress in a pregnant and postpartum population from Southwestern Pennsylvania.

Methods: We leveraged data from the ongoing Postpartum Mothers Mobile Study (PMOMS), which surveys participants in real time throughout the pregnancy and postpartum periods via ecological momentary assessment (EMA) and smartphone technology. We analyzed data from a subset of PMOMS participants (n=85) who were either Black or White, and who submitted EMA responses regarding stress between November 1, 2019, and August 31, 2020, the time frame of this study. We divided data into four phases based on significant events during the COVID-19 pandemic: “pre” phase (baseline), “early” phase (first case of COVID-19 reported in United States), “during” phase (stay-at-home orders), and “post” phase (stay-at-home orders eased). We assessed mean stress levels at each phase using linear mixed-effects models and post hoc contrasts based on the models.

Results: Overall mean stress (0=not at all to 4=a lot) during the pre phase was 0.8 for Black and White participants (range for Black participants: 0-3.9; range for White participants: 0-2.8). There was an increase of 0.3 points (t_{5649}=5.2, *P*<.001) in the during phase as compared with the pre phase, and an increase of 0.2 points (t_{5649}=3.1, *P*=.002) in the post phase compared with the pre phase (n=85). No difference was found between Black and White participants in the change in mean stress from the pre phase to the during phase (overall change predicted for the regression coefficient=–0.02, *P*=.87). There was a significant difference between Black and White participants in the change in mean stress from the during phase to the post phase (overall change predicted for the regression coefficient=0.4, *P*<.001).

Conclusions: There was an overall increase in mean stress levels in this subset of pregnant and postpartum participants during the same time as the emergency declarations/stay-at-home orders in the United States. Compared to baseline, mean stress levels remained elevated when stay-at-home orders eased. We found no significant difference in the mean stress levels by race. Given that stress is associated with adverse birth outcomes and postpartum health, stress induced by the ongoing COVID-19 pandemic may have adverse implications for birthing populations in the United States.

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KEYWORDS

COVID-19; ecological momentary assessment; health status disparities; pandemics; postpartum; pregnancy; psychological stress

Introduction

Background

By late 2019, the world had become increasingly aware of the novel coronavirus, SARS-CoV-2, which causes the disease COVID-19. The first case of this coronavirus in the United States was identified in the state of Washington on January 21, 2020 [1]. Shortly thereafter, the US Secretary of Health and Human Services declared a public health emergency on January 31, 2020 [2]. On March 11, 2020, the World Health Organization (WHO) declared COVID-19 a pandemic, signifying the virus had spread to more than one hundred countries [3]. Two days later, the US federal government declared the pandemic a national emergency [2]. On March 16, 2020, the US president and the White House Coronavirus Taskforce members presented guidelines to slow the spread of the virus during a press conference targeted to the US public. These guidelines included listening to local authorities, staying home if sick, and isolating if someone in your household tested positive for the virus [4]. This was federal guidance, but much of the public health intervention needed to address the outbreak was left to local officials. Since there was initially limited federal intervention to address the outbreak, the response to the coronavirus in the United States varied by parish, county, state, and region.

In the initial stages of the pandemic, local government officials had limited tools, knowledge, and resources to address the public's concern about the virus and to mediate risk to the public. Furthermore, this was a new coronavirus, which impeded the US development and scaling up of diagnostic tests to confirm diagnoses of the virus [5]. Additionally, inconsistent health communication to the public regarding how individuals contracted the virus and which symptoms were indicative of COVID-19 left the public vulnerable to contracting the virus [6]. Since local officials had limited resources to test for the virus and isolate infected individuals, they used other methods to reduce the risk of disease to the public. To slow the spread of the virus and to attempt to avoid overburdening the health care system, some government officials across the nation declared a state of emergency and issued stay-at-home orders as a public health intervention to break the chain of infection by decreasing person-to-person contact. These emergency declarations and policy actions included temporary business closures [7], movement of education to online/remote formats [8,9], and changes in health care system protocols [10]. Employment was affected as well, as 20.4% of US workers were employed in industries impacted by state and local business restrictions aimed at reducing the spread of the virus [11]. In April 2020, employment payrolls fell by 20.5 million people and the unemployment rate was 14.7% [12]. Moreover, uncertainty about the virus and limited mechanisms to mediate the risk to the public greatly disturbed the daily lives of US residents.

Experts have seen a global increase in the incidence of anxiety, depression, posttraumatic stress disorder (PTSD), and psychological distress in the general population during the pandemic [13]. Czeisler et al [14] used representative panel surveys (administered June 24-30, 2020) to assess mental health, substance use, and suicidal ideation among US adults. Of their respondent sample, 40.9% of adults reported at least one adverse mental health condition (symptoms of anxiety or depressive disorder) and 30.9% reported symptoms of trauma or stressors related to the pandemic. Moreover, young adults, Hispanic persons, Black persons, essential workers (eg, health care workers), unpaid caregivers for adults, and persons receiving treatment for pre-existing psychiatric disorders were disproportionately impacted by adverse mental health due to the pandemic [14]. Park et al [15] found common stressors related to COVID-19 included media coverage of viral contagiousness, uncertainty about the length of quarantine or social distancing measures, disruption to social and personal care routines, lack of job security and financial strain, and perceived risk of infection among a sample of US adults. This previous study also found that individuals with caregiver status, younger adults, sexual minorities, and non-White participants were at greater risk for stressors related to the pandemic [15]. Thus, several stressors related to uncertainty about the pandemic impacted populations in the United States, which was felt disproportionately among marginalized communities (ie, Black people, LGBTQ people) and individuals experiencing adverse mental health prior to the pandemic.

Given that psychological stress is associated with adverse birth outcomes and maternal health, stress induced by the COVID-19 pandemic may have implications for perinatal and birthing populations in the United States. Several international studies have reported an increase in psychological stress and psychiatric symptoms during the COVID-19 pandemic among childbearing populations; however, few studies are based in the United States [16-18]. Preis et al [19] found that pregnant people in the United States (recruited late April 2020) reported mild (35.6%), moderate (21.6%), and severe (21.7%) anxiety. Using a pandemic-related stress scale (Pandemic-Related Pregnancy

Stress Scale), they found that pandemic preparedness stress (OR 1.75, 95% CI 1.35-2.26) and anxiety related to perinatal COVID-19 infection stress (OR 1.55, 95% CI 1.28-1.88) were associated with a greater likelihood of moderate or severe anxiety symptoms after adjustment for sociodemographic, medical, and obstetrical variables. In a follow-up study (conducted April-May 2020), pandemic preparedness stress (30%) and perinatal infection stress (27.2%) were associated with income loss, prenatal care disruption, and perceived COVID-19 infection among pregnant people [20]. A mixed methods study conducted March to April of 2020 found that 60% of surveyed pregnant participants (n=27) reported experiencing moderate or severe anxiety symptoms and 68% reported moderate stress. In the qualitative results (N=31), participants reported uncertainty related to prenatal care, stress related to the risk of COVID-19 infection, disruption of birth plans, and lack of postpartum support [21]. One study also found that over 50% of pregnant participants reported increased stress related to food insecurity, loss of job or household income, and loss of childcare [22]. Another study found COVID-19 health worries (eg, fear of infection) and grief (eg, loss of meaningful experiences) were associated with clinically significant levels of depression, generalized anxiety, and PTSD among pregnant and postpartum participants. This study also found that participants who reported pre-existing mental illness diagnoses were more likely to report these symptoms [23]. These studies suggest that stress related to lack of support, income loss, uncertainty regarding prenatal/postnatal care, perceived risk of COVID-19 infection, and inability to meet basic needs (eg, secure food) were associated with reports of increased stress and symptoms of mental health illnesses among perinatal populations in the United States. Prior studies based in the United States have not examined longitudinal changes in stress among perinatal populations by race, thus creating the impetus to examine these experiences in this population.

Objective of Study

This study is a secondary analysis of data from the Postpartum Mothers Mobile Study (PMOMS), a prospective longitudinal study examining factors associated with racial disparities in postpartum weight retention and cardiometabolic health. PMOMS uses smartphone technology to remotely collect survey data via ecological momentary assessment (EMA). EMA allows for the assessment of study participants' experiences, moods, and behaviors in the context of their natural environment and in real time [24]. The EMA component of PMOMS enabled the continuation of primary data collection during the COVID-19 pandemic, since participants answered survey questions via smartphone. Further details about the study are published elsewhere [25-27].

We investigated changes in reported stress during different phases of the pandemic in a sample of US pregnant and postpartum people. The aims of this manuscript are the following: (1) assess changes in reported stress before, during, and after initial emergency declarations/stay-at-home orders were in place, and (2) assess whether reported stress differed by race during these time periods over the COVID-19 pandemic. We hypothesized the following: (1) all participants would report higher mean stress levels in the during phase compared to the pre phase; (2) in the post phase, reported mean stress levels would return to pre phase levels for all participants; and (3) reported mean stress levels would increase for all participants from the pre phase to the during phase, but the change in reported stress levels would be higher for Black participants than for White participants.

Methods

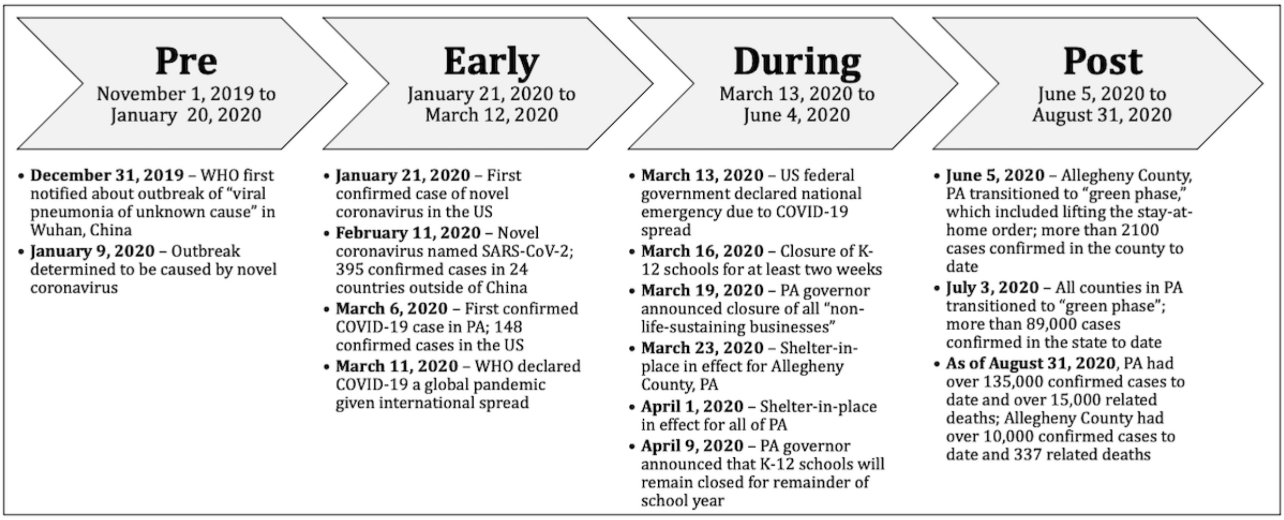
Study Design

PMOMS is an ancillary study to GDM^2 (Comparison of Two Screening Strategies for Gestational Diabetes) [28-30], a randomized controlled trial conducted in a single women's hospital in Southwestern Pennsylvania. In addition to the participants recruited to PMOMS from the GDM^2 clinical trial (n=284), participants were also directly recruited into the PMOMS study (n=29). The study participants are recruited during the second and third trimester (18-28 weeks of gestation) and followed up to 1 year postpartum. Once participants consented to the study, they completed baseline surveys, received smartphones and a smart scale, and downloaded a companion app to weigh themselves. Participants completed EMA surveys for the duration of the study. The protocol for PMOMS was approved by the Human Research Protection Office at the University of Pittsburgh.

Setting and Participants

A subset of participants from PMOMS contributing data from November 1, 2019-August 31, 2020, served as the analytic sample (n=85). We divided the study period into four phases based on significant events in the COVID-19 pandemic timeline in the United States, Pennsylvania, and Allegheny County. Most of the study participants (n=81) lived in Allegheny County during the study period. The "pre" phase (November 1, 2019-January 20, 2020; 81 days) represents a reference baseline period before the first confirmed case of COVID-19 in the United States. The "early" phase (January 21, 2020-March 12, 2020; 52 days) began on the day the first COVID-19 case was reported in the United States [1]. The "during" phase (March 13, 2020-June 4, 2020; 84 days) began on the day COVID-19 was declared a national emergency and Pennsylvania officials implemented statewide stay-at-home orders (closure of all businesses that were not life sustaining) [31]. This period also included remote and online educational learning for public schools, business closures, and the introduction of stay-at-home orders specifically in Allegheny and surrounding counties [32]. The "post" phase of this study (June 5, 2020-August 31, 2020; 88 days) covered the transition from previous stay-at-home orders to the restricted opening of nonessential businesses (eg, bars, gyms) in Allegheny County (Figure 1).

Figure 1. Phases of COVID-19 response as applied in the present analysis, based on administrative actions at the national, state, and county levels. Data obtained from [32-34]. PA: Pennsylvania; WHO: World Health Organization.



- **December 31, 2019** – WHO first notified about outbreak of "viral pneumonia of unknown cause" in Wuhan, China
- **January 9, 2020** – Outbreak determined to be caused by novel coronavirus

- **January 21, 2020** – First confirmed case of novel coronavirus in the US
- **February 11, 2020** – Novel coronavirus named SARS-CoV-2; 395 confirmed cases in 24 countries outside of China
- **March 6, 2020** – First confirmed COVID-19 case in PA; 148 confirmed cases in the US
- **March 11, 2020** – WHO declared COVID-19 a global pandemic given international spread

- **March 13, 2020** – US federal government declared national emergency due to COVID-19 spread
- **March 16, 2020** – Closure of K-12 schools for at least two weeks
- **March 19, 2020** – PA governor announced closure of all "non-life-sustaining businesses"
- **March 23, 2020** – Shelter-in-place in effect for Allegheny County, PA
- **April 1, 2020** – Shelter-in-place in effect for all of PA
- **April 9, 2020** – PA governor announced that K-12 schools will remain closed for remainder of school year

- **June 5, 2020** – Allegheny County, PA transitioned to "green phase," which included lifting the stay-at-home order; more than 2100 cases confirmed in the county to date
- **July 3, 2020** – All counties in PA transitioned to "green phase"; more than 89,000 cases confirmed in the state to date
- **As of August 31, 2020**, PA had over 135,000 confirmed cases to date and over 15,000 related deaths; Allegheny County had over 10,000 confirmed cases to date and 337 related deaths

Measurements

Overview

Participants used a smartphone to complete daily EMA surveys via a web-based app. EMA data were collected at the beginning of day, end of day, and random times throughout the day. Participants chose the timing of the beginning of day and end of day surveys. There were at least nine hours between these two surveys. Using a random sampling design (described in detail elsewhere [25]), random EMA surveys were delivered 0-3 times per day between the beginning of day and end of day survey times, targeting a mean of one random assessment per day over a 7-day period. Data collected via the GDM^2 study included baseline demographic information.

Primary Outcome

The primary outcome of interest in this study was mean self-reported stress levels. Self-reported stress levels were assessed in random EMA surveys using a single item from the Cohen Perceived Stress Scale [35]. The item was adapted, as participants were asked to rate their current level ("right now" as opposed to "in the last month") of nervousness or stress. In each random survey, participants were asked to "rate if you are feeling nervous or stressed right now." The response scale ranged from 0 (not at all) to 4 (a lot).

Main Predictors

The main predictors in the model were stage (whether the participant was in the pregnancy or postpartum stage), race, and phase of the COVID-19 pandemic timeline (ie, study phases as described in the Setting and Participants section). Participants self-reported race via self-administered electronic surveys at the baseline visit (18-28 weeks of gestation).

Covariates

We selected covariates based on the literature and our understanding of stress during pregnancy [36,37]. Education level, employment status, annual household income, marital status, and maternal age were included as covariates. All covariates except maternal age were dichotomized, with education dichotomized as less than college versus college degree or higher, employment status as unemployed versus employed, annual household income as earning less than $50,000 per year versus over $50,000 per year, and marital status as unmarried versus married.

Analytical Sample

The overall PMOMS population included 313 participants. Of these, 197 (62.9%) completed PMOMS prior to the time frame of this study (November 1, 2019-August 31, 2020), leaving a total of 116 participants (37.1%). Of those, 24 (20.7%) did not complete EMA surveys with stress data, resulting in 92 participants (79.3%) with stress data. We excluded participants that identified as Asian (n=5) or more than one race (n=2) since our primary aim was to examine Black-White differences in stress levels during the study period; this resulted in a total of 85 participants in the final analytic sample. The analytical sample included participants that self-identified as White (n=53, 62%), Black or African American (n=31, 37%), and African (n=1, 1%) who completed EMA surveys. The participants included in the analytic sample were more likely to be White, be married, be college educated, be employed full-time or part-time, and have a household income of $50,000 or higher compared to participants that were excluded.

Statistical Methods

Participants were included in the analytic sample for a phase if they contributed at least one survey during that phase. Not all participants contributed surveys in every phase. Descriptive analyses reported frequencies and percentages of categorical demographic variables including race, ethnicity, student status, education level, employment status, annual household income, and marital status, and mean (SD) for the continuous variable maternal age. We also report mean numbers of random survey responses contributed per participant in each of the four phases (overall and by race) and unadjusted mean stress levels in each of the four phases (overall and by race). Variance inflation factors (VIF) were used to assess the multicollinearity among education level, annual household income, employment status, and marital status. Since all VIFs were less than 5, we included all covariates in the model.

We used linear mixed-effects models with random subject effects to describe the effect of COVID-19–related emergency declarations/stay-at-home orders on repeated measures of stress levels in random EMA assessments. The initial adjusted model included stage, race, study phase, and the interaction between race and study phase. The fully adjusted model included stage, race, study phase, the interaction between race and study phase, education level, employment status, household income, marital status, and maternal age. *F* tests were used to determine the significance of fixed effects. Mean stress levels by phase and race were computed for each model. Post hoc contrasts based on the models were used to address the study aims. Additionally, since the stress variable was based on a scale of 0 to 4, we conducted analyses using an ordinal generalized linear mixed-effects model with random subject effects (see Multimedia Appendix 1). Due to small numbers of responses in stress levels 3 and 4, we collapsed the original 5 levels into 3 categories, where stress level 0=0, 1=1 and 2, and 2=3 and 4. This model included the same variables as in the adjusted linear mixed-effects model. We conducted all analyses using SAS (version 9.4; SAS Institute Inc).

Results

Table 1 presents the baseline demographic characteristics of the study participants who contributed EMA data in each phase. As participants completed the PMOMS study, the sample size declined across the COVID-19 pandemic phases. One Black participant withdrew from the study but contributed survey data to the pre phase prior to doing so. The study sample had a mean age of 29.9 (SD 4.8) years and was mostly White (n=53, 62%), married (n=48, 57%), and employed full-time or part-time (n=63, 74%), with an income greater than $50,000 (n=43, 51%) and a college degree or higher (n=44, 52%). The percentage of Black participants contributing to the data in each phase ranged between 34% (n=12, during phase) and 42% (n=10, post phase), whereas the percentage of White participants contributing data ranged between 58% (n=14, post phase) and 66% (n=23, during phase).

Table 2 displays the mean number of EMA surveys contributed by participants overall and in each phase, stratified by race. White participants contributed a higher mean number of surveys overall (overall mean 63.7) and in each phase (mean range 25.2-57.9) compared to Black participants (overall mean 43.9; mean range 15.4-26.1).

Table 1. Frequencies of participants contributing data in each phase by demographic variable and stratified by race (Black and White)[a].

Variable	All (N=85)		Pre phase (n=66)		Early phase (n=52)		During phase (n=35)		Post phase (n=24)	
	Black (n=32; 38%)	White (n=53; 62%)	Black (n=23; 35%)	White (n=43; 65%)	Black (n=19; 37%)	White (n=33; 64%)	Black (n=12; 34%)	White (n=23; 66%)	Black (n=10; 42%)	White (n=14; 58%)
Hispanic, n (%)	0 (0)	3 (4)	0 (0)	3 (5)	0 (0)	1 (2)	0 (0)	1 (3)	0 (0)	0 (0)
Current student, n (%)	3 (4)	4 (5)	3 (5)	4 (6)	1 (2)	2 (4)	1 (3)	1 (3)	0 (0)	0 (0)
College degree or higher, n (%)	6 (7)	38 (45)	5 (8)	31 (47)	2 (4)	26 (50)	2 (6)	18 (51)	1 (4)	11 (46)
Currently employed, n (%)	18 (21)	45 (53)	17 (26)	35 (53)	9 (17)	29 (56)	3 (9)	19 (54)	1 (4)	13 (54)
Annual household income >$50,000, n (%)	3 (4)	40 (47)	3 (5)	32 (49)	1 (2)	26 (50)	1 (3)	18 (51)	0 (0)	11 (46)
Married, n (%)	6 (7)	42 (50)	5 (8)	33 (50)	2 (4)	29 (56)	2 (6)	20 (58)	1 (5)	12 (50)
Maternal age (years), mean (SD)	28.2 (4.8)	30.9 (4.5)	28.7 (5.0)	30.9 (4.3)	28.8 (3.9)	32.0 (4.6)	27.7 (3.5)	32.4 (5.2)	27.7 (3.5)	32.4 (5.2)

[a] All covariates were measured at baseline. Black was defined as Black/African American or African. Percentages (in parentheses) were calculated for all participants contributing data in each phase.

Table 2. Distribution of number of completed surveys per participant by phase and race (N=85).

Phase and race	Median	Minimum	Maximum
All (N=85)			
Black (n=32)	33	1	153
White (n=53)	55	1	199
Pre (81 days; n=66)			
Black (n=23)	25	1	74
White (n=43)	38	2	75
Early (52 days; n=52)			
Black (n=19)	13	1	34
White (n=33)	23	3	49
During (84 days; n=35)			
Black (n=12)	18.5	1	59
White (n=23)	58	2	73
Post (88 days; n=24)			
Black (n=10)	20	3	61
White (n=14)	62.5	1	87

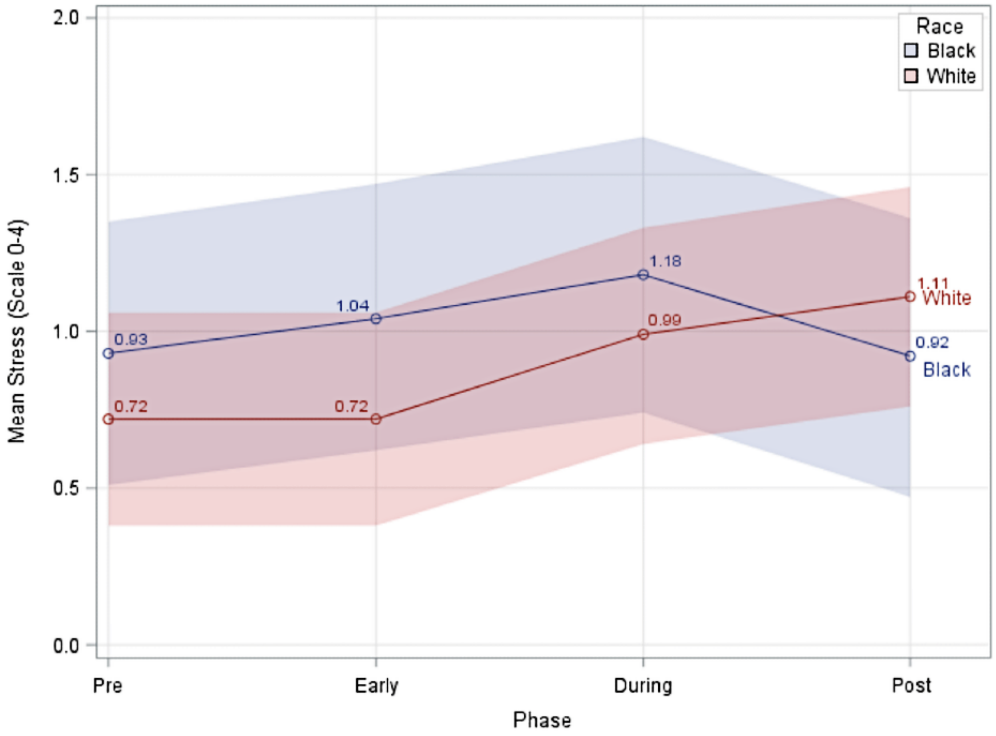
The distribution of unadjusted mean stress levels for Black and White participants is shown in Table 3. The overall mean stress levels between Black and White participants were not different during the pre phase; however, differences were observed at each of the other phases.

Since results from the unadjusted model were very similar to those from the adjusted model, results from the adjusted model were used to address the three main hypotheses of the study. Based on the adjusted model, the interaction term regarding race and study phase was statistically significant ($F_{1,3}$=14.8, P<.001). Figure 2 shows the mean stress levels for Black and White participants.

Table 3. Distribution of unadjusted mean stress levels by phase and race (N=85).

Phase and race	Mean	Minimum	Maximum
Pre (n=66)			
Black (n=23)	0.8	0	3.9
White (n=43)	0.8	0	2.8
Early (n=52)			
Black (n=19)	0.8	0	2.9
White (n=33)	0.9	0	2.7
During (n=35)			
Black (n=12)	1.4	0	4.0
White (n=23)	1.1	0	4.0
Post (n=24)			
Black (n=10)	0.5	0	1.8
White (n=14)	1.3	0.1	4.0

Figure 2. Mean level of stress for each phase by race, adjusted for marriage, education level, employment, and income level.



Post hoc contrasts regarding all participants, based on the linear mixed-effects model, showed an increase in mean stress level of 0.26 points (t_{5649}=5.2, *P*<.001) in the during phase compared to the pre phase, and an increase of 0.2 points (t_{5649}=3.1, *P*=.002) in the post phase compared to the pre phase (Table 4). Results showed that there was no difference between Black and White participants in the change in mean stress from the pre phase to the during phase (=–0.02, *P*=.90). Given the significant race and phase interaction and the mean stress trajectories in Figure 2, which showed that mean stress increased between the during and post phases for White participants and decreased for Black participants between these phases, we conducted an ancillary analysis focused on a final contrast between Black and White participants regarding the change in reported stress levels between the during and post phases. There was a significant difference between Black and White participants in the change in mean stress levels from the during phase to the post phase (=0.4, *P*<.001).

In the additional analyses conducted using ordinal generalized linear mixed-effects models, the results were consistent with those from the linear mixed-effects model for the first and third hypotheses. However, the ordinal generalized linear mixed-effects model supported the second hypothesis, while the linear mixed-effects model did not. Further details regarding the results from the ordinal generalized linear mixed-effects model can be found in Multimedia Appendix 1.

Table 4. Phase-to-phase comparison of mean stress in the adjusted model.

Phase comparison	Difference in adjusted mean stress (SE)	*T* value (*df*)	*P* value
During to pre	0.3 (0.1)	5.2 (5649)	<.001
Post to pre	0.2 (0.1)	3.1 (5649)	.002

Discussion

Principal Results

We found an increase in mean reported perceived stress levels during initial emergency declarations and stay-at-home orders in Allegheny County, Pennsylvania, compared to baseline (pre phase) among study participants. This finding supports our first hypothesis that participants would report increased stress levels during the period of initial emergency declarations/stay-at-home orders (during phase), which were enacted to decrease the public's risk of infection with COVID-19 due to limited knowledge and resources to address the outbreak. The second hypothesis predicted that reported stress levels would return to baseline (pre phase) in the post phase (when stay-at-home orders eased), as residents could resume some of their normal daily activities. However, we found that stress levels remained elevated during this period and did not return to baseline. Our third hypothesis anticipated that Black participants would report higher stress levels from the pre phase to the during phase than White participants, based on previous studies indicating that Black people reported higher stress levels during pregnancy than non-Black people [38,39]. We found no significant difference in mean stress level between Black and White participants during the phases (pre, early, and during) of the study. We also found that only Black participants' mean levels of stress were near baseline levels during the post phase. In fact, mean stress levels among White participants increased in each phase of the study (pre, early, during, and post), and did not return to baseline levels. In our ancillary analysis (Multimedia Appendix 1), we found a significant Black-White difference in mean stress levels from the during to the post phase, when mean stress levels decreased for Black but not White participants.

The psychological, economic, and other short-term and long-term consequences of the COVID-19 pandemic are still emerging. During our study period, the US public experienced varying risk levels based on community spread of the virus. Uncertainty related to anticipated surges of cases without a vaccine or treatment to sufficiently reduce risk of illness or death was a potential stressor. Additionally, unemployment—even briefly—may have longer-term financial consequences as families recover from income loss, including the risk of housing insecurity. As noted during the COVID-19 pandemic in the United States, even as restrictions on nonessential businesses eased, the easing of restrictions was not a panacea. The unemployment rate was 8.4% when public health–related restrictions eased in August 2020, which was still 4.9 percentage points higher than it was in February 2020, prior to stay-at-home orders [40]. Changes in employment and formal and informal resources during the different phases of the pandemic may have contributed to the increasing reported stress levels for Black and White participants. We collected limited sociodemographic data longitudinally, which prevented us from elucidating differences in reported stress levels for both Black and White participants based on changes in sociodemographic characteristics (eg, employment). In addition, there may be racial differences in completion rates of surveys. However, we do not know if survey completion rates were an effect of the pandemic or a true racial difference. Although this is a limitation, our study findings provide important insight into the experiences of pregnant and postpartum people during the pandemic.

Previously, two studies found that working from home, spending more time with a new baby, saving money, managing expectations, having access to outdoor spaces, and practicing healthy behaviors were all positive coping mechanisms among US pregnant and postpartum people during the pandemic [20,21]. However, parents who continued to work during stay-at-home orders, returned to work, or telecommuted as a work option potentially experienced disruptions or challenges to childcare due to uncertainty regarding the reopening of schools, remote learning for children, and disruptions in other childcare options [9,41]. These factors as well as loss of household income, difficulty meeting basic needs (eg, rent/mortgage), and other unmet needs (eg, food insecurity) may contribute to experiences of stress. Additionally, national protests against racism and calls for police reform in the wake of the killing of George Floyd ensued over the summer of 2020. The inability to cope with unmet needs related to the pandemic in tandem with the effects of state-sanctioned violence had the potential to exacerbate experiences of stress among childbearing people. Further research is necessary to establish whether resources to cope with these challenges contributed to racial differences in reported stress levels in perinatal populations and to identify the protective factors that were most beneficial to different racial groups.

It is important to note that we modeled stress both as an ordinal and a continuous variable. The results from these two models were consistent for the first and third hypotheses. The discrepancy between results for the second hypothesis may be attributed to the difference in how stress levels were categorized. In the ordinal generalized mixed-effects model, response categories were collapsed into 3 categories from the original 5 levels due to smaller numbers of responses in the higher stress categories (stress levels 3 and 4). Thus, the ordinal generalized mixed-effects model could not detect the nuanced changes from one stress level to the next given the collapsed categories.

Limitations

We are aware that our study findings have some limitations. First, this study did not collect data on changes in sociodemographic information over time, but baseline measures provided some indication of participants' status. As previously stated, this was a limitation in examining racial differences in our sample. Second, our overall sample size decreased from one phase of the study to the next, especially for Black participants. In addition, Black participants contributed fewer surveys throughout the study period, and their responses were the lowest in the post phase. Our findings indicated that Black participants' mean stress levels returned to baseline during the post phase. Lower survey responses among Black participants throughout the study period could bias findings, especially if the reduction in response rates was due to experiences of stress during the study period. Finally, since our sample was drawn from one county served by one maternity hospital in Pennsylvania, our findings may not be generalizable to other settings.

Strengths

Several strengths of this study should be noted. The participants were already enrolled in an ongoing longitudinal study, which allowed for the examination of stress over significant phases of the COVID-19 pandemic in the United States, particularly in a diverse population in southwestern Pennsylvania. The use of EMA methods and smartphone technology meant that survey responses were obtained in real time and in the social context of the participants. Additionally, we used a random sampling design in administering random assessments to provide a representative sample of participants' survey responses over the study interval. Moreover, survey responses collected in real time via smartphone technology provided insight into participants' experiences of stress during the initial emergency declarations related to the pandemic and stay-at-home orders intended to reduce the public's risk of infection.

Conclusions

In this paper, we explored racial differences in stress over time among childbearing people during the COVID-19 pandemic using EMA data collection methods via smartphone technology. To our knowledge, this is the first study using these methods to examine stress over time in a diverse US sample of childbearing people. Evidence from this study suggests there are racial differences in experiences of stress during the pandemic. Moreover, differences in socioeconomic status and support systems, such as marriage, may influence the degree of the impact of the COVID-19 pandemic. The impact of COVID-19 on US residents is ongoing and the risk of infection is still a public concern. Our research highlights the need for medical and public health practitioners to understand stress among perinatal populations during an ongoing pandemic and public health emergency, so they know how to intervene to reduce adverse maternal health outcomes. Ongoing research is needed to understand the enduring and long-term impact of the COVID-19 pandemic on childbearing individuals in the United States, and how best to address these concerns for different populations.

Acknowledgments

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Conflicts of Interest

ED is a member of the United States Preventive Services Task Force (USPSTF). This article does not necessarily represent the views and policies of the USPSTF. MLW is a consultant for Noctem, but the author's work is not related to this project.

Multimedia Appendix 1
Ordinal generalized linear mixed-effects modeling.
[DOCX File , 25 KB - mental_v8i9e30422_app1.docx]

References

1. CDC Media Relations. First Travel-related Case of 2019 Novel Coronavirus Detected in United States. CDC Newsroom. 2020 Jan 21. URL: https://www.cdc.gov/media/releases/2020/p0121-novel-coronavirus-travel-case.html [accessed 2021-02-16]
2. Trump D. Proclamation on Declaring a National Emergency Concerning the Novel Coronavirus Disease (COVID-19). The White House. 2020 Mar 13. URL: https://trumpwhitehouse.archives.gov/presidential-actions/proclamation-declaring-national-emergency-concerning-novel-coronavirus-disease-covid-19-outbreak/ [accessed 2020-10-08]
3. Listings of WHO’s response to COVID-19. World Health Organization. 2020 Jun 29. URL: https://www.who.int/news/item/29-06-2020-covidtimeline [accessed 2020-10-08]
4. The White House. 15 Days to Slow the Spread. 1600 Daily. 2020 Mar 16. URL: https://trumpwhitehouse.archives.gov/articles/15-days-slow-spread/ [accessed 2021-02-16]
5. Jernigan DB, CDC COVID-19 Response Team. Update: Public Health Response to the Coronavirus Disease 2019 Outbreak - United States, February 24, 2020. MMWR Morb Mortal Wkly Rep 2020 Feb 28;69(8):216-219 [FREE Full text] [doi: 10.15585/mmwr.mm6908e1] [Medline: 32106216]
6. Nagler RH, Vogel RI, Gollust SE, Rothman AJ, Fowler EF, Yzer MC. Public perceptions of conflicting information surrounding COVID-19: Results from a nationally representative survey of U.S. adults. PLoS One 2020 Oct 21;15(10):e0240776 [FREE Full text] [doi: 10.1371/journal.pone.0240776] [Medline: 33085719]
7. State COVID-19 Data and Policy Actions. Kaiser Family Foundation. URL: https://www.kff.org/coronavirus-covid-19/issue-brief/state-covid-19-data-and-policy-actions/ [accessed 2020-11-09]
8. Auger KA, Shah SS, Richardson T, Hartley D, Hall M, Warniment A, et al. Association Between Statewide School Closure and COVID-19 Incidence and Mortality in the US. JAMA 2020 Sep 01;324(9):859-870 [FREE Full text] [doi: 10.1001/jama.2020.14348] [Medline: 32745200]
9. Sharfstein JM, Morphew CC. The Urgency and Challenge of Opening K-12 Schools in the Fall of 2020. JAMA 2020 Jul 14;324(2):133-134. [doi: 10.1001/jama.2020.10175] [Medline: 32478827]
10. Shields AD, Wagner RK, Knutzen D, Deering S, Nielsen PE. Maintaining access to maternal fetal medicine care by telemedicine during a global pandemic. J Telemed Telecare 2020 Sep 26:1357633X2095746. [doi: 10.1177/1357633x20957468]
11. US Bureau of Labor Statistics. The Employment Situation — April 2020. Economic News Release. 2020. URL: https://www.bls.gov/news.release/archives/empsit_05082020.htm [accessed 2020-10-08]
12. Dey M, Loewenstein M. How many workers are employed in sectors directly affected by COVID-19 shutdowns, where do they work, and how much do they earn? Monthly Labor Review. 2020 Apr. URL: https://www.bls.gov/opub/mlr/2020/article/covid-19-shutdowns.htm [accessed 2020-10-08]

13. Xiong J, Lipsitz O, Nasri F, Lui LM, Gill H, Phan L, et al. Impact of COVID-19 pandemic on mental health in the general population: A systematic review. J Affect Disord 2020 Dec 01;277:55-64 [FREE Full text] [doi: 10.1016/j.jad.2020.08.001] [Medline: 32799105]
14. Czeisler M, Lane RI, Petrosky E, Wiley JF, Christensen A, Njai R, et al. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic - United States, June 24-30, 2020. MMWR Morb Mortal Wkly Rep 2020 Aug 14;69(32):1049-1057 [FREE Full text] [doi: 10.15585/mmwr.mm6932a1] [Medline: 32790653]
15. Park CL, Russell BS, Fendrich M, Finkelstein-Fox L, Hutchison M, Becker J. Americans' COVID-19 Stress, Coping, and Adherence to CDC Guidelines. J Gen Intern Med 2020 Aug 29;35(8):2296-2303 [FREE Full text] [doi: 10.1007/s11606-020-05898-9] [Medline: 32472486]
16. Lebel C, MacKinnon A, Bagshawe M, Tomfohr-Madsen L, Giesbrecht G. Elevated depression and anxiety symptoms among pregnant individuals during the COVID-19 pandemic. J Affect Disord 2020 Dec 01;277:5-13 [FREE Full text] [doi: 10.1016/j.jad.2020.07.126] [Medline: 32777604]
17. Berthelot N, Lemieux R, Garon-Bissonnette J, Drouin-Maziade C, Martel É, Maziade M. Uptrend in distress and psychiatric symptomatology in pregnant women during the coronavirus disease 2019 pandemic. Acta Obstet Gynecol Scand 2020 Jul;99(7):848-855. [doi: 10.1111/aogs.13925] [Medline: 32449178]
18. Wu Y, Zhang C, Liu H, Duan C, Li C, Fan J, et al. Perinatal depressive and anxiety symptoms of pregnant women during the coronavirus disease 2019 outbreak in China. Am J Obstet Gynecol 2020 Aug;223(2):240.e1-240.e9 [FREE Full text] [doi: 10.1016/j.ajog.2020.05.009] [Medline: 32437665]
19. Preis H, Mahaffey B, Heiselman C, Lobel M. Pandemic-related pregnancy stress and anxiety among women pregnant during the coronavirus disease 2019 pandemic. Am J Obstet Gynecol MFM 2020 Aug;2(3):100155 [FREE Full text] [doi: 10.1016/j.ajogmf.2020.100155] [Medline: 32838261]
20. Preis H, Mahaffey B, Heiselman C, Lobel M. Vulnerability and resilience to pandemic-related stress among U.S. women pregnant at the start of the COVID-19 pandemic. Soc Sci Med 2020 Dec;266:113348 [FREE Full text] [doi: 10.1016/j.socscimed.2020.113348] [Medline: 32927382]
21. Farewell CV, Jewell J, Walls J, Leiferman JA. A Mixed-Methods Pilot Study of Perinatal Risk and Resilience During COVID-19. J Prim Care Community Health 2020 Jul 16;11:2150132720944074 [FREE Full text] [doi: 10.1177/2150132720944074] [Medline: 32674654]
22. Moyer CA, Compton SD, Kaselitz E, Muzik M. Pregnancy-related anxiety during COVID-19: a nationwide survey of 2740 pregnant women. Arch Womens Ment Health 2020 Dec;23(6):757-765 [FREE Full text] [doi: 10.1007/s00737-020-01073-5] [Medline: 32989598]
23. Liu CH, Erdei C, Mittal L. Risk factors for depression, anxiety, and PTSD symptoms in perinatal women during the COVID-19 Pandemic. Psychiatry Res 2021 Jan;295:113552. [doi: 10.1016/j.psychres.2020.113552] [Medline: 33229122]
24. Burke LE, Shiffman S, Music E, Styn MA, Kriska A, Smailagic A, et al. Ecological Momentary Assessment in Behavioral Research: Addressing Technological and Human Participant Challenges. J Med Internet Res 2017 Dec 15;19(3):e77 [FREE Full text] [doi: 10.2196/jmir.7138] [Medline: 28298264]
25. Mendez DD, Sanders SA, Karimi HA, Gharani P, Rathbun SL, Gary-Webb TL, et al. Understanding Pregnancy and Postpartum Health Using Ecological Momentary Assessment and Mobile Technology: Protocol for the Postpartum Mothers Mobile Study. JMIR Res Protoc 2019 Jun 26;8(6):e13569 [FREE Full text] [doi: 10.2196/13569] [Medline: 31244478]
26. Mendez DD, Sanders SA, Lai Y, Wallace ML, Rathbun SL, Gary-Webb TL, et al. Ecological momentary assessment of stress, racism and other forms of discrimination during pregnancy using smartphone technology. Paediatr Perinat Epidemiol 2020 Sep 13;34(5):522-531. [doi: 10.1111/ppe.12619] [Medline: 31930744]
27. Gharani P, Karimi HA, Syzdykbayev M, Burke LE, Rathbun SL, Davis EM, et al. Geographically-explicit Ecological Momentary Assessment (GEMA) Architecture and Components: Lessons Learned from PMOMS. Inform Health Soc Care 2021 Jun 02;46(2):158-177. [doi: 10.1080/17538157.2021.1877140] [Medline: 33612061]
28. Abebe KZ, Scifres C, Simhan HN, Day N, Catalano P, Bodnar LM, et al. Comparison of Two Screening Strategies for Gestational Diabetes (GDM) Trial: Design and rationale. Contemp Clin Trials 2017 Dec;62:43-49 [FREE Full text] [doi: 10.1016/j.cct.2017.08.012] [Medline: 28823926]
29. Davis E, Abebe K, Simhan HN, Catalano P, Costacou T, Comer D, et al. Perinatal Outcomes of Two Screening Strategies for Gestational Diabetes Mellitus: A Randomized Controlled Trial. Obstet Gynecol 2021 Jul 01;138(1):6-15. [doi: 10.1097/AOG.0000000000004431] [Medline: 34259458]
30. Scifres CM, Abebe KZ, Jones KA, Comer DM, Costacou T, Freiberg MS, et al. Gestational diabetes diagnostic methods (GD2M) pilot randomized trial. Matern Child Health J 2015 Jul;19(7):1472-1480. [doi: 10.1007/s10995-014-1651-4] [Medline: 25424454]
31. Wolf T. Order of the Governor of the Commonwealth of Pennsylvania for Individuals to Stay At Home. Office of the Governor. 2020. URL: https://www.governor.pa.gov/wp-content/uploads/2020/03/03.23.20-TWW-COVID-19-Stay-at-Home-Order.pdf [accessed 2020-10-08]
32. Allegheny County Health Department. COVID-19. ACHD Resources. 2020. URL: https://www.alleghenycounty.us/Health-Department/Resources/COVID-19/COVID-19.aspx [accessed 2020-11-23]

33. COVID-19 in Pennsylvania. PA Department of Health. URL: https://www.health.pa.gov/topics/disease/coronavirus/Pages/Coronavirus.aspx [accessed 2020-11-23]
34. Timeline: WHO's COVID-19 response. World Health Organization. URL: https://www.who.int/emergencies/diseases/novel-coronavirus-2019/interactive-timeline [accessed 2020-11-23]
35. Cohen S, Kamarck T, Mermelstein R. A Global Measure of Perceived Stress. Journal of Health and Social Behavior 1983 Dec;24(4):385. [doi: 10.2307/2136404]
36. Mendez DD, Hogan VK, Culhane JF. Stress during pregnancy: the role of institutional racism. Stress Health 2013 Oct 10;29(4):266-274. [doi: 10.1002/smi.2462] [Medline: 23055409]
37. Shah PS, Zao J, Ali S, Knowledge Synthesis Group of Determinants of preterm/LBW births. Maternal marital status and birth outcomes: a systematic review and meta-analyses. Matern Child Health J 2011 Oct 6;15(7):1097-1109. [doi: 10.1007/s10995-010-0654-z] [Medline: 20690038]
38. Borders AEB, Wolfe K, Qadir S, Kim K, Holl J, Grobman W. Racial/ethnic differences in self-reported and biologic measures of chronic stress in pregnancy. J Perinatol 2015 Aug 19;35(8):580-584 [FREE Full text] [doi: 10.1038/jp.2015.18] [Medline: 25789817]
39. Seng JS, Kohn-Wood LP, McPherson MD, Sperlich M. Disparity in posttraumatic stress disorder diagnosis among African American pregnant women. Arch Womens Ment Health 2011 Aug 15;14(4):295-306 [FREE Full text] [doi: 10.1007/s00737-011-0218-2] [Medline: 21573930]
40. US Bureau of Labor Statistics. The Employment Situation — August 2020. Economic News Release. 2020. URL: https://www.bls.gov/news.release/archives/empsit_09042020.htm [accessed 2020-10-14]
41. Patrick SW, Henkhaus LE, Zickafoose JS, Lovell K, Halvorson A, Loch S, et al. Well-being of Parents and Children During the COVID-19 Pandemic: A National Survey. Pediatrics 2020 Oct;146(4):e2020016824. [doi: 10.1542/peds.2020-016824] [Medline: 32709738]

Abbreviations

EMA: ecological momentary assessment
GDM^2: Comparison of Two Screening Strategies for Gestational Diabetes Trial
PMOMS: Postpartum Mothers Mobile Study
PTSD: posttraumatic stress disorder
VIF: variance inflation factor
WHO: World Health Organization

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Original Paper

Investigating Viewership of Season 3 of “13 Reasons Why” and the Mental Wellness of Adolescents: Partially Randomized Preference Trial

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Abstract

Background: A conflicting body of research suggests that additional investigation is needed to understand how globally watched television shows featuring social and mental health issues, such as *13 Reasons Why*, might affect adolescents’ mental wellness.

Objective: This study aims to investigate adolescents’ viewership of the third season of the Netflix drama *13 Reasons Why* (13RW-3) and their engagement with show-related content, paying special attention to mental health outcomes and conversational partners.

Methods: A panel-based research platform operated by the National Opinion Research Center at the University of Chicago recruited 157 adolescents aged 13 to 17 years from its nationally representative pool of participants. Participants answered questions about how they discussed and learned about social and mental health issues portrayed in 13RW-3 (eg, masculine role pressure and sexual assault) and questions about mental wellness (eg, mental health self-efficacy and depression). After the participants completed the survey (T1), they were directed to either watch 13RW-3 as it aired for the first time (intervention group) or *not* watch 13RW-3 (control group). Approximately one month later (T2), all the participants were asked to complete the postsurvey. Additional survey questions about conversational partners, information seeking because of watching the show, and use of show-related content were included in the intervention postsurvey.

Results: Our sample (N=157) was 52.2% (n=82) female and 54.8% (n=86) White, with a mean age of 14.99 (SD 1.4) years. At T2, viewers of 13RW-3 spoke about suicide significantly more frequently than nonviewers (*P*=.007). From T1 to T2, viewers increasingly discussed issues explored by 13RW-3 (*P*=.002), especially suicide, mental health, and bullying. Adolescent viewers were most likely to speak with friends, and parents were the second most commonly named. Two variables emerged as consistent moderators of conversational choices—having depressive symptoms and being impacted by sexual assault. There was no association between conversational frequency and information seeking around social and mental health issues, and neither mental health self-efficacy scores nor masculine role pressure scores significantly differed between viewers and nonviewers at T2.

Conclusions: Viewing 13RW-3, a globally watched television show featuring social and mental health issues, led to adolescent conversations and information searches about topics explored by the show. Depressive symptoms and the impact of sexual assault moderated several relationships, guiding participants toward engaging with certain issues and seeking out specific conversational partners. As 13RW-3’s stories drove conversations—and story-driven conversations can raise awareness, reduce stigma, shift attitudes, normalize certain behaviors, and strengthen supportive relationships—potential wellness implications for television shows featuring social and mental health issues are considerable.

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KEYWORDS

media; adolescence; mental health; narrative; 13 Reasons Why; conversation; television; depression; sexual assault

Introduction

Background

The first season of the Netflix drama *13 Reasons Why* (13RW-1), which examined a 17-year-old girl's reasons for death by suicide, took the world by storm. It garnered unprecedented levels of engagement across social media, becoming the *most tweeted-about show ever* in the history of streaming television [1]. It drew favorable reviews from critics and viewers (78% and 80%, respectively, on the Rotten Tomatoes website) and high-profile recognition, including an Emmy nomination, a Golden Globes nomination, and a National Association for the Advancement of Colored People Image Award win.

However, the subject matter of 13RW-1 also elicited speculation of possible harm to youth. It flouted several recommendations for suicide-themed stories, including the established injunction against graphically depicting suicidal acts and newer best practices of providing trigger warnings and recommending resource providers, such as Crisis Text Line or Rape, Abuse & Incest National Network. In doing so, some argued that Netflix put a target on its back and put young people at risk. Myriad public health experts and organizations published condemnations, warnings, and recommendations [2-4], whereas many researchers used diverse methods to study the impact of the show [5-16].

For example, Ayers et al [5] found higher than predicted suicide-related keyword search activity on Google, whereas Cooper et al [6] found higher than predicted admissions to a children's hospital because of an intent to self-harm. Another study found a postexposure worsening in mood that was particularly pronounced among the most vulnerable adolescent viewers [7]. Other researchers found that, among adolescent viewers who had ever considered suicide, a minority reported increases in suicidal ideation, whereas more than twice as many reported decreases [8]. A large survey of young adults, adolescents, and parents across 4 countries reported positive outcomes from viewing 13RW-1, including higher rates of suicide awareness, empathy, information seeking, outreach, and interpersonal discussion [9].

This conflicting corpus suggests that more research is needed to understand how television shows like *13 Reasons Why* (13RW) might affect adolescents. For example, despite numerous studies about the program, investigators had not conducted an experiment in real time, assigning adolescent participants to watch the show during its initial airing. Few studies investigated how viewers navigated show-related content. Finally, hardly any studies explored whether or how the show indirectly affected vulnerable youth by activating conversations in their networks, despite decades of research documenting how shows that spark interpersonal discussion are more likely to promote behavioral change [17,18].

Developmental Stage

Adolescence is a critical age for identity development, characterized by elevated social-affective engagement and goal flexibility [19]. Physiologically, it is also a time when the brain is most receptive to the environment [20]. The sheer number of hours that adolescents spend with screen media daily—7 hours and 22 minutes, not including the time spent using screens for school or homework [21]—demonstrates that media shapes adolescents' lived experiences.

Since the emergence of COVID-19, the number of hours that youth spend with media has skyrocketed [22], whereas early data [23] and youths' own testimonies [24,25] suggest that the pandemic's immediate and long-term impacts on adolescent mental wellness may be considerable. Entertainment media can contribute to adolescents' well-being by destigmatizing mental health issues, modeling help-seeking behavior, and helping vulnerable youth to feel less alone. Collectively, this suggests that media consumed during adolescence may be an especially powerful socializing agent and thus raises the stakes around global media franchises targeted to young people.

This Study

Overview

This study was designed to investigate adolescents' viewership of the third season of *13 Reasons Why* (13RW-3) and their engagement with show-related content, with special attention paid to mental health outcomes and conversational partners. The research design was a two-wave panel in which adolescents were aged 13-17 years, recruited from across the United States, and answered a survey at each wave. We developed the questions in our survey by taking into account the extensive body of literature documenting the positive relationships among viewing entertainment, talking about the content, and seeking relevant information [17,18]. We also considered the 13RW-3 storyline, which prominently featured masculine role pressure, sexual assault, and the journey toward healing. Finally, we considered other 13RW studies' examination of viewers' mental health outcomes [14-16,26-29].

Between time 1 (T1) and time 2 (T2), participants were directed to either watch 13RW-3 (as it was aired for the first time) or *not* watch it. Our primary aim was to discover whether or how watching 13RW-3 was related to shifts in knowledge, attitudes, and behavior around mental wellness. Our secondary aim was to identify variables that moderated the experiences of more vulnerable adolescents.

Season 3 Summary

Although 13RW-1 unpacked protagonist Hannah's death by suicide and the second season of 13RW pursued legal accountability for this tragedy, 13RW-3 centered on sexual assault and bullying. The show's third season explored characters' home lives, implicitly suggesting that masculine role pressure (enacted via elders' homophobia, objectification of women, and physical abuse) might have facilitated antagonists' peer-to-peer violence. Sexual assault survivors also took space and demanded justice. Similar to 13RW-1, the season's first episode revealed the death of a young person, serial rapist Bryce Walker. Subsequent episodes unraveled how that happened and who was to blame.

Hypotheses

We hypothesized that after watching 13RW-3, adolescent viewers would speak about social and mental health issues more frequently than nonviewers and they had at T1, score higher on mental health self-efficacy measures than nonviewers, score lower on masculine role pressure measures than nonviewers, and seek out information about social and mental health issues. We also linked conversation and information seeking, hypothesizing that viewers who spoke about 13RW-3 and show-related issues would seek out more information about social and mental health issues than viewers who did not report these conversations. In addition to interrogating these hypotheses, we explored the moderating effects of age, gender, race, sexual orientation, and experiences with suicidal ideation, depression, and sexual assault.

Methods

Recruitment

A panel-based research platform operated by the National Opinion Research Center (NORC) at the University of Chicago recruited adolescents aged 13 to 17 years from its nationally representative pool of participants. NORC solely retained participants' personally identifiable information, submitting anonymized data to our research team (details on their recruitment practices are given in Multimedia Appendix 1).

Intervention

Overview

The NORC first reached out to parents of eligible adolescents to obtain their consent for their children to participate in the study. Next, they invited adolescents of consenting parents or guardians to take the T1 survey. If an adolescent clicked "YES" in the invitation, the NORC system brought them to a screener question—whether they had watched any of 13RW-3. If they had not (a prerequisite for participation), they were brought to a webpage that used a language approved by the institutional review board to support informed consent (Multimedia Appendix 2). When the adolescents clicked "YES" to indicate consent, the system brought them to the T1 survey. After completing the T1 survey, the NORC system randomly assigned participants to either watch 13RW-3 (intervention group) or *not* watch 13RW-3 (control group). The T1 survey was open for 1 month, closing on September 20, 2019. During this time, 263 participants (130 assigned to the intervention group and 133 assigned to the control group) completed the T1 survey.

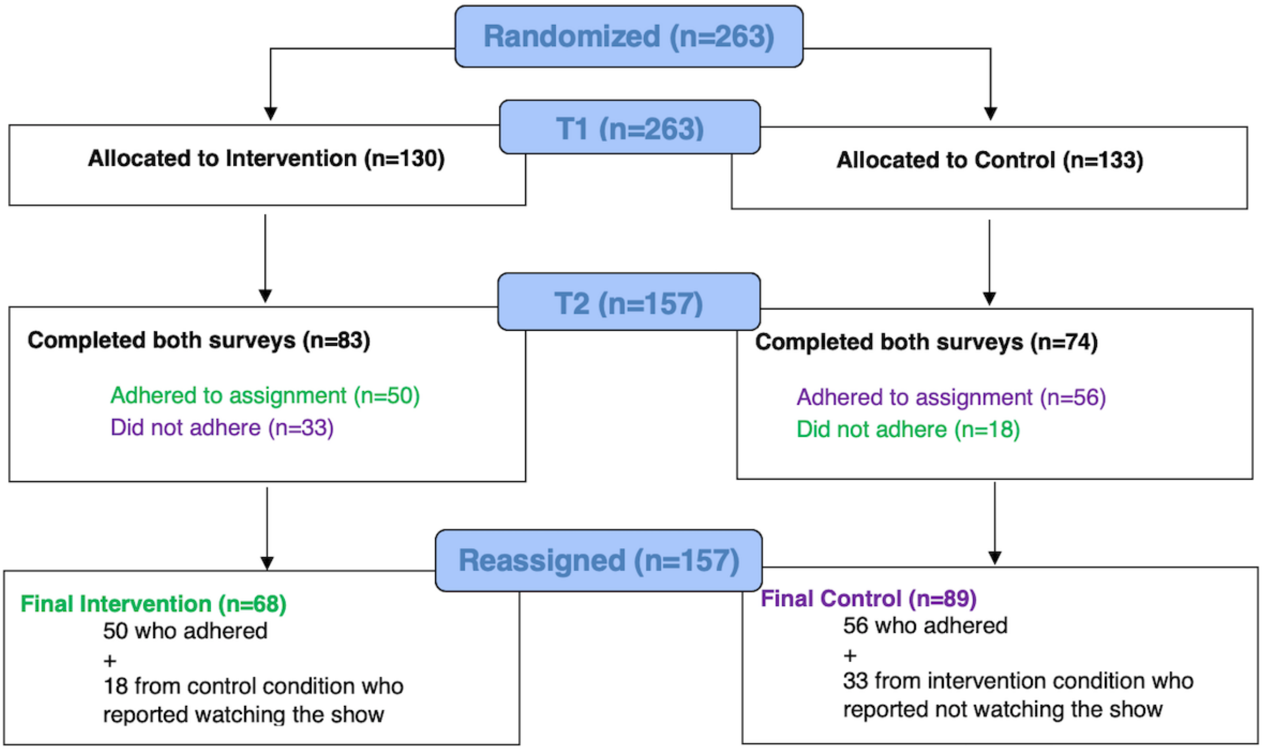
The T2 survey was launched on September 26, 2019 (approximately a month after Netflix released 13RW-3) and closed on November 18, 2019. During this time, 157 participants completed the full survey—83 members of the intervention group and 74 members of the control group, representing a 59.7% (157/263) retention rate from T1 to T2. This rate is normative for social science research with teen and young adult populations [30], nearly mirroring a recent study by Cantrell et al [31] that retained 63.45% (7756/12,223) of its 15- to 21-year-old sample from T1 to T2.

Protocol Adherence

Despite the research team's instructions to watch or not watch per random assignment, about one-third (51/157, 32.5%) of the sample disclosed in the T2 survey that they did not follow the protocol. Adolescent nonadherence is common across clinical and social science research. In this study, 51 participants did not adhere; 33 of the 83 participants randomly assigned to the intervention group did not watch the show, whereas 18 of the 74 participants randomly assigned to the control group watched the show (Figure 1).

Consequently, to maximize the statistical power, researchers shifted nonadherent participants to the group in which they actually participated so that their data would reflect their viewership [32]. After reassignment, the intervention group included 68 participants, with a quarter of these (18 participants) self-selecting into this condition from the control group; the control group included 89 participants, with approximately a third (33 participants) self-selecting into this condition from the intervention group (Figure 1). We used two-tailed independent sample *t* tests to compare whether the adherent and nonadherent participants differed on demographic data such as age, gender, race, sexual orientation, parental income, and geographical location and whether they had watched the previous seasons of the show. We found no differences between the 2 groups except for race (χ^2_4=11.5; *P*=.02), with Asian and mixed-race participants oversampling in nonadherence. We also ran independent *t* tests for all measures at T1 and found a significant difference for mental health self-efficacy (t_{155}=–2.546; *P*=.01), with the nonadherent group scoring an average of 3.65 (SD 0.81) on this question versus 3.98 (SD 0.74) for the adherent group.

Figure 1. Participation flowchart from T1 to T2 to reassignment.



Protective Measures for At-Risk Adolescents

To support participants' wellness, study participation was restricted to lower risk adolescents and all the participants were advised, "In the event that you disclose information about your possible intentions to do harm to yourself or others, NORC will provide information about your intentions to your parent(s) or legal guardian(s)." Therefore, if an adolescent answered in the T1 survey that they had seriously considered suicide, they were sent to a termination page and NORC personnel notified their parents. In addition to standard consent information, the survey offered a list of relevant resource providers (eg, Crisis Text Line) with the encouragement to "copy, screenshot, or print these resources now so that you can draw upon them at any time" (list given in Multimedia Appendix 3). The footer on every survey page at T1 and T2 also featured the following text: "If you are experiencing distress or discomfort, see this list of resources for help." These procedures were approved by University of California, Los Angeles's institutional review board.

Measures

Overview

Approximately 6 weeks before the third season's launch, 13RW-3 producers provided 3 members of the research team access to the show's locked footage. This allowed researchers to craft a survey that asked about social and mental health issues central to 13RW-3 (eg, masculine role pressure, sexual assault, etc). Owing to space limitations, the described measures were found to be significant in the analysis. The full survey also included questions related to psychological and communication constructs (the full survey given in Multimedia Appendix 4).

Conversations Around Social and Mental Health Issues

A 7-item scale developed specifically for this investigation was used to assess conversational frequency around various social and mental health issues. Participants were asked how often they had spoken with their friends over the past 30 days about (1) *suicide* (*ie, considering and attempting*), (2) *mental health* (*ie, severe anxiety, anorexia, depression, etc*), (3) *bullying* (*ie, online and offline*), (4) *sexual assault* (*ie, inappropriate touching, lewd comments, rape, etc*), (5) *rigid gender stereotypes* (*ie, boys will be boys, girls are too emotional, etc*), (6) *substance abuse* (*ie, drugs, alcohol, etc*), and (7) *sexuality* (*ie, hookups, gender identity, sexual orientation, etc*). Response choices included 0=*not at all*, 1=*once a week*, 2=*a few times a week*, and 3=*every day or almost every day of the week.*

For participants in the intervention group only, the T2 survey included additional measures of conversation. One item asked whether participants discussed the 13RW-3 and show-related issues. The other item asked participants to select all of the people with whom they discussed 13RW-3 and issues related to the show after watching. Response choices included (1) *friends*, (2) *parents*, (3) *partner, boyfriend or girlfriend*, (4) *sibling*, (5) *teacher*, (6) *school counselor*, (7) *mental health professional or someone at a mental health resource hotline*, (8) *I did not discuss the show with anyone*, and (9) *other*.

Information Seeking

For participants in the intervention group only, 2 additional T2 survey questions were developed to assess whether viewers sought information about mental health issues either during or after watching the show. One item asked, "During or after watching the show, due to something you watched in the show, did you try to learn more about any of the following (through online search, asking an adult, etc.)?" Response choices included 10 items, such as (1) *suicide (considering and attempting)* and (2) *mental health (eg, severe anxiety, anorexia, depression, etc)*. Responses for each topic were tallied. The other item asked participants to select all of the show-affiliated crisis or informational resources that they visited. Response choices included 6 items ("www.13reasonswhytoolkit.org," "13reasonswhy.info," etc). Responses for each resource were tallied (the entire list of responses are given in Multimedia Appendix 4).

Masculine Role Pressure

A 6-item scale was developed to assess masculine role pressure, drawn from a survey used to inform Plan International's *The State of Gender Equality for US Adolescents* report [33]. Participants were asked to indicate their agreement with questions such as "I know what makes a romantic relationship healthy" and "I know how to tell if my partner is uncomfortable in a sexual relationship" (the entire list of responses are given in Multimedia Appendix 4). Response choices across a 5-point scale ranged from 1 (*strongly disagree*) to 5 (*strongly agree*). Responses were averaged to create a composite score, with higher scores representing more masculine role pressure.

Sexual Assault

A 3-item scale assessed participants' experiences with sexual assault, drawn from the 2017 Youth Risk Behavior Survey [34]. Participants were asked to indicate whether the following had occurred: "Have you ever been forced to have sexual intercourse when you did not want to?" "Have you ever been forced to do sexual things that you did not want to do? (Count such things as kissing, touching, or being physically forced to have sexual intercourse)," and "Are you close with anyone (friend, family member, romantic or sexual partner) who has ever forced someone else to do sexual things that the other person did not want to?" Response choices included 1=*Yes*, 2=*No*, and 3=*I don't know*.

Depression

To assess participants' level of depression, we used the Patient Health Questionnaire-2, a practical screening tool [35] that has been validated with adolescents [36]. Participants were asked how often they were bothered by each of the following symptoms during the past 7 days: (1) "Feeling down, depressed, irritable, or hopeless," (2) "Little interest or pleasure in doing things." Because of the complex role that sleep plays in adolescent depression [37], we added one item from the Severity Measure for Depression—Child Age 11-17 (adapted from Patient Health Questionnaire-9 modified for adolescents) [32] that asked how often participants experienced (3) "Trouble falling asleep, staying asleep, or sleeping too much." Response choices included 1=*not at all*, 2=*several days*, 3=*more than half of the days*, and 4=*nearly every day*. Item scores were averaged to create a composite score, with higher scores representing more depressive symptoms.

Mental Wellness Self-Efficacy

A 3-item scale was developed to assess participants' (1) mental health self-awareness ("I can recognize my own mental health-related 'warning signs,' or indicators that my own mental health may be poor"), (2) knowledge about mental health resources ("I know how to find helpful mental health-related information and/or professional support"), and (3) behavioral intention to access necessary mental health support ("If/whenever I need mental health-related information and/or professional support, I would reach out to get what I need"). Response choices across a 5-point scale ranged from 1 (*Strongly disagree*) to 5 (*Strongly agree*). Item scores for this scale were averaged to create a composite score, with higher scores representing higher mental wellness self-efficacy.

Data Analysis

Descriptive statistics and frequencies were used to analyze the demographic data of the participants. A combination of statistical tests, including *t* tests, one-way analysis of variance (ANOVA), chi-square tests, and logistic regressions, were used to analyze the impact of the intervention. Difference scores were calculated between measures at the two time points (representing increases or decreases in measures from T1 to T2) by subtracting T1 data from T2 data (T2−T1). Posthoc power analyses were conducted using G*Power [38]. Sets of analyses primarily using *t* tests and one-way ANOVA were conducted independently to compare (1) intervention versus control groups and (2) the intervention group only. For the intervention versus control analyses, the power analysis of our 2-tailed *t* tests, measuring the differences between the experimental and control groups, resulted in a power of β=.802 (control: N=89; intervention: N=68; Cohen d=0.455; α=.05). The power analysis of our one-way ANOVA, measuring fixed effects omnibus tests between our 2 groups, resulted in a power of β=.968 (N=157; Cohen f=0.306; α=.05). For the intervention-only analyses, the power analysis of our 2-tailed *t* tests, measuring a difference from a constant, resulted in a power of β=.896 (N=68; Cohen d=0.396; α=.05). SPSS version 26 was used for all analyses.

Results

Participants

The final sample consisted of 157 participants—68 in the intervention group and 89 in the control group (demographics broken down by conditions are given in Table 1). The mean age of the sample was 14.99 years. The sample was fairly well balanced in terms of gender, with 82 females and 75 males. Most of the sample 54.8% (86/157) was White and non-Hispanic, 18.5% (29/157) identified as Hispanic, 17.2% (27/157) identified as Black, non-Hispanic, 6.4% (10/157) identified as mixed race, and 3.2% (5/157) identified as Asian, non-Hispanic.

Table 1. Demographics of participants.

Demographics	Intervention group (n=68)	Control group (n=89)
Age (years), mean (SD)	15.06 (1.35)	14.91 (1.49)
Gender, n (%)		
Male	33 (49)	42 (47)
Female	35 (51)	47 (53)
Race, n (%)		
Combined White, non-Hispanic	35 (52)	51 (57)
Black, non-Hispanic	13 (19)	14 (16)
Hispanic	14 (21)	15 (17)
Mixed	4 (6)	6 (7)
Asian, non-Hispanic	2 (3)	3 (3)
Geographical location, n (%)		
Northeast	10 (15)	7 (8)
The Midwest	17 (25)	28 (32)
South	23 (34)	34 (38)
West	18 (27)	20 (23)
Household income (US $), range	40,000-49,000	50,000-59,000
Sexual orientation, n (%)		
Heterosexual	51 (75)	75 (84)
Bisexual	3 (4)	3 (3)
Asexual	2 (3)	2 (2)
Homosexual	0 (0)	3 (3)
Other or prefer not to say or do not know	12 (17)	6 (7)

Conversations Around Social and Mental Health Issues

At T2, viewers of 13RW-3 (mean difference [M_{diff}] 0.368, SD 0.827) engaged in conversations around suicide significantly more frequently ($t_{124.580}$=–2.735; *P*=.007; Cohen *d*=0.455) than nonviewers (M_{diff} 0.034, SD 0.651). In addition, compared with T1, at T2, the viewers engaged in significantly more conversations (M_{diff} 0.368, SD 0.827) about social and mental health issues (t_{66}=3.243; *P*=.002; Cohen *d*=0.396), with the number of conversations about suicide (M_{diff} 0.367, SD 0.827), mental health (M_{diff} 0.324, SD 0.999), and bullying (M_{diff} 0.294, SD 0.915) increasing the most.

Two variables emerged as moderators of conversational frequency: depressive symptoms and knowing a survivor of sexual assault. Viewers with higher levels of depressive symptoms at T2 reported more frequent conversations about suicide from T1 to T2 than viewers with lower levels of depressive symptoms ($F_{8,59}$=2.265; between-groups mean square [MS]=1.345; *P*=.04; Cohen *f*=0.554). Knowing a survivor of sexual assault moderated how often viewers spoke about bullying and sexuality, respectively, from T1 to T2. Viewers who knew a survivor of sexual assault reported more frequent conversations about bullying ($F_{1,57}$=5.318; MS=3.813; *P*=.03; Cohen *f*=0.306) from T1 to T2 than viewers who did not. Viewers who knew a survivor of sexual assault spoke about sexuality less frequently from T1 to T2 ($F_{1,57}$=9.985; MS=10.161; *P*=.003; Cohen *f*=0.419) than viewers who did not know a survivor of sexual assault.

Mental Wellness Self-Efficacy and Masculine Role Pressure

After watching 13RW-3, the scores of adolescent viewers on mental wellness self-efficacy measures (M_{diff}–0.152, SD 1.010) did not significantly differ (t_{155}=0.746; *P*=.46) from nonviewers' scores (M_{diff}–0.041, SD 0.853). After watching 13RW-3, scores on masculine role pressure measures (M_{diff} 0.072, SD 0.613) did not significantly differ (t_{151}=–0.134; *P*=.89) from nonviewers' scores (M_{diff} 0.058, SD 0.625).

Information Seeking

After watching 13RW-3, nearly all viewers (58/63, 92%) sought information on social and mental health issues. *Bullying* and *mental health* were the most frequently searched issues.

Once again, depressive symptoms and experiences with sexual assault emerged as moderating variables, influencing the extent to which viewers sought information. Viewers who reported little interest or pleasure in doing things sought information about suicide more than those who did not (B=0.806, SE 0.319; *df*=1; Exp (B)=2.238; *P*=.01; frequencies and significant moderators are given in Table 2). Viewers who reported having trouble with sleep sought more information about rigid gender stereotypes than those who did not report such sleep issues (B=0.663, SE 0.326; *df*=1; Exp (B)=1.940; *P*=.04). Viewers who self-identified as being forced to do sexual things they did not want to (kissing, touching, etc) sought more information about sexual assault than those who did not (Fisher exact test, *P*=.047). Viewers who reported being close to a survivor of sexual assault sought out more information about rigid gender stereotypes than those who did not report such a relationship (Fisher exact test, *P*=.03).

Approximately one-third (21/63, 33%) of viewers engaged with informative resources produced by or affiliated with 13RW (the entire list is given in Table 3).

Table 2. Information seeking by the intervention group and significant moderators.

Topic of information sought	Frequency (n=68), n (%)[a]	Significant moderators
Suicide (eg, considering and attempting)	10 (15)	• Depression subscore: little interest or pleasure in doing things (B=0.806, SE 0.319; *df*=1; Exp (B)=2.238; *P*=.01)
Mental health (eg, severe anxiety, anorexia, and depression)	21 (31)	• N/A[b]
Bullying (eg, web-based and face-to-face)	23 (33)	• N/A
Sexual assault (eg, inappropriate touching, lewd comments, and rape)	16 (24)	• Sexual assault subscore: being forced to do sexual things they did not want to (Fisher exact test, *P*=.047)
Rigid gender stereotypes (eg, boys will be boys)	11 (16)	• Sexual assault subscore: Knowing a survivor (Fisher exact test, *P*=.03) • Depression subscore: Trouble with sleep (B=0.663, SE 0.326; *df*=1; Exp (B)=1.940; *P*=.04)
Substance Abuse (ie, drugs, alcohol, etc)	13 (19)	• N/A
Sexuality (eg, hookups, gender identity, and sexual orientation)	8 (12)	• N/A
Abortions	8 (12)	• N/A
Illegal immigration	9 (13)	• N/A
Other (please specify)	2 (3)	• N/A

[a] The question was “During or after watching the show, due to something you watched in the show, did you try to learn more about any of the following (through web-based search, asking an adult, etc)?” Frequency numbers represent those who checked this response item. Differences were tested by age, gender, race, sexual orientation, depression, and answers to questions about sexual assault.

[b] N/A: not applicable.

Table 3. Engaging with 13 Reasons Why-produced resources (intervention group).

Resource	Frequency (n=63), n (%)[a]
www.13reasonswhytoolkit.org	4 (6)
www.13reasonswhy.info	11 (16)
Discussion Guide on the 13 Reasons Why information webpage	3 (4)
Beyond The Reasons documentary on Netflix	14 (21)
Did not visit any 13 Reasons Why–related crisis or information resources	42 (62)

[a] The question was “Which crisis/informational resources did you visit or watch that are affiliated with the show?” Frequency numbers represent those who checked this response item.

Conversational Partners

The vast majority of viewers (60/68, 88%) reported speaking about 13RW-3 and issues related to the show. Adolescent viewers most commonly chose friends (43/68, 63%) as their conversational partners, followed by parents (32/68, 47%); frequencies and significant moderators are given in Table 4).

Table 4. Conversational partners (intervention group).

Conversational partner	Frequency (n=68), n (%)[a]	Significant moderators
Friends	43 (63)	Sexual assault subscore: viewers who reported knowing a survivor spoke to their friends more than those who did not know a survivor (Fisher exact test, *P*=.047)
Parents	32 (47)	Depression subscore: Viewers who reported feeling down, depressed, irritable, or hopeless spoke to their parents less (B=–0.923, SE 0.373; *df*=1; Exp (B)=0.397; *P*=.01)
Partner or boyfriend or girlfriend	9 (13)	N/A[b]
Sibling	13 (19)	N/A
Other family members	7 (10)	Race or ethnicity: Black and mixed-race participants reported speaking more to other family members (χ^2_4=13.8; *P*=.008)
Teacher	5 (7)	N/A
School counselor	2 (3)	N/A
Mental health professional or someone at a mental health resource hotline	1 (2)[c]	N/A
No one	8 (12)	N/A

[a] The question was “With whom did you discuss 13 Reasons Why and issues related to the show after watching?” Frequency numbers represent those who checked this response item. Differences were tested by age, gender, race, sexual orientation, depression, and answers to questions about sexual assault.

[b] N/A: not applicable.

[c] This respondent reported feeling depressed nearly every day.

In addition to depressive symptoms and knowing a survivor of sexual assault, race or ethnicity also moderated the extent to which viewers spoke about 13RW-3 and show-related issues with certain conversational partners. Viewers who reported higher levels of feeling down, depressed, irritable, or hopeless at T2 spoke to their parents less (B=–0.923, SE 0.373; *df*=1; Exp (B)=0.397; *P*=.01) than those who reported lower levels of depressive symptoms. Viewers who knew a survivor of sexual assault spoke to their friends more than those who did not know a sexual assault survivor (Fisher exact test, *P*=.047). Viewers who identified their race or ethnicity as *Black, non-Hispanic* and *Mixed* spoke with *other family members* (ie, neither parents nor siblings) more than viewers who identified with other races or ethnicities (χ^2_4=13.8; *P*=.008).

Discussion

Principal Findings

As hypothesized, watching the show was associated with significantly more conversations about social and mental health issues. A vast majority (60/68, 88%) of viewers reported discussing the show and related issues. The potential wellness implications were significant. Story-driven conversations can raise awareness, reduce stigma, shift attitudes [39], normalize certain behaviors [40], and strengthen supportive relationships [41]. For example, in a study of a popular TV show with a public health storyline, viewers’ interpersonal discussions facilitated and amplified the show’s impact; when viewers discussed the show, they were more likely to demonstrate show-related shifts in knowledge, attitude, and behavior [42]. By supporting adolescents’ narrative-inspired conversations, parents, educators, and public health officials may reap these types of benefits.

As expected, adolescents most often reported *friends* as their conversational partner (43/68, 63%); more surprisingly, *parents* did not trail far behind. Almost half of the sample participants (32/68, 47%) chose to discuss the show and issues related to the show with parents, with no differences based on gender or age. Intrigued by this finding, we searched for other parent data. We found that 60% (36/60) of 13RW-3 viewers watched the show with a parent at least once, similar to a global study on 13RW-1 [9] wherein 39.1% (184/471) of its sample reported coviewing with a parent and 43% (123/286) of those who did not coview reported talking about the show with a parent. Collectively, these data present parents as important members of adolescents’ media ecologies, at least with respect to shows like 13RW. Despite adolescents’ engagement with individuation, a developmental imperative that has them turning away from parents and toward their peer group [43], adolescents seem to rely on parents’ support for processing this challenging content—even traditionally, harder-to-reach adolescents, such as males.

Supporting our hypothesis, nearly all viewers (58/63, 92%) tried to learn more about issues explored by the show, with *bullying* and *mental health* drawing the most searches. This high rate of engagement outstrips a recent research finding [44], in which approximately half of an adult sample sought more information about something they learned from a fictional movie or TV show. Approximately one-third (21/63, 33%) of viewers engaged with informative resources produced by or affiliated with 13RW. These findings suggest that providing credible, engaging resources is a worthwhile effort for content creators for reasons that are not simply performative.

Additional Findings

We also aimed to identify moderator variables, particularly those that moderated the experiences of more vulnerable adolescent viewers. Our explorations of age, gender, race, and sexual orientation and relationships with suicidal ideation, depression, and sexual assault revealed that lived experience—rather than demographic characteristics—were most likely to significantly affect viewers’ decisions.

Depressive symptoms emerged as an important moderator. Two of our findings related to engaging with the topic of suicide, namely, viewers who reported higher levels of depression talked about suicide more frequently at T2 than those with lower levels of depression. In addition, viewers who reported that they had little interest or pleasure in doing things (a subscale of our depression measure) looked up information on suicide more frequently. It is important to note that the content of these conversations and searches is unknown. Although the popular press tended to frame similar findings from Ayers et al [5] as sinister, assuming or implying that suicide-related information seeking meant procuring strategies on how to end one’s life, this is not necessarily the case. Depressed youth might have sought information or broached a conversation about suicide to get help; for youth, talking about suicide can serve as a protective factor [45]. It is also possible that depressed adolescent viewers initiated conversations to reassure their support networks that, despite their affect, they were not contemplating death by suicide. Interestingly, teen suicide rates declined in 2019, the year in which the show came out [46].

We also found that viewers who reported feeling down or depressed spoke to their parents less than nondepressed peers. This is unsurprising, given the nature of depression, which commonly reduces individuals’ interest in social interaction. Depressed adolescents might have been particularly loath to speak with their parents, who may have been worried about or critical of their condition.

Being affected by sexual assault also moderated several relationships. Adolescent viewers who knew a survivor of sexual assault spoke about bullying more than their peers, whereas they talked about sexuality less. This might suggest viewers’ learning from 13RW-3, which framed sexual assault as oppression—a means for violent bullies to exert power—and not as intimacy. Owing to their knowledge of their friends’ experiences, these viewers might have been more receptive to such framing and/or more curious to learn more.

Indeed, viewers who knew survivors of sexual assault sought information about rigid gender stereotypes more than their peers. Again, this hints at learning from 13RW-3. Season 3 showed how rigid gender stereotypes, especially a set of male heterosexual stereotypes commonly known as toxic masculinity, shaped the home life of the show’s serial rapist. It is possible that, because of their friendship with sexual assault survivors, these viewers were particularly interested in discovering whether or how internalizing rigid gender stereotypes can lead to sexual assault. Similarly, viewers who reported having trouble with sleep (a subscale of our depression measure) sought more information about rigid gender stereotypes than those who did not report such sleep issues. This is consistent with international research that has identified an association between traditional gender role attitudes and poor mental health outcomes (eg, depression and suicidal ideation) [47-49]. Finally, viewers who reported surviving sexual assault sought more information about it than their peers. Owing to their lived experience, these viewers likely were more motivated to make sense of this scourge and work toward healing. Of note, healing from sexual assault was a significant storyline in 13RW-3.

Finally, viewers who identified their race or ethnicity as *Black, non-Hispanic* and *Mixed* spoke with *other family members* (ie, neither parents nor siblings) more than viewers who identified with other races or ethnicities. This aligns with the established research that has found that “the extended kin network is a more salient structure for Black families than it is for White families” [50] and a newer research finding that African Americans and Black Caribbeans give and receive support from extended networks (eg, fictive kin and fellow congregants) more than non-Hispanic White people [51].

Limitations

By design, study participation was limited to adolescents who reported they had never seriously considered suicide; as such, we cannot answer whether or how 13RW-3 impacted suicidal youth. As we only recruited adolescents across the United States, our results are limited to this population.

We did not measure the valence of adolescents’ conversations and/or information seeking and thus cannot definitively claim that these actions were positive. Depending on how the conversations unfolded, the more vulnerable youth may have suffered or benefited. Our modest qualitative data suggest, however, that viewers embraced a prosocial message (eg, “The show made me think about the things that teens go through [sic] and then on top of that all the bullying and family problems. I can now say I am much more careful about the things I say. I was made aware of the language I use on a day to day basis”).

Other limitations emerged in process. Our sample size, although considerable, could have been larger. Some participants did not adhere to the randomized conditions, making the study a partially randomized preference trial rather than a randomized controlled trial. Adolescent nonadherence is common across clinical and social science research. For example, according to the Children’s Hospital of Philadelphia [52], adolescent transplant recipients disregard the protocol at a 60% higher rate than adults, although such behavior risks their lives. We found a significant difference between adherents and nonadherents on the mental health self-efficacy measure, which may have influenced our results. In addition, the 18 nonadherents originally assigned to the control condition did not receive T2 questions about 13RW-3.

Finally, some of our measures were not validated, and this may have affected our outcomes. To assess both mental health self-efficacy and masculine role pressure, we used the unvalidated scales that we developed for this study. Both outcomes also may suggest insufficient *dosage*—that is, perhaps the storyline of 13RW-3 met the threshold to raise consciousness and catalyze discussion around social and mental health issues but did not deliver (enough) content to impact specific constructs.

Comparison With Previous Work

The neutral and positive outcomes documented in our study align with a growing collection of studies that have found salubrious effects associated with watching 13RW [9,10,14,26-29]. These effects include lower depressive symptoms [27], decline in incidences of suicidal ideation and self-harm [14], decreases in stigmatized beliefs about suicide [27], increased sense of mental illness being socially acceptable [26], increased knowledge of suicide risk factors [28], engagement in prosocial mental health–related behaviors [26], and increased likelihood of expressing interest in helping a suicidal person [14]. It also strengthens another group of methodologically driven studies that problematize claims of 13RW viewership, leading to harm [11,29]. Of note, a reanalysis [11] of the data presented by Bridge et al [29] repudiated (widely reported) claims that suicide rates increased in the months following the debut of 13RW.

Future Research

Our findings suggest that globally watched television shows featuring social and mental health issues drive conversation and that social media are regarded as a promising avenue to support adolescents' well-being [53-55]. Thus, we are currently exploring whether second-screen content (ie, content appearing on a phone, tablet, or laptop that does not simultaneously exhibit a television show) can amplify the impacts of a narrative by facilitating conversations and information seeking around the topics raised within the show.

As noted, we do not know the content of adolescents' conversations. Future research should examine the impact and valence of narrative-inspired conversations on vulnerable youth. For example, scornful conversations might deliver a boomerang effect, intensifying mental health stigma. Appreciative conversations might enrich vulnerable adolescents' social context, normalizing challenges around mental wellness and improving peers' abilities to identify warning signs. Future research might also investigate narrative-inspired information seeking. Are adolescents more likely to seek information about topics featured in popular media than adults? Do narratives like 13RW drive more information seeking than other types of narratives?

Understanding whether and how parents' media choices impact adolescents—for example, whether subscribing to streaming services such as Netflix or whether enforcing media rules is associated with adolescents' mental wellness—would be another fruitful arena of investigation. Similarly, researchers could query whether and how adolescents' media choices affect parents (known as the *child effect* [56]). A recent study found that children actively mediate their parents' television use [57], a phenomenon attested by our own study and a global study on 13RW-1 [9]. Therefore, it would be interesting to examine how parent-child engagement with adolescent-selected media might affect the parent-child relationship and parenting practices.

Finally, it is important for future research to examine the more vulnerable minority—youth with a history of suicidal ideation—and whether and how narrative affects their ideation.

Implications and Conclusions

Our findings should have implications for diverse stakeholders, including entertainment content creators, studios, public health experts, parents, and adolescents seeking to support adolescent mental health. Previous research has documented popular film and television's tendency to stigmatize and trivialize mental health [58], stoking some creators' resolve to correct mental health's representation or misrepresentation. This study suggests that such efforts do not just improve the optics; they can facilitate meaningful outcomes in viewers' lives. It complements recently released data on narratives' capacity to shift viewers' mindsets, "which can transform the way Americans think about health and influence policy" [44]. Therefore, executives can use this research to emphasize how stories matter and further inspire entertainment content creators' efforts to enrich representation. As their content can drive conversations and information seeking, studios could also create resources that amplify these outcomes, including mini documentaries like *Beyond the Reasons* (the most used resource in our sample) and omnichannel promotion of companion content. Companion content might include conversational toolkits created by public health experts, designed to support the two most common types of dialogues: peer-to-peer and adolescent-parent. Clinicians and advocacy organizations can leverage the insight that adolescents who are most sensitive to this content are those who cope with depressive symptoms and/or are affected by sexual assault. First, they can seek to proactively identify adolescents who meet these criteria. Second, they can tailor programming to account for their lived experiences.

Most importantly, this investigation suggests that when all stakeholders work together well in advance of a global franchise's release, they can better harness the content's potential to enrich adolescent wellness. In fact, several entertainment outlets (eg, MTV, Comedy Central, VH1, and Paramount Plus) recently committed to representing mental health with greater frequency, accuracy, and empathy [59]. Indeed, this study's lead author is speaking to this group about how the findings can enhance the resources for content creators.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Head of household consent email.
[DOCX File , 15 KB - mental_v8i9e25782_app1.docx]

Multimedia Appendix 2
Adolescent consent.
[DOCX File , 17 KB - mental_v8i9e25782_app2.docx]

Multimedia Appendix 3
Resources for parents, guardians, or heads of household.
[DOCX File , 14 KB - mental_v8i9e25782_app3.docx]

Multimedia Appendix 4
Postsurvey intervention.
[DOCX File , 24 KB - mental_v8i9e25782_app4.docx]

References

1. '13 Reasons Why' just broke a Netflix record. Seventeen Magazine. 2017. URL: https://www.seventeen.com/celebrity/movies-tv/news/a46406/13-reasons-why-netflix-broke-record/ [accessed 2021-06-22]
2. Arensman E, Niederkrotenthaler T, Reidenberg D. Briefing in connection with the Netflix series '13 Reasons Why'. International Association for Suicide Prevention (IASP). 2017. URL: https://www.iasp.info/pdf/2017_iasp_statement_13_reasons_why.pdf [accessed 2021-06-22]
3. '13 Reasons Why' Netflix Series: considerations for educators. National Association of School Psychologists. 2017. URL: https://www.nasponline.org/resources-and-publications/resources-and-podcasts/school-climate-safety-and-crisis/mental-health-resources/preventing-youth-suicide/13-reasons-why-netflix-series/13-reasons-why-netflix-series-considerations-for-educators [accessed 2021-06-22]
4. Tips for watching new Netflix series '13 Reasons Why'. Suicide Awareness Voices of Education. 2017. URL: https://save.org/blog/tips-watching-new-netflix-series-13-reasons/ [accessed 2021-06-22]
5. Ayers JW, Althouse BM, Leas EC, Dredze M, Allem J. Internet searches for suicide following the release of '13 Reasons Why'. JAMA Intern Med 2017 Oct 01;177(10):1527-1529 [FREE Full text] [doi: 10.1001/jamainternmed.2017.3333] [Medline: 28759671]
6. Cooper MT, Bard D, Wallace R, Gillaspy S, Deleon S. Suicide attempt admissions from a single children's hospital before and after the introduction of Netflix series '13 Reasons Why'. J Adolesc Health 2018 Dec;63(6):688-693. [doi: 10.1016/j.jadohealth.2018.08.028] [Medline: 30454731]
7. da Rosa GS, Andrades G, Caye A, Hidalgo M, de Oliveira MA, Pilz L. Thirteen Reasons Why: The impact of suicide portrayal on adolescents' mental health. J Psychiatr Res 2019 Jan;108:2-6 [FREE Full text] [doi: 10.1016/j.jpsychires.2018.10.018] [Medline: 30412785]
8. Zimerman A, Caye A, Zimerman A, Salum GA, Passos IC, Kieling C. Revisiting the Werther effect in the 21st century: bullying and suicidality among adolescents who watched '13 Reasons Why'. J Am Acad Child Adolesc Psychiatry 2018 Aug;57(8):610-613. [doi: 10.1016/j.jaac.2018.02.019] [Medline: 30071982]
9. Lauricella A, Cingel D, Wartella E. Exploring how teens and parents responded to '13 Reasons Why'. Center on Media and Human Development, Northwestern University, Evanston, IL. 2018. URL: https://13reasonsresearch.soc.northwestern.edu/netflix_brazil-report_final-print.pdf [accessed 2021-06-22]
10. Ferguson CJ. 13 Reasons Why Not: A methodological and meta-analytic review of evidence regarding suicide contagion by fictional media. Suicide Life Threat Behav 2019 Aug 14;49(4):1178-1186. [doi: 10.1111/sltb.12517] [Medline: 30318609]
11. Romer D. Reanalysis of the Bridge et al. study of suicide following release of '13 Reasons Why'. PLoS One 2020;15(1):e0227545 [FREE Full text] [doi: 10.1371/journal.pone.0227545] [Medline: 31945088]
12. Campo JV, Bridge JA. Exploring the Impact of 13 Reasons Why: Looking for light amidst the heat. J Am Acad Child Adolesc Psychiatry 2018 Aug;57(8):547-549. [doi: 10.1016/j.jaac.2018.05.012] [Medline: 30071975]

13. Alloway T, Runac R, Qureshi M, Kemp G. Is Facebook linked to selfishness? Investigating the relationships among social media use, empathy, and narcissism. Soc Netw 2014;03(03):150-158 [FREE Full text] [doi: 10.4236/sn.2014.33020]
14. Arendt F, Scherr S, Pasek J, Jamieson PE, Romer D. Investigating harmful and helpful effects of watching season 2 of 13 Reasons Why: Results of a two-wave U.S. panel survey. Soc Sci Med 2019 Jul;232:489-498. [doi: 10.1016/j.socscimed.2019.04.007] [Medline: 31029484]
15. Thompson LK, Michael KD, Runkle J, Sugg MM. Crisis Text Line use following the release of Netflix series 13 Reasons Why Season 1: Time-series analysis of help-seeking behavior in youth. Prev Med Rep 2019 Jun;14:100825 [FREE Full text] [doi: 10.1016/j.pmedr.2019.100825] [Medline: 30828539]
16. Sugg MM, Michael KD, Stevens SE, Filbin R, Weiser J, Runkle JD. Crisis text patterns in youth following the release of Season 2 and celebrity suicides: a case study of summer 2018. Prev Med Rep 2019 Dec;16:100999 [FREE Full text] [doi: 10.1016/j.pmedr.2019.100999] [Medline: 31750076]
17. Papa M, Singhal A. How entertainment-education programmes promote dialogue in support of social change. J Creat Commun 2011 Mar 25;4(3):185-208 [FREE Full text] [doi: 10.1177/097325861000400304]
18. Singhal A, Rogers EM. A theoretical agenda for entertainment-education. Commun Theory 2002 May;12(2):117-135. [doi: 10.1111/j.1468-2885.2002.tb00262.x]
19. Crone E, Dahl R. Understanding adolescence as a period of social-affective engagement and goal flexibility. Nat Rev Neurosci 2012 Sep;13(9):636-650 [FREE Full text] [doi: 10.1038/nrn3313] [Medline: 22903221]
20. Casey B, Jones R, Hare T. The adolescent brain. Ann N Y Acad Sci 2008 Mar;1124:111-126 [FREE Full text] [doi: 10.1196/annals.1440.010] [Medline: 18400927]
21. Rideout V, Robb M. The common sense census: media use by tweens and teens. Common Sense Media. 2019. URL: https://www.commonsensemedia.org/sites/default/files/uploads/research/2019-census-8-to-18-full-report-updated.pdf [accessed 2021-06-22]
22. Richtel M. Children's screen time has soared in the pandemic, alarming parents and researchers. New York Times. 2021. URL: https://www.nytimes.com/2021/01/16/health/covid-kids-tech-use.html [accessed 2021-06-22]
23. Liang L, Ren H, Cao R, Hu Y, Qin Z, Li C, et al. The effect of COVID-19 on youth mental health. Psychiatr Q 2020 Sep 21;91(3):841-852 [FREE Full text] [doi: 10.1007/s11126-020-09744-3] [Medline: 32319041]
24. COVID-19 and youth mental health. UNICEF - Voices of Youth. URL: https://www.voicesofyouth.org/campaign/covid-19-and-youth-mental-health [accessed 2021-06-22]
25. Ito M, Odgers C, Salen K, Schueller S, Tanksley T. Spaces of Refuge: supporting youth wellbeing through equitable and relatable online connection. University of California Irvine Connected Learning Lab. URL: https://connectedlearning.uci.edu/blog/supporting-youth-wellbeing-through-equitable-and-relatable-online-connection/ [accessed 2021-06-22]
26. Ferguson CJ. One less reason why: Viewing of suicide-themed fictional media is associated with lower depressive symptoms in youth. Mass Commun Soc 2020 May 05;24(1):85-105. [doi: 10.1080/15205436.2020.1756335]
27. Carter M, Cingel D, Lauricella A, Wartella E. 13 Rreasons Why, perceived norms, and reports of mental health-related behavior change among adolescent and young adult viewers in four global regions. Commun Res 2020 Jun 11:009365022093046 [FREE Full text] [doi: 10.1177/0093650220930462]
28. Chesin M, Cascardi M, Rosselli M, Tsang W, Jeglic EL. Knowledge of suicide risk factors, but not suicide ideation severity, is greater among college students who viewed. J Am Coll Health 2020 Apr 02;68(6):644-649. [doi: 10.1080/07448481.2019.1586713] [Medline: 30939105]
29. Bridge JA, Greenhouse JB, Ruch D, Stevens J, Ackerman J, Sheftall AH, et al. Association between the release of Netflix's '13 Reasons Why' and suicide rates in the United States: an interrupted time series analysis. J Am Acad Child Adolesc Psychiatry 2019 Apr 28:236-243. [doi: 10.1016/j.jaac.2019.04.020] [Medline: 31042568]
30. Price SM, Park CH, Brenner RA, Lo A, Adams S, Baetz RA, et al. Participant retention in a longitudinal study: do motivations and experiences matter? Surv Pract 2016 Oct 01;9(4):1-10 [FREE Full text] [doi: 10.29115/sp-2016-0022]
31. Cantrell J, Bennett M, Thomas R, Rath J, Hair E, Vallone D. It’s getting late: improving completion rates in a hard-to-reach sample. Surv Pract 2017 Dec 28;11(2):0019 [FREE Full text] [doi: 10.29115/sp-2018-0019]
32. Wasmann KA, Wijsman P, van Dieren S, Bemelman W, Buskens C. Partially randomised patient preference trials as an alternative design to randomised controlled trials: systematic review and meta-analyses. BMJ Open 2019 Oct 16;9(10):e031151 [FREE Full text] [doi: 10.1136/bmjopen-2019-031151] [Medline: 31619428]
33. Undem T, Wang A. Full Report: The state of gender equality for U.S. adolescents. PLAN International USA. 2018. URL: https://www.planusa.org/full-report-the-state-of-gender-equality-for-us-adolescents [accessed 2021-06-22]
34. Kann L, Olsen EO, McManus T, Harris WA, Shanklin SL, Flint KH, et al. Sexual identity, sex of sexual contacts, and health-related behaviors among students in grades 9-12 - United States and selected sites, 2015. MMWR Surveill Summ 2016 Aug 12;65(9):1-202 [FREE Full text] [doi: 10.15585/mmwr.ss6509a1] [Medline: 27513843]
35. Kroenke K, Spitzer R, Williams J. The Patient Health Questionnaire-2: validity of a two-item depression screener. Med Care 2003;41(11):1284-1292 [FREE Full text] [doi: 10.1097/01.mlr.0000093487.78664.3c]
36. Allgaier A, Pietsch K, Frühe B, Sigl-Glöckner J, Schulte-Körne G. Screening for depression in adolescents: validity of the patient health questionnaire in pediatric care. Depress Anxiety 2012 Oct 02;29(10):906-913. [doi: 10.1002/da.21971] [Medline: 22753313]

37. Clarke G, Harvey AG. The complex role of sleep in adolescent depression. Child Adolesc Psychiatr Clin N Am 2012 Apr;21(2):385-400 [FREE Full text] [doi: 10.1016/j.chc.2012.01.006] [Medline: 22537732]
38. Faul F, Erdfelder E, Lang A, Buchner A. G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. Behav Res Methods 2007 May;39(2):175-191. [doi: 10.3758/BF03193146]
39. Kalla JL, Broockman DE. Reducing exclusionary attitudes through interpersonal conversation: evidence from three field experiments. Am Polit Sci Rev 2020 Feb 03;114(2):410-425. [doi: 10.1017/s0003055419000923]
40. Paluck EL. Reducing intergroup prejudice and conflict using the media: a field experiment in Rwanda. J Pers Soc Psychol 2009 Mar;96(3):574-587. [doi: 10.1037/a0011989] [Medline: 19254104]
41. Goldsmith DJ, Baxter LA. Constituting relationships in talk a taxonomy of speech events in social and personal relationships. Human Comm Res 1996 Sep;23(1):87-114 [FREE Full text] [doi: 10.1111/j.1468-2958.1996.tb00388.x]
42. Frank LB, Chatterjee JS, Chaudhuri ST, Lapsansky C, Bhanot A, Murphy ST. Conversation and compliance: role of interpersonal discussion and social norms in public communication campaigns. J Health Commun 2012 Jul 18;17(9):1050-1067 [FREE Full text] [doi: 10.1080/10810730.2012.665426] [Medline: 22808934]
43. Grotevant HD, Cooper CR. Individuation in family relationships. Hum Dev 1986;29(2):82-100. [doi: 10.1159/000273025]
44. Rosenthal E. Stories Matter: How new entertainment narratives about health can influence mindsets and policy. USC Annenberg Norman Lear Center Media Impact Project. 2021. URL: https://www.mediaimpactproject.org/healthequity [accessed 2021-04-05]
45. Talking to teens: Suicide prevention: Tools to help prevent youth suicide. American Psychological Association. 2018. URL: https://www.apa.org/topics/teen-suicide-prevention [accessed 2021-06-22]
46. Stone D, Jones C, Mack K. Changes in suicide rates - United States, 2018-2019. Morbidity and Mortality Weekly Report (MMWR). 2021. URL: https://www.cdc.gov/mmwr/volumes/70/wr/mm7008a1.htm#T1_down [accessed 2021-06-22]
47. Neitzke AB. An illness of power: gender and the social causes of depression. Cult Med Psychiatry 2016 Mar 28;40(1):59-73. [doi: 10.1007/s11013-015-9466-3] [Medline: 26215590]
48. Jaehn P, Bobrova N, Saburova L, Kudryavtsev AV, Malyutina S, Cook S. The relation of gender role attitudes with depression and generalised anxiety disorder in two Russian cities. J Affect Disord 2020 Mar 01;264:348-357 [FREE Full text] [doi: 10.1016/j.jad.2020.01.027] [Medline: 32056771]
49. Hunt K, Sweeting H, Keoghan M, Platt S. Sex, gender role orientation, gender role attitudes and suicidal thoughts in three generations. A general population study. Soc Psychiatry Psychiatr Epidemiol 2006 Aug 26;41(8):641-647. [doi: 10.1007/s00127-006-0074-y] [Medline: 16732400]
50. Hays WC, Mindel CH. Extended kinship relations in black and white families. J Marriage Fam 1973 Feb;35(1):51. [doi: 10.2307/351096]
51. Taylor RJ, Chatters LM, Woodward AT, Brown E. Racial and ethnic differences in extended family, friendship, fictive kin and congregational informal support networks. Fam Relat 2013 Oct 01;62(4):609-624 [FREE Full text] [doi: 10.1111/fare.12030] [Medline: 25089067]
52. Improving adolescent adherence rates. Children's Hospital of Philadelphia. URL: https://www.chop.edu/pages/improving-adolescent-adherence-rates [accessed 2021-03-20]
53. Rideout V, Fox S, Well Being Trust. Digital health practices, social media use, and mental well-being among teens and young adults in the US. Providence St. Joseph Health Digital Commons - Articles, Abstracts, and Reports. 2018. URL: https://digitalcommons.psjhealth.org/publications/1093/ [accessed 2020-11-22]
54. Wong CA, Merchant RM, Moreno MA. Using social media to engage adolescents and young adults with their health. Healthc (Amst) 2014 Dec;2(4):220-224 [FREE Full text] [doi: 10.1016/j.hjdsi.2014.10.005] [Medline: 25984444]
55. Odgers CL, Jensen MR. Annual Research Review: Adolescent mental health in the digital age: facts, fears, and future directions. J Child Psychol Psychiatry 2020 Mar 17;61(3):336-348. [doi: 10.1111/jcpp.13190] [Medline: 31951670]
56. Bell R. A reinterpretation of the direction of effects in studies of socialization. Psychol Rev 1968 Mar;75(2):81-95 [FREE Full text] [doi: 10.1037/h0025583] [Medline: 4870552]
57. Nelissen S, Van den Bulck J. Expanding the unidirectional view on parental television mediation: children’s guidance of their parent’s television use. J Broadcast Electron Media 2018 May 03;62(2):232-250. [doi: 10.1080/08838151.2018.1451855]
58. Smith S, Choueiti M, Choi A, Pieper K, Moutier C. USC Annenberg Inclusion Initiative. 2019. URL: http://assets.uscannenberg.org/docs/aii-study-mental-health-media_052019.pdf [accessed 2021-06-22]
59. Zeitchik S. In a rare admission, MTV says its mental-health portrayals are sometimes damaging. Washington Post. 2021. URL: https://www.washingtonpost.com/business/2021/04/01/viacom-mental-health-reality-tv/ [accessed 2021-06-22]

Abbreviations

13RW: 13 Reasons Why
13RW-1: 13 Reasons Why, Season 1
13RW-3: 13 Reasons Why, Season 3
ANOVA: analysis of variance
MS: between-groups mean square

NORC: National Opinion Research Center

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Original Paper

A Cyberbullying Media-Based Prevention Intervention for Adolescents on Instagram: Pilot Randomized Controlled Trial

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Abstract

Background: Between 15% and 70% of adolescents report experiencing cybervictimization. Cybervictimization is associated with multiple negative consequences, including depressed mood. Few validated, easily disseminated interventions exist to prevent cybervictimization and its consequences. With over 97% of adolescents using social media (such as YouTube, Facebook, Instagram, or Snapchat), recruiting and delivering a prevention intervention through social media and apps may improve accessibility of prevention tools for at-risk youth.

Objective: This study aims to evaluate the feasibility and acceptability of and obtain preliminary outcome data on IMPACT (Intervention Media to Prevent Adolescent Cyber-Conflict Through Technology), a brief, remote app-based intervention to prevent and reduce the effect of cyberbullying.

Methods: From January 30, 2020, to May 3, 2020, a national sample of 80 adolescents with a history of past-year cybervictimization was recruited through Instagram for a randomized control trial of IMPACT, a brief, remote research assistant–led intervention and a fully automated app-based program, versus enhanced web-based resources (control). Feasibility and acceptability were measured by consent, daily use, and validated surveys. Although not powered for efficacy, outcomes (victimization, bystander self-efficacy, and well-being) were measured using validated measures at 8 and 16 weeks and evaluated using a series of longitudinal mixed models.

Results: Regarding feasibility, 24.5% (121/494) of eligible participants provided contact information; of these, 69.4% (84/121) completed full enrollment procedures. Of the participants enrolled, 45% (36/80) were randomized into the IMPACT intervention and 55% (44/80) into the enhanced web-based resources groups. All participants randomized to the intervention condition completed the remote intervention session, and 89% (77/80) of the daily prompts were answered. The retention rate was 99% (79/80) at 8 weeks and 96% (77/80) at 16 weeks for all participants. Regarding acceptability, 100% (36/36) of the intervention participants were at least moderately satisfied with IMPACT overall, and 92% (33/36) of the participants were at least moderately satisfied with the app. At both 8 and 16 weeks, well-being was significantly higher (β=1.17, SE 0.87, P=.02 at 8 weeks and β=3.24, SE 0.95, P<.001 at 16 weeks) and psychological stress was lower (β=−.66, SE 0.08, P=.04 at 8 weeks and β=−.89, SE 0.09, P<.001 at 16 weeks) among IMPACT users than among control group users. Participants in the intervention group attempted significantly more bystander interventions than those in the control group at 8 weeks (β=.82, SE 0.42; P=.02).

Conclusions: This remote app-based intervention for victims of cyberbullying was feasible and acceptable, increased overall well-being and bystander interventions, and decreased psychological stress. Our findings are especially noteworthy given that the trial took place during the COVID-19 pandemic. The use of Instagram to recruit adolescents can be a successful strategy for identifying and intervening with those at the highest risk of cybervictimization.

Trial Registration: ClinicalTrials.gov NCT04259216; http://clinicaltrials.gov/ct2/show/NCT04259216.

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KEYWORDS

cyberbullying; adolescents; mobile application; messaging; brief interventions; social media; recruitment; mobile phone

Introduction

Background

American adolescents' access to smartphones has increased from 73% in 2015 to 95% in 2018 [1]. Correspondingly, adolescents report increases in web activity, with 45% reporting that they are on the web *almost constantly* in 2018 compared with 24% in 2015 [1]. This increased exposure to electronic devices and social media increases the chances of an adolescent experiencing cybervictimization, defined as aggression or bullying by means of computers, cellphones, other electronic devices, and the internet [2]. Adolescent cybervictimization is related to depressive symptoms, suicidality, posttraumatic stress symptoms, alcohol and other drug use, physical peer violence, and dating violence [3-10]. Anywhere from 15% to 70% of adolescents have reported cybervictimization (through texting, Instagram, Facebook, or other social media), with the percentage increasing in recent years [11-20]. In 2018, approximately 60% of adolescents aged 13-17 years across the United States reported having experienced at least one of the six types of abusive web behaviors in the past year, which included offensive name-calling; spreading of false rumors; receiving unsolicited explicit images or having explicit images of them shared without their consent; incessant inquiries regarding where they are, what they are doing, and who they are with by someone other than a parent; and physical threats [21]. Racial and ethnic minority youth and youth identifying as LGBTQ+ are at a higher risk of cybervictimization [22,23]. Research aimed at both reducing cyberbullying experiences and fostering resilience in response to cyberbullying can have a significant impact on the adolescent mental health.

There are several school-based interventions to reduce cybervictimization. Some use long and intensive in-person sessions plus electronic content [24,25], some are educational simulation video games [26], and several include web-based informational sites [27]. Schools are, however, addressing numerous competing goals, with challenges in including time-intensive cyberbullying interventions in the already packed curricula. School-based interventions also assume student attendance, with some of the highest-risk students evidencing inconsistent attendance [24,28,29].

Technology-based prevention interventions have several benefits, including cost-effectiveness and scalability. The limitations of these interventions generally revolve around participants' engagement with the technology provided [27]. In our team's prior work, we have developed, iteratively refined, and piloted technology-augmented prevention interventions for victims of cyberbullying to be delivered during a clinic visit [28]; although these interventions had high acceptability, identifying participants in person was challenging. These findings have been recently corroborated [30].

Social media has the potential to both identify and deliver interventions to adolescents at the highest risk of cybervictimization and its consequences. Among this age group, social media use, especially Instagram, is high [21]. It is likely easier to identify at-risk groups using web-based recruitment strategies [31-34] than using in-person strategies. Social media has reduced barriers to participation (eg, transportation and stigma) [31] and offers the potential for improved honesty and increased comfort for participants [27,35]. Moreover, web-based recruitment and intervention studies can adhere to physical distancing regulations related to the COVID-19 pandemic. Interventions conducted during pandemics or forced isolations are vitally important given that many youth report worsening mental health and increased anxiety, which can have lasting effects [36].

Objectives

This study, IMPACT (Intervention Media to Prevent Adolescent Cyber-Conflict Through Technology), was a pilot randomized controlled trial of a remote-only, 2-part intervention (brief remote video intervention plus 8-week app-based automated messaging)—built off our prior clinic-based work—to reduce the consequences of cybervictimization and improve bystander intervention behaviors [28]. Our primary hypothesis was that it would be feasible and acceptable to recruit and deliver this technology-augmented intervention purely remotely (through social media and app). The exploratory goal of this study is to examine whether this intervention would increase bystander interventions and decrease cybervictimization and postvictimization consequences, specifically social support, psychological stress, and well-being.

Methods

Recruitment

From January 30,2020, to May 3, 2020, targeted Instagram advertisements were used to recruit a national sample of adolescents for a screening survey. These findings have recently been corroborated [30]. Briefly, the Facebook Business Manager platform was used to present Instagram advertisements to our target audience of adolescents, who were aged 13-17 years, English speaking, and residing in the United States. Through these advertisements, adolescents were invited to complete a brief screening survey, administered using REDCap (Research Electronic Data Capture) [37], which confirmed the basic demographics (age and US residence) and eligibility requirements for the randomized controlled trial (own a cellphone and cybervictimization in the past 12 months) [38]. Eligible participants were then asked to complete a web-based assent form and six assent-related comprehension questions (eg, “If you agree to be in this study, what are we asking you to do?”). Participants that completed the assent and demonstrated comprehension of the study (by answering all six questions correctly within three attempts) were asked to complete a short baseline survey (see measures in Table 1). Contact information was verified for eligible enrolled youth through a phone call.

Table 1. Outline of measures and timepoints.

Measure	Screening	Baseline	8 Weeks	16 Weeks
Cybervictimization				
UNH[a] Internet Safety Education Survey: cybervictimization incidents	✓	✓	✓	✓
UNH Internet Safety Education Survey: bystander solutions		✓	✓	✓
UNH Internet Safety Education Survey: bystander efficacy		✓	✓	✓
YBS[b]	✓		✓	✓
CVEI[c] scale	✓		✓	✓
Accessibility, feasibility, and usability				
UEX[d]			✓	
SUS[e]			✓	
Demographics				
National Study for Adolescent Health	✓			
GenIUSS[f] group	✓			
Network for LGBT[g] Health Equity at the Fenway Institute	✓			
Mental well-being				
WHO-5[h] Well-Being Index		✓	✓	✓
PROMIS-PS[i]		✓	✓	✓
PROMIS-PA[j]		✓	✓	✓
MSPSS[k]		✓	✓	✓
Other violence				
CADRI[l]		✓	✓	✓
YRBS[m]		✓	✓	✓
IBS[n]		✓	✓	✓

[a] UNH: University of New Hampshire.

[b] YBS: Ybarra Bullying Scale.

[c] CVEI: Cybervictimization Emotional Impact.

[d] UEX: User Experience Questionnaire.

[e] SUS: System Usability Scale.

[f] GenIUSS: Gender Identity in US Surveillance.

[g] LGBT: lesbian, gay, bisexual, transgender.

[h] WHO-5: World Health Organization-Five.

[i] PROMIS-PS: Patient-Reported Outcomes Measurement Information System-Psychological Stress.

[j] PROMIS-PA: Patient-Reported Outcomes Measurement Information System-Positive Affect.

[k] MSPSS: Multidimensional Scale of Perceived Social Support.

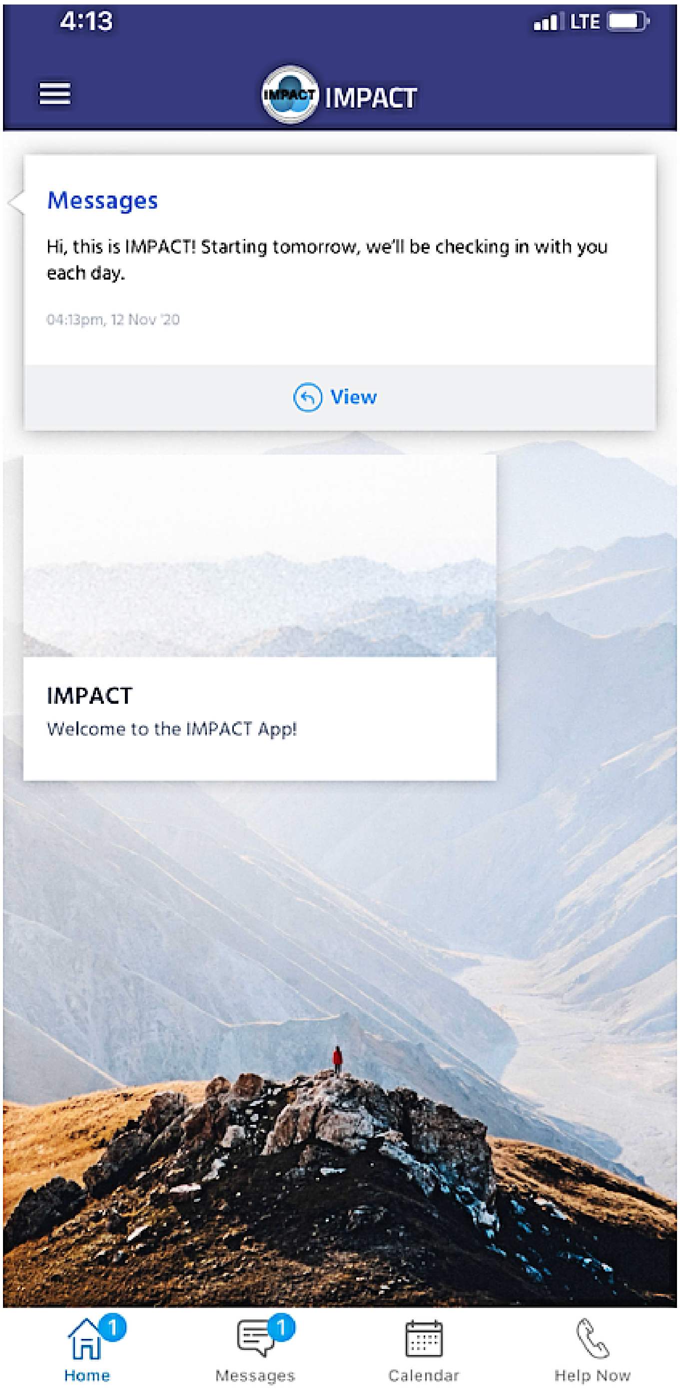
[l] CADRI: Conflict in Adolescent Dating Relationships Inventory.

[m] YRBS: Youth Risk Behavior Survey.

[n] IBS: Illinois Bully Scale.

Teens were then randomized using REDCap into either the previously piloted cyberbullying prevention intervention app (*app*; Figure 1) or into an enhanced web-based resource (control) group [28]. The randomization scheme was generated based on a permuted block randomization procedure with small, random-sized blocks. Group assignment was stratified by age and gender to ensure equal allocation of participants in each condition across the stratum. Participants and the recruiting research assistant (RA) were made aware of their group assignments; however, coinvestigators and outcome assessors were blinded. A waiver of parental consent was requested in accordance with the Common Rule [39] and in accordance with the recommendations from the Society of Adolescent Medicine [40]. This study received approval from the Rhode Island Hospital Institutional Review Board and is registered at Clinical Trials (NCT04259216).

Figure 1. Screenshot of the IMPACT (Intervention Media to Prevent Adolescent Cyber-Conflict Through Technology) “app”.



Messages

Hi, this is IMPACT! Starting tomorrow, we'll be checking in with you each day.

04:13pm, 12 Nov '20

IMPACT

Welcome to the IMPACT App!

Study Design

Intervention

The purpose of the intervention was to increase self-efficacy for bystander interventions against cyberbullying and to reduce the psychosocial consequences of cybervictimization. These interventions were iteratively developed and refined through adolescent feedback [28]. Adolescents in the intervention group received a brief (15-20 minutes) remote PowerPoint intervention, delivered by a bachelor’s level RA with training in motivational interviewing (MI) principles and basic cognitive behavioral therapy (CBT) techniques [28,41-43]. The RA guided the participants through the PowerPoint, asking open-ended questions and engaging the participant in brief discussions revolving around the thoughts-feelings-actions triangle and bystander responses [42,43]. The brief intervention session covered 3 primary strategies in cybervictimization prevention and intervention: (1) Learn how to handle it, once it has happened to you or someone else; (2) Keep it from happening (sometimes impossible to do); and (3) Help stop it when you see it. Participants were asked to give an example of a prior experience with cybervictimization and then walked through how their thoughts, feelings, and actions are all connected and how changing one can influence the others. The interventionist then instructed the participants about the goal-setting procedures. They were then onboarded to the app (developed by JourneyLabs) and assisted with downloading the app onto their phone. The fully automated app delivered a daily query, at the time of the participants' choice, asking the following: (1) "How are you feeling in general today (1=really bad and 5=great)?" and (2) "Any drama or conflict online today? (Reply 'yes' or 'no')." On the basis of the participants' responses as well as their baseline characteristics, the participants then received an automated, tailored intervention message. There were 8 weeks of structured intervention messages, based on MI, CBT, and bystander intervention methodologies, delivered through these daily messages. Participants also had the option of requesting additional messages at any time if they were feeling *Happy*, *Sad*, *Angry* or *Stressed*, through a part of the app labeled *on-demand mood messages*. These on-demand messages were available 24 hours a day, and respondents could request as many messages as they needed.

Participants were informed that their responses were not monitored in real time and if they wished for immediate assistance, they should call a family member; a friend; 911; or the National Suicide Prevention Lifeline, the number to which was embedded into the *Help Now* tab on the app (Figure 1). We also had an institutional review board–approved crisis protocol for participants with multiple days of negative messages. The crisis protocol was never activated throughout the course of this pilot study.

Before the launch of the study, the RA was extensively trained on MI and CBT approaches (including personalized goal setting and normative feedback, cognitive restructuring techniques, and behavioral activation) as well the study rationale and crisis management procedures; they also completed role-playing exercises, as per our prior studies, to confirm expertise in intervention delivery [44].

Control

Adolescents in the control group participated in an RA-conducted study orientation phone call and received an enhanced web-based resource packet, which was discussed with the participants by the RA, providing a variety of websites, phone numbers, and other universal resources for cyberbullying, dating violence, sexual health, and mental health.

Follow-Up Procedures

All participants completed a baseline, 8-week, and 16-week self-report survey. At 8 weeks, participants in the intervention group were additionally asked to complete a 30-minute semistructured remote interview using Google Meet.

Measures

Refer to Table 1 for an outline of the primary and secondary measures and the timepoints at which they were assessed.

Cybervictimization

Cyberbullying questions used to determine eligibility were adapted from the University of New Hampshire Internet Safety Education Survey cybervictimization questions, including victimization incidents, bystander solutions, and bystander efficacy subscales [45]. The cybervictimization incidents 5-item subscale measures actual behaviors in response to cyberbullying (ie, did adolescents respond to their own victimization in ways that are productive). Responses were given on a 5-point scale that ranged from *0=Never* to *4=7 or more times*. The bystander solutions 11-item subscale measures bystander responses (ie, did adolescents intervene in *others'* victimization in productive ways). Response options were mostly Yes, or No. One item was given on a 5-point scale that ranged from *0=Never* to *4=7 or more times*, and if the participant endorsed 1 or more times to the prior question, they were asked to choose from a list of bystander responses. Finally, the 13-item bystander efficacy subscale measures intended behaviors if they were to witness cybervictimization: self-efficacy in bystander response, acceptance of responsibility for response, knowledge about how to intervene, and intent to use a bystander response. Responses were given on a 5-point Likert scale that ranged from *1=Strongly Disagree* to *5=Strongly Agree*. Cybervictimization impairment during normal life events was measured using the Ybarra Bullying Scale [46]. The emotional impact of cybervictimization on participants was measured using the Cybervictimization Emotional Impact 7-item scale [47]. Responses were given on a 5-point Likert scale that ranged from *0=Not at all* to *4=Extremely*. All were measured at past 12-month (baseline only) and past-2-month (if endorsing one or more incidents at baseline and at both follow-ups) timeframes. All scales were summed, with higher sums corresponding to higher numbers of experiences or behaviors.

Acceptability, Feasibility, and Usability

Acceptability, measured using the User Experience Questionnaire, a 15-item self-report measure created for the study, was defined as 80% agree or strongly agree ratings. Feasibility was defined as 80% completion of the intervention protocol, including daily responses to app-based surveys. Usability was measured using the System Usability Scale (SUS), a 10-item scale used to assess the ease and appropriateness of the use of mobile intervention components [48]. Responses were given on a 5-point Likert scale that ranged from *1=Strongly Disagree* to *5=Strongly Agree*. As is the standard for this scale, responses were summed and evaluated as a continuous measure.

Demographics

To measure age, race, ethnicity, and socioeconomic status, selected questions from the National Study for Adolescent Health were asked during the screening survey [38]. Gender was measured using a question from the Gender Identity in the US Surveillance Group [49]. Sexual orientation was measured using a question from the Network for Lesbian, Gay, Bisexual, Transgender Health Equity at the Fenway Institute [50].

Mental Well-being

The World Health Organization-Five Well-Being Index was used to measure overall well-being in the past 2 weeks [51-53]. The World Health Organization-Five assesses current mental well-being using five statements on a 5-point Likert scale ranging from *0=At no time* to *5=All of the time*. The Patient-Reported Outcomes Measurement Information System (PROMIS)-Psychological Stress is a 4-item subscale that assesses cognitive-perceptual disruption, feeling overwhelmed, and perceived lack of control to manage one's own life [54,55]. The PROMIS-Positive Affect is a subscale that assesses in-the-moment positive and rewarding affective experiences over the past 7 days [56]. Response options for both PROMIS scales were given on a 5-point Likert scale ranging from *0=At no time* to *5=All of the time.* The Multidimensional Scale of Perceived Social Support was used to assess social support systems from friends, family, and significant others [57-59]. Responses were given on a 7-point Likert scale that ranged from *1=Very Strongly Disagree* to *4=Half and half* to *7=Very Strongly Agree.* As per standard practice, all scales were scored as sums and used as continuous measures.

Other Violence

The Conflict in Adolescent Dating Relationships Inventory was used to assess the history of physical dating violence in adolescents who have been in a relationship during the given time points. This scale uses sum scoring, with higher scores indicating greater amounts of abuse [60]. Experiences with physical assault were measured using a single item from the Youth Risk Behavior Survey, which is consistent with prior work [61]. In-person bullying was measured using 7 items from the victim and bully subscales of the Illinois Bully Scale [62,63]. Response options for all 3 of these scales that measure *other violence* were on a 5-point Likert scale ranging from *0=Never* to *4=7 or more times.* All these scales were assessed at past 12-month (baseline only) and past 2-months (if endorsing one or more incidents answer at baseline and at both follow-ups) timeframes.

Semistructured Interviews

To further assess acceptability, feasibility, and usability, a trained RA conducted semistructured interviews with all participants in the intervention arm. Participants were asked open-ended questions regarding the content of the app message intervention, remote intervention, and any logistical changes or improvements (Multimedia Appendix 1). Interviews lasted between 12 and 36 minutes (average length: 23 minutes, SD 5.67) and were digitally recorded. Overarching categories for a framework matrix–guided analysis were created by the interviewer (a bachelor's-level RA) and a senior coinvestigator. Within each category, answers were further divided by sentiment codes (positive, negative, neutral, or suggesting change). Summaries were abstracted directly from the recordings in a framework matrix format by a team of 3 RAs. The first 10% (4/36) of interviews were double coded for content or sentiment by an RA and the interviewer; thereafter, 10% (3/32) of codes were double checked for accuracy. All abstractions were verified by the interviewer while listening to the recordings. Key quotes were transcribed into the aforementioned categories by the RA [64,65]. Any discrepancies were discussed and resolved by the RA, interviewer, and coinvestigator. The abstracted results were reviewed by the study team, and themes from the summaries were developed by the senior coinvestigator and the study team.

Statistical Analysis

Descriptive statistics for the entire sample were calculated; between-group differences were examined using two-tailed *t* tests for continuous variables and chi-square tests for categorical variables and nonparametrics as appropriate.

The primary outcomes of feasibility and acceptability were examined in both conditions using descriptive statistics, including measures of self-reported satisfaction with the intervention, as well as objective retention and adherence rates. Between-group differences in the SUS scores were examined using two-tailed *t* tests.

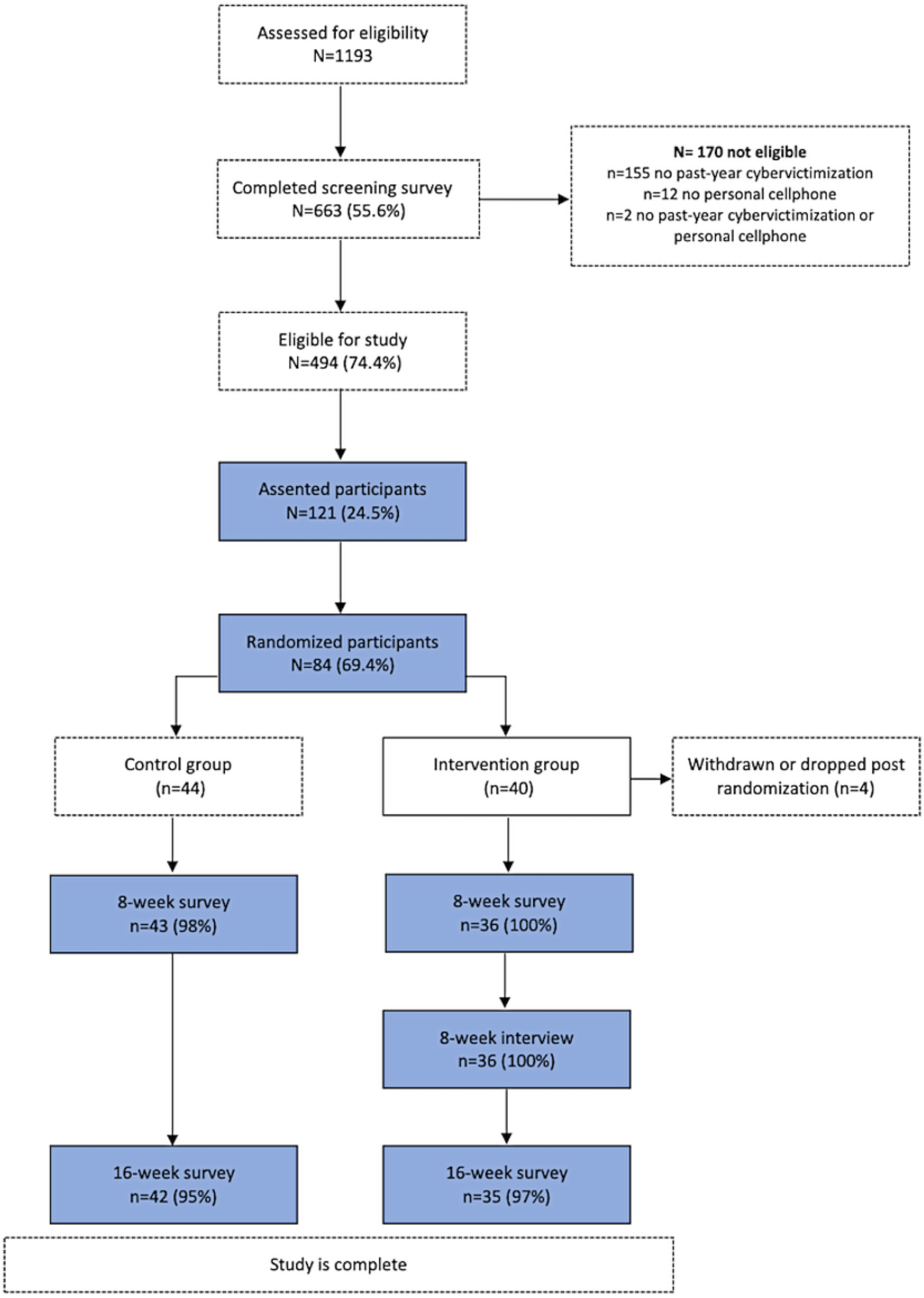
The exploratory outcomes of interest were changes from baseline in cybervictimization (measured by the University of New Hampshire Internet Safety Education Survey [45]); bystander interventions; and postvictimization consequences, specifically social support, psychological stress, and well-being. A secondary set of exploratory outcomes included other types of violence. Using a series of longitudinal mixed-effects models, we assessed the effects of condition on these outcomes. The outcome at each follow-up was simultaneously regressed on condition, time, condition×time, baseline value, and sex (a covariate chosen a priori). The models included subject-specific intercepts to adjust for repeated measures over time within the participants. All analyses were conducted on the intent-to-treat sample (all randomized participants included in the analysis). Mixed-effects models take a likelihood approach to estimation, thus making use of all available data without directly imputing missing outcomes. The significance level was set at .05 a priori, and all analyses were conducted using SAS 9.3. As this was a pilot study, no power analysis was performed before the initiation of the study.

Results

Overview

Recruitment continued for 907.5 nonconsecutive hours of Instagram advertisements until the target goal of 80 enrolled participants (Figure 2) was achieved [30]. During this period, 1193 screening surveys were conducted. Of the 663 participants who completed the screening survey, 494 (74.4%) met the eligibility criteria, 121 (24.5%) completed the assent form (37 participants either did not respond to the contact information verification calls or did not pass the verification process), and 84 (69.4%) were randomized into the intervention (n=36) or control groups (n=44). Four participants randomized to the intervention group were either withdrawn or dropped before receiving any intervention materials. A full description of the study flow is presented in Figure 2.

Figure 2. Participant recruitment flow through the IMPACT (Intervention Media to Prevent Adolescent Cyber-Conflict Through Technology) pilot trial.



On average, participants were 15.3 (SD 1.35) years old and predominantly identified their gender as female (47/80, 59%) and non-Hispanic (70/80, 88%). More than two-thirds of the participants reported that Instagram was their most commonly used social media platform (Table 2). There were no between-group differences in baseline demographics and psychosocial or baseline bullying scores (*P*>.05 for all).

The CONSORT (Consolidated Standards of Reporting Trials)-eHealth checklist (V 1.6.1) of this study can be found in Multimedia Appendix 2 [1,3-23,27,28,30,36,66-68].

Table 2. Participants' baseline demographics, cybervictimization, history of physical violence, and overall mental health (N=80).

Characteristic	Intervention (n=36)	Control (n=44)
Age (years), mean (SD)	15.28 (1.32)	15.36 (1.38)
Self-reported gender, n (%)		
Cisgender female	22 (61)	25 (57)
Cisgender male	10 (28)	11 (25)
Transgender, nonbinary, or "other"	4 (11)	8 (18)
Sexual orientation, n (%)		
Not straight	16 (47)	28 (67)
Race, n (%)		
White	24 (67)	30 (68)
Black	1 (3)	5 (11)
Multiracial	5 (14)	7 (16)
Other	1 (4)	2 (5)
Ethnicity, n (%)		
Non-Hispanic	31 (86)	39 (89)
SES[a], n (%)		
Lower income	12 (33)	15 (34)
Prior use of mental health services[b], n (%)	16 (44)	22 (50)
Region, n (%)		
Northeast	4 (11)	7 (16)
Southeast	10 (28)	7 (16)
Midwest	6 (17)	12 (27)
West	11 (30)	10 (23)
Southwest	5 (14)	8 (18)
Most common social media, n (%)		
Instagram	23 (64)	31 (71)
Prior violence exposure, mean (SD)		
Past-year cybervictimization[c]	6.00 (4.76)	4.86 (4.70)
Past-year physical fights[d]	0.11 (0.32)	0.07 (0.33)
Past-year dating violence[e]	1.47 (1.31)	1.05 (0.22)
Past-year in-person bullying[f]	7.86 (4.86)	6.70 (4.71)
Psychological well-being, mean (SD)		
Well-being[g]	12.66 (4.03)	11.80 (4.65)
Positive affect[h]	12.67 (3.39)	12.02 (2.93)
Psychological stress[i]	14.19 (3.48)	14.09 (4.05)
Perceived social support[j]	45.23 (9.34)	40.02 (11.97)

[a] SES: socioeconomic status.

[b] Seeing a counselor or being hospitalized in a psychiatric facility in the past 12 months.

[c] University of New Hampshire Internet Safety Education Survey number of cybervictimization incidents subscale.

[d] Youth Risk Behavior Survey fighting subscale.

[e] Conflict in Adolescent Dating Relationships.

[f] Illinois Bully Scale.

[g] World Health Organization-Five.

[h] Patient-Reported Outcomes Measurement Information System-Positive Affect.

[i] Patient-Reported Outcomes Measurement Information System-Psychological Stress.

[j] Multidimensional Scale of Perceived Social Support.

Feasibility and Acceptability

All participants who scheduled remote interventions completed the session and downloaded the app. We had over 98% retention rate at 8 and 16 weeks for intervention and over 95% for control groups, representing the proportion of participants who completed the follow-up survey at that time point. All participants randomized into the intervention group completed an 8-week remote interview. There were 3587 responses to the daily mood surveys (out of 4032 potential responses), resulting in a daily response rate of 89%. A total of 71 on-demand messages from 19 unique participants were requested (happy=36, sad=15, stressed=12, and angry=8). Taken together, the intervention was considered feasible based on a priori benchmarks.

All participants reported on the User Experience Questionnaire that they were at least moderately satisfied with IMPACT overall, with 92% (33/36) of intervention participants reporting that they were at least moderately satisfied with the IMPACT app. When asked about the frequency of messaging, 86% (31/36) of participants endorsed that it was *just right*; the remaining 14% (5/36) felt that the messaging was too frequent. When asked if they would recommend IMPACT, 86% (68/80) responded positively. There were no significant between-group differences in the SUS scores.

Exploratory Outcomes

A full description of the adjusted treatment effects on the cybervictimization and bystander scores at 8 and 16 weeks are presented in Table 3. Although point estimates of the overall prevalence of personal cybervictimization were in the expected direction, there was no significant between-group effect at 8 or 16 weeks. However, a significant treatment effect was observed on the number of solutions tried for combating personal cybervictimization, with intervention participants reporting a significantly higher number of strategies at 8 weeks (β=.82, SE 0.42; *P*=.02). Although not significant, the point estimate was similar at 16 weeks. Finally, intervention participants had significantly higher bystander self-efficacy and intention to help others (β=2.65, SE 1.32; *P*=.04) at 8 weeks than participants in the control group.

Table 4 presents adjusted treatment effects of exploratory outcomes of well-being and other secondary violence outcomes. Results indicate significant treatment effects on well-being at 8 and 16 weeks such that intervention participants had significantly better overall well-being (β=1.17, SE 0.87, *P*=.02 at 8 weeks and β=3.24, SE 0.95, *P*<.001 at 16 weeks), decreased stress (β=−.66, SE 0.08, *P*=.04 at 8 weeks and β=−.89, SE 0.09, *P*<.001 at 16 weeks), and higher social support (β=3.50, SE 2.02, *P*=.049 at 16 week, with no differences at 8 weeks) than control participants. Intervention participants reported significantly fewer physical fights at 8 weeks than control participants (β=−.60, SE 0.28, *P*=.01) but no change in dating violence or in-person bullying.

Table 3. Treatment effects on exploratory outcomes of cyberbullying and bystander interventions in the past 2 months (comparing baseline to 8 weeks to 16 weeks).

Exploratory outcome	8 Weeks		16 Weeks	
	β[a] (SE)	*P* value[b]	β (SE)	*P* value
Number of experiences of cybervictimization[c]	−3.25 (3.32)	.35	−.83(2.26)	.72
Interference of cybervictimization with normal life[d]	−.31 (0.45)	.49	−.14 (0.54)	.79
Emotional effect of cybervictimization[e]	.18 (1.26)	.89	.51 (1.48)	.73
Solutions tried for combating cybervictimization[f]	*.82 (0.42)*[g]	*.02*	.74 (0.56)	.10
Frequency of observed cyberbullying[f]	.21 (0.24)	.38	.10 (0.17)	.57
Frequency of bystander intervention[f]	.49 (0.45)	.28	.43 (0.49)	.39
Efficacy and intention for bystander intervention[h]	*2.65 (1.32)*	*.04*	1.82 (1.44)	.21

[a] Unstandardized regression coefficient.

[b] *P* values are obtained from the model of intervention versus control on scores at 8 weeks and 16 weeks controlling for baseline and sex.

[c] University of New Hampshire Internet Safety Education Survey number of cybervictimization incidents subscale.

[d] Ybarra Bullying Scale summed, 3-item.

[e] Cybervictimization Emotional Impact.

[f] University of New Hampshire Internet Safety Education Survey bystander solutions.

[g] Italics indicates *P*<.05.

[h] University of New Hampshire Internet Safety Education Survey bystander self-efficacy and intention to help others.

Table 4. Secondary outcomes of general mental health, well-being, and other violence (comparing baseline to 8 weeks and to 16 weeks).

Secondary outcomes	8 Weeks		16 Weeks	
	β[a] (SE)	*P* value[b]	β (SE)	*P* value
Well-being[c]	*1.17 (0.87)*[d]	*.02*	*3.24 (0.95)*	*<.001*
Psychological stress[e]	*−.66 (.08)*	*.04*	*−.89 (0.09)*	*<.001*
Positive affect[f]	.61 (0.60)	.32	.55 (0.69)	.42
Perceived social support[g]	−.45 (1.59)	.78	*3.50 (2.02)*	*.05*
Dating violence in the past 2 months[h]	.38 (0.28)	.18	1.15 (1.07)	.29
In-person bullying in the past 2 months[i]	3.07 (3.00)	.41	1.66 (2.70)	.60
Number of physical fights[j]	*−.60 (0.28)*	*.01*	−.07 (0.04)	.10

[a] Unstandardized regression coefficient.

[b] *P* values are obtained from model of intervention versus control on scores at 8 weeks and 16 weeks controlling for baseline and sex.

[c] World Health Organization-Five.

[d] Italicized values indicate statistical significance (*P*<.05).

[e] Patient-Reported Outcomes Measurement Information System-Psychological Stress.

[f] Patient-Reported Outcomes Measurement Information System-Positive Affect.

[g] Multidimensional Scale of Perceived Social Support.

[h] Conflict in Adolescent Dating Relationships.

[i] Illinois Bully Scale.

[j] Youth Risk Behavior Survey fighting subscale, 1-item.

User Experience

Semistructured interviews (Multimedia Appendix 1) were conducted with the intervention group only (n=36). The interview material was coded into 5 general themes: message content and tone, remote intervention content, usability or helpfulness of the app, preference between app-based messaging and text-based messaging, and recommending the program (Table 5). All intervention participants had positive comments on the message content and tone, and some participants had useful suggestions about future changes. Almost all participants had positive comments regarding the remote intervention content; negative reactions mostly focused on the length of the presentation. Approximately one-fourth of the participants suggested improvements to the app interface. Three-quarters of the participants said that they preferred an app-based intervention (compared with other technology-based intervention modalities such as text messaging or the web). They said that the app has the potential to hold more resources, it is separate from personal conversations with friends, and it sends them reminders to answer the survey if they forget. Finally, all participants said that they would recommend the program to friends. Two participants provided a caveat that they would not recommend the program to adults in general or to adolescents who do not check their notifications often.

Table 5. Representative quotes from the qualitative interviews (n=36).

Theme	Quote	Participant
Message content and tone	"I actually really liked the messages and I felt like especially when I was like at a friend's house or just not really focusing or like really remembering, the messages helped me look back at what the whole point of this was and helped me remember all the helpful tricks...I really enjoyed the content because especially at my school, they have touched on it very lightly. But it was not something I fully understood like thoroughly and I feel like all the content really helped me get a better understanding."	14-year-old female
Remote intervention content	"...Mostly the little class or whatever you would call it at the beginning was most helpful for me, but the links were still good...I felt like I got the most tools from like that lesson we did at the beginning and the messages were more a reminder that I skimmed through to remember what we talked about."	17-year-old male
Usability or helpfulness of the app	"It was a nice appearance...a nice aesthetic...Instead of the tabs [at the bottom of the app labeled 'Home, Messages, Calendar, and Help now'] you could have push buttons on the Home-screen kind of like the apps on your phone, and then maybe at the top where it says welcome to the app you could put the messages and notification board there."	17-year-old male
App-based messaging	"I like the app better [than other formats] because it was a separate thing and I feel like with text messages you would respond different...I wouldn't have responded as much to text messages"	16-year-old male
Recommending the program	"Yes, I have already tried to recommend it before I love it a lot...[I recommended it to] several of my friends especially ones that I find getting down more easily or seem to get in a lot of arguments online I recommended it to them."	15-year-old nonbinary

Discussion

Principal Findings

In this study, we demonstrated that IMPACT, an entirely remote intervention, is feasible, is acceptable, and may be effective in improving bystander intervention and well-being among adolescents with a history of cybervictimization. Our analysis is encouraging given the increasing social isolation of youth during COVID-19, reported increases in web-based and in-person violence during the pandemic, and difficulty in disseminating school-based programs. It is possible that a positive change can be made using the same device that is used for cyberbullying. These results add to a growing body of work showing that it is possible for technology-augmented interventions to reduce violence and improve mental health among at-risk adolescents, and provides a strong rationale for the public health imperative of disseminating these remote and technology-based interventions [26,27,44].

The IMPACT intervention and study design were not just feasible but also highly engaging. The daily response rate to the 2-question survey was 89%, and study retention was close to 100% up to 4 months after enrollment. Many web-based interventions struggle with engagement and retention [27,66]. The reasons for our higher-than-average engagement likely include our design process, in which we iteratively refined our app based on participant feedback [28], and our use of 2-way communication, which has been shown to increase retention and engagement [67]. It may also reflect youths' willingness to participate in research to help others.

Despite not being powered for effect sizes, we observed a significant, positive effect at 8 weeks on intervention group participants' efficacy in and intention to use cyberbullying bystander interventions and in the number of strategies tried in response to their own cybervictimization, compared with the control group. This finding is remarkable, given that other studies have reported nonsignificant effects on increasing behavioral changes related to cybervictimization [25]. These significant effect sizes may reflect participants' repeated exposure to bystander intervention content and modeling of bystander interventions during the 8-week intervention. The lack of effect at 16 weeks may reflect a small sample size or the need for continuous exposure, and it should be further investigated with boosters or enhanced interventions. The lack of change in the prevalence of cybervictimization was expected given the period of measurement (16 weeks), lack of intervention with those who perpetrated bullying, and possible increased awareness of experiences of cybervictimization due to study participation.

Participants in the intervention group also showed significant increases in overall mental well-being and decreases in psychological stress compared with the control group. Other studies have shown that during pandemics or forced isolations, many youth report worsening mental health and likely increased anxiety, which can extend for months to years [36]. The increase in well-being and decrease in psychological stress in the intervention group is, therefore, particularly noteworthy given that all follow-up time points occurred during the government-enforced quarantine of the COVID-19 pandemic. These findings correspond with our prior work with text-message-based interventions to reduce physical violence and improve mental health among at-risk adolescents [44], showing that technology-augmented interventions can help increase adolescents' overall well-being.

A high percentage of participants reported being LGBTQ+ and having a low socioeconomic status. These groups are at the highest risk of cybervictimization and poor mental health [22,23]. During the COVID-19 pandemic, a time in which in-person support was decreased for all, web-based recruitment, and delivery of interventions to these youth are critically important. Our findings suggest that web-only recruitment and interventions can be used strategically to reach the youth at the highest risk of cybervictimization. Future work should also examine the relative diversity of recruitment and efficacy of interventions for remote-only secondary prevention interventions such as IMPACT versus in-person universal prevention interventions in schools.

Overall, the participants provided positive feedback regarding the remote intervention and app-based messaging program. Notably, all participants in the intervention group said that they would recommend the program to friends or other adolescents experiencing cyberbullying. During the interview process, it became clear that participants were highly familiar with the structure and format of popular social media apps; therefore, they were able to provide informative comments on improvements to the intervention app. This acceptability of an app-based intervention provides further evidence that a mobile app and brief remote session can be an effective format for adolescent behavioral interventions [68].

Future refinement and dissemination are indicated.

Limitations

Despite the high percentage of participants that reported a low socioeconomic status and identified as a gender and sexual minority, the overall percentage of eligible participants enrolled in the study was low; our participants may not, therefore, be fully representative of the national adolescent population. Semistructured interviews were conducted by the same RA who guided the participants through the brief intervention. As rapport was built through these interactions, participants may have felt more comfortable sharing their beliefs about the acceptability and feasibility of the study; however, rapport may also have led to social desirability bias in responses. As we used a single social media tool (Instagram) for recruitment, we may have missed youth who primarily used other forms of social media. Although Instagram is one of the most popular social media sites among adolescents [21], other social media sites such as Snapchat and TikTok might lead to a more inclusive representation. Importantly, we began recruitment on January 30, 2020, before COVID-19 was declared a national pandemic. Due to these environmental changes, the baseline characteristics of participants enrolled before the national emergency status may be slightly different than those enrolled after March 2020.

Conclusions

Overall, this study suggests that remote recruitment and enrollment in an app-based intervention is highly acceptable and feasible and may be effective in improving well-being, increasing bystander intervention, and growing coping strategies among adolescents who experience cybervictimization. Although the prevalence of cybervictimization was not changed by the intervention, this was not expected because of the focus on increasing bystander effects. Finally, this study suggested that adolescents who are at high risk of cybervictimization can be successfully reached through web-based recruitment methods.

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Conflicts of Interest

The authors have no conflicts directly related to this paper, but MLR notes National Institute of Health and Center for Disease Control funding; fees from Medscape to provide talks about COVID; Board of Directors (volunteer) for GetUsPPE, a 501c3; and Chief Research Officer (volunteer) for American Foundation for Firearm Injury Reduction in Medicine Research, a 501c3.

Multimedia Appendix 1
Semistructured interview questions.
[DOCX File , 17 KB - mental_v8i9e26029_app1.docx]

Multimedia Appendix 2
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 364 KB - mental_v8i9e26029_app2.pdf]

References

1. Anderson M, Jiang J. Pew Research Center. 2018. URL: https://www.pewresearch.org/internet/2018/05/31/teens-social-media-technology-2018/ [accessed 2019-05-16]
2. Álvarez-García D, Núñez JC, Barreiro-Collazo A, García T. Validation of the cybervictimization questionnaire (CYVIC) for adolescents. Comput Hum Behav 2017 May;70:270-281. [doi: 10.1016/j.chb.2017.01.007]

3. Bottino SM, Bottino CM, Regina CG, Correia AV, Ribeiro WS. Cyberbullying and adolescent mental health: systematic review. Cad Saude Publica 2015 Mar;31(3):463-475 [FREE Full text] [doi: 10.1590/0102-311x00036114] [Medline: 25859714]
4. Messias E, Kindrick K, Castro J. School bullying, cyberbullying, or both: correlates of teen suicidality in the 2011 CDC Youth Risk Behavior Survey. Compr Psychiatry 2014 Jul;55(5):1063-1068 [FREE Full text] [doi: 10.1016/j.comppsych.2014.02.005] [Medline: 24768228]
5. Hinduja S, Patchin JW. Bullying, cyberbullying, and suicide. Arch Suicide Res 2010;14(3):206-221. [doi: 10.1080/13811118.2010.494133] [Medline: 20658375]
6. Kowalski RM, Giumetti GW, Schroeder AN, Lattanner MR. Bullying in the digital age: a critical review and meta-analysis of cyberbullying research among youth. Psychol Bull 2014 Jul;140(4):1073-1137. [doi: 10.1037/a0035618] [Medline: 24512111]
7. Rémond JJ, Kern L, Romo L. [A cyberbullying study: analysis of cyberbullying, comorbidities and coping mechanisms]. Encephale 2015 Sep;41(4):287-294. [doi: 10.1016/j.encep.2014.08.003] [Medline: 25240939]
8. Smokowski PR, Evans CB, Cotter KL. The differential impacts of episodic, chronic, and cumulative physical bullying and cyberbullying: the effects of victimization on the school experiences, social support, and mental health of rural adolescents. Violence Vict 2014;29(6):1029-1046. [doi: 10.1891/0886-6708.vv-d-13-00076] [Medline: 25905143]
9. Schneider SK, O'Donnell L, Stueve A, Coulter RW. Cyberbullying, school bullying, and psychological distress: a regional census of high school students. Am J Public Health 2012 Jan;102(1):171-177. [doi: 10.2105/ajph.2011.300308]
10. Sinclair KO, Bauman S, Poteat VP, Koenig B, Russell ST. Cyber and bias-based harassment: associations with academic, substance use, and mental health problems. J Adolesc Health 2012 May;50(5):521-523. [doi: 10.1016/j.jadohealth.2011.09.009] [Medline: 22525118]
11. Kann L, McManus T, Harris WA, Shanklin SL, Flint KH, Queen B, et al. Youth risk behavior surveillance - United States, 2017. MMWR Surveill Summ 2018 Jun 15;67(8):1-114 [FREE Full text] [doi: 10.15585/mmwr.ss6708a1] [Medline: 29902162]
12. Aboujaoude E, Savage M, Starcevic V, Salame W. Cyberbullying: review of an old problem gone viral. J Adolesc Health 2015 Jul;57(1):10-18. [doi: 10.1016/j.jadohealth.2015.04.011] [Medline: 26095405]
13. Ybarra M, Mitchell K, Wolak J, Finkelhor D. Examining characteristics and associated distress related to internet harassment: findings from the second youth internet safety survey. Pediatrics 2006 Oct;118(4):e1169-e1177. [doi: 10.1542/peds.2006-0815] [Medline: 17015505]
14. Ybarra ML, Mitchell KJ. Online aggressor/targets, aggressors, and targets: a comparison of associated youth characteristics. J Child Psychol Psychiatry 2004 Oct;45(7):1308-1316. [doi: 10.1111/j.1469-7610.2004.00328.x] [Medline: 15335350]
15. Mishna F, Cook C, Gadalla T, Daciuk J, Solomon S. Cyber bullying behaviors among middle and high school students. Am J Orthopsychiatry 2010 Jul;80(3):362-374. [doi: 10.1111/j.1939-0025.2010.01040.x] [Medline: 20636942]
16. Juvonen J, Gross EF. Extending the school grounds?--Bullying experiences in cyberspace. J Sch Health 2008 Sep;78(9):496-505. [doi: 10.1111/j.1746-1561.2008.00335.x] [Medline: 18786042]
17. Elgar FJ, Napoletano A, Saul G, Dirks MA, Craig W, Poteat VP, et al. Cyberbullying victimization and mental health in adolescents and the moderating role of family dinners. JAMA Pediatr 2014 Nov;168(11):1015-1022. [doi: 10.1001/jamapediatrics.2014.1223] [Medline: 25178884]
18. Selkie E, Fales J, Moreno M. Cyberbullying prevalence among US middle and high school-aged adolescents: a systematic review and quality assessment. J Adolesc Health 2016 Mar;58(2):125-133 [FREE Full text] [doi: 10.1016/j.jadohealth.2015.09.026] [Medline: 26576821]
19. Peskin MF, Markham CM, Shegog R, Temple JR, Baumler ER, Addy RC, et al. Prevalence and correlates of the perpetration of cyber dating abuse among early adolescents. J Youth Adolesc 2017 Feb;46(2):358-375. [doi: 10.1007/s10964-016-0568-1] [Medline: 27665278]
20. Mitchell KJ, Jones LM, Turner HA, Shattuck A, Wolak J. The role of technology in peer harassment: does it amplify harm for youth? Psychol Violence 2016;6(2):193-204. [doi: 10.1037/a0039317]
21. Anderson M, Smith A, Rainie L, Jiang J, Hefferon M, Perrin A. A Majority of Teens Have Experienced Some Form of Cyberbullying. Pew Research Center. 2018 Oct. URL: https://www.pewinternet.org/2018/09/27/a-majority-of-teens-have-experienced-some-form-of-cyberbullying/ [accessed 2019-08-13]
22. Bucchianeri MM, Gower AL, McMorris BJ, Eisenberg ME. Youth experiences with multiple types of prejudice-based harassment. J Adolesc 2016 Aug;51:68-75. [doi: 10.1016/j.adolescence.2016.05.012] [Medline: 27310725]
23. Bouris A, Everett BG, Heath RD, Elsaesser CE, Neilands TB. Effects of victimization and violence on suicidal ideation and behaviors among sexual minority and heterosexual adolescents. LGBT Health 2016 Apr;3(2):153-161 [FREE Full text] [doi: 10.1089/lgbt.2015.0037] [Medline: 26789401]
24. Espelage DL, Hong JS. Cyberbullying prevention and intervention efforts: current knowledge and future directions. Can J Psychiatry 2017 Jun;62(6):374-380 [FREE Full text] [doi: 10.1177/0706743716684793] [Medline: 28562094]
25. Schultze-Krumbholz A, Schultze M, Zagorscak P, Wölfer R, Scheithauer H. Feeling cybervictims' pain-the effect of empathy training on cyberbullying. Aggress Behav 2016;42(2):147-156. [doi: 10.1002/ab.21613] [Medline: 26349848]

26. Garaigordobil M, Martínez-Valderrey V. Technological resources to prevent cyberbullying during adolescence: the cyberprogram 2.0 program and the cooperative cybereduca 2.0 videogame. Front Psychol 2018;9:745 [FREE Full text] [doi: 10.3389/fpsyg.2018.00745] [Medline: 29867695]
27. Jacobs NC, Völlink T, Dehue F, Lechner L. Online Pestkoppenstoppen: systematic and theory-based development of a web-based tailored intervention for adolescent cyberbully victims to combat and prevent cyberbullying. BMC Public Health 2014 Apr 24;14:396 [FREE Full text] [doi: 10.1186/1471-2458-14-396] [Medline: 24758264]
28. Ranney ML, Pittman S, Riese A, Ybarra M, Huang J, Spirito A, et al. Mobile health intervention development principles: lessons from an adolescent cyberbullying intervention. HICSS 2018 Jan:3329-3338. [doi: 10.24251/hicss.2018.422]
29. Siry B, Betz M, Azrael D, Knoepke C, Simpson S, Omeragic F, et al. A Pilot Trial of Suicidal Adults Within Emergency Departmentsnrollment Challenges and Strategies Related to Firearm Access Internet. New York, USA: Sage Publications; 2020.
30. Kutok ER, Doria N, Dunsiger S, Patena JV, Nugent NR, Riese A, et al. Feasibility and cost of using Instagram to recruit adolescents to a remote intervention. J Adolesc Health 2021 May 28:A [FREE Full text] [doi: 10.1016/j.jadohealth.2021.04.021] [Medline: 34059428]
31. Ramo DE, Rodriguez TM, Chavez K, Sommer MJ, Prochaska JJ. Facebook recruitment of young adult smokers for a cessation trial: methods, metrics, and lessons learned. Internet Interv 2014 Apr;1(2):58-64 [FREE Full text] [doi: 10.1016/j.invent.2014.05.001] [Medline: 25045624]
32. Guillory J, Wiant KF, Farrelly M, Fiacco L, Alam I, Hoffman L, et al. Recruiting hard-to-reach populations for survey research: using Facebook and Instagram advertisements and in-person intercept in LGBT bars and nightclubs to recruit LGBT young adults. J Med Internet Res 2018 Jun 18;20(6):e197 [FREE Full text] [doi: 10.2196/jmir.9461] [Medline: 29914861]
33. Kayrouz R, Dear BF, Karin E, Titov N. Facebook as an effective recruitment strategy for mental health research of hard to reach populations. Internet Interv 2016 May;4:1-10 [FREE Full text] [doi: 10.1016/j.invent.2016.01.001] [Medline: 30135786]
34. Moreno M, Waite A, Pumper M, Colburn T, Holm M, Mendoza J. Recruiting adolescent research participants: in-person compared to social media approaches. Cyberpsychol Behav Soc Netw 2017 Jan;20(1):64-67. [doi: 10.1089/cyber.2016.0319] [Medline: 27976951]
35. Webb M, Burns J, Collin P. Providing online support for young people with mental health difficulties: challenges and opportunities explored. Early Interv Psychiatry 2008 May;2(2):108-113. [doi: 10.1111/j.1751-7893.2008.00066.x] [Medline: 21352141]
36. Loades ME, Chatburn E, Higson-Sweeney N, Reynolds S, Shafran R, Brigden A, et al. Rapid systematic review: the impact of social isolation and loneliness on the mental health of children and adolescents in the context of covid-19. J Am Acad Child Adolesc Psychiatry 2020 Nov;59(11):1218-39.e3 [FREE Full text] [doi: 10.1016/j.jaac.2020.05.009] [Medline: 32504808]
37. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009 Apr;42(2):377-381 [FREE Full text] [doi: 10.1016/j.jbi.2008.08.010] [Medline: 18929686]
38. Harris K, Halpern C, Whitsel E. Study Design - Add Health. The National Longitudinal Study of Adolescent Health: Research Design. 2009. URL: https://addhealth.cpc.unc.edu/documentation/study-design/ [accessed 2020-09-15]
39. Protection of Human Subjects. US Department of Health and Human Services. 2009. URL: https://www.govinfo.gov/content/pkg/CFR-2016-title45-vol1/pdf/CFR-2016-title45-vol1-part46.pdf [accessed 2020-11-05]
40. Santelli J. Guidelines for adolescent health research, a position paper of the society for adolescent medicine. J Adol Health 2003 Nov;33(5):396-409. [doi: 10.1016/j.jadohealth.2003.06.009]
41. Ranney ML, Choo EK, Cunningham RM, Spirito A, Thorsen M, Mello MJ, et al. Acceptability, language, and structure of text message-based behavioral interventions for high-risk adolescent females: a qualitative study. J Adolesc Health 2014 Jul;55(1):33-40 [FREE Full text] [doi: 10.1016/j.jadohealth.2013.12.017] [Medline: 24559973]
42. Ranney ML, Patena JV, Nugent N, Spirito A, Boyer E, Zatzick D, et al. PTSD, cyberbullying and peer violence: prevalence and correlates among adolescent emergency department patients. Gen Hosp Psychiatry 2016;39:32-38 [FREE Full text] [doi: 10.1016/j.genhosppsych.2015.12.002] [Medline: 26786845]
43. Bandura A. Social cognitive theory: an agentic perspective. Annu Rev Psychol 2001;52:1-26.
44. Ranney ML, Pittman SK, Dunsiger S, Guthrie KM, Spirito A, Boyer EW, et al. Emergency department text messaging for adolescent violence and depression prevention: a pilot randomized controlled trial. Psychol Serv 2018 Nov;15(4):419-428 [FREE Full text] [doi: 10.1037/ser0000193] [Medline: 30382737]
45. Jones LM, Mitchell KJ. Defining and measuring youth digital citizenship. New Med Soc 2016 Jul 9;18(9):2063-2079. [doi: 10.1177/1461444815577797]
46. Ybarra ML, Espelage DL, Mitchell KJ. Differentiating youth who are bullied from other victims of peer-aggression: the importance of differential power and repetition. J Adolesc Health 2014 Aug;55(2):293-300 [FREE Full text] [doi: 10.1016/j.jadohealth.2014.02.009] [Medline: 24726463]

47. Elipe P, Mora-Merchán JA, Nacimiento L. Development and validation of an instrument to assess the impact of cyberbullying: the cybervictimization emotional impact scale. Cyberpsychol Behav Soc Netw 2017 Aug;20(8):479-485. [doi: 10.1089/cyber.2017.0069] [Medline: 28806126]
48. Brooke J. SUS: a 'quick and dirty' usability scale. In: Jordan PW, Thomas B, McClelland IL, Weerdmeester B, editors. Usability Scale. London, UK: CRC Press; Jun 11, 1996:207-212.
49. Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys. The Williams Institute. 2014. URL: https://williamsinstitute.law.ucla.edu/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf [accessed 2021-06-29]
50. Transgender Health: Data Requirements/Policy Implications. Centers for Disease Control and Prevention. 2012. URL: https://www.cdc.gov/nchs/ppt/nchs2012/SS-37_SCOUT.pdf [accessed 2021-06-29]
51. Use of Well-Being Measures in Primary Health Care. Regional Office for Europe WHO. 1998. URL: https://www.euro.who.int/__data/assets/pdf_file/0016/130750/E60246.pdf [accessed 2020-10-28]
52. Blom EH, Bech P, Högberg G, Larsson JO, Serlachius E. Screening for depressed mood in an adolescent psychiatric context by brief self-assessment scales-testing psychometric validity of WHO-5 and BDI-6 indices by latent trait analyses. Health Qual Life Outcomes 2012 Dec 11;10:149 [FREE Full text] [doi: 10.1186/1477-7525-10-149] [Medline: 23227908]
53. Hall T, Krahn G, Horner-Johnson W, Lamb G, Rehabilitation ResearchTraining Center Expert Panel on Health Measurement. Examining functional content in widely used health-related quality of life scales. Rehabil Psychol 2011 May;56(2):94-99. [doi: 10.1037/a0023054] [Medline: 21574727]
54. Bevans KB, Gardner W, Pajer K, Riley AW, Forrest CB. Qualitative development of the PROMIS(R) pediatric stress response item banks. J Pediatr Psychol 2013 Mar;38(2):173-191 [FREE Full text] [doi: 10.1093/jpepsy/jss107] [Medline: 23124904]
55. Bevans K, Gardner W, Pajer K, Becker B, Carle A, Tucker C, et al. Psychometric evaluation of the PROMIS® pediatric psychological and physical stress experiences measures. J Pediatr Psychol 2018 Jul 1;43(6):678-692 [FREE Full text] [doi: 10.1093/jpepsy/jsy010] [Medline: 29490050]
56. Forrest CB, Ravens-Sieberer U, Devine J, Becker BD, Teneralli RE, Moon J, et al. Development and evaluation of the PROMIS® pediatric positive affect item bank, child-report and parent-proxy editions. J Happiness Stud 2018 Mar;19(3):699-718 [FREE Full text] [doi: 10.1007/s10902-016-9843-9] [Medline: 29760578]
57. Canty-Mitchell J, Zimet GD. Psychometric properties of the multidimensional scale of perceived social support in urban adolescents. Am J Community Psychol 2000 Jun;28(3):391-400. [doi: 10.1023/A:1005109522457] [Medline: 10945123]
58. Zimet GD, Powell SS, Farley GK, Werkman S, Berkoff KA. Psychometric characteristics of the multidimensional scale of perceived social support. J Pers Assess 1990;55(3-4):610-617. [doi: 10.1080/00223891.1990.9674095] [Medline: 2280326]
59. Zimet GD, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of perceived social support. J Pers Assess 1988 Mar;52(1):30-41. [doi: 10.1207/s15327752jpa5201_2]
60. Cunningham RM, Whiteside LK, Chermack ST, Zimmerman MA, Shope JT, Bingham CR, et al. Dating violence: outcomes following a brief motivational interviewing intervention among at-risk adolescents in an urban emergency department. Acad Emerg Med 2013 Jun;20(6):562-569 [FREE Full text] [doi: 10.1111/acem.12151] [Medline: 23758302]
61. Brener N, Kann L, Kinchen S, Grunbaum J, Whalen L, Eaton D, et al. Methodology of the youth risk behavior surveillance system. MMWR Recomm Rep 2004 Sep 24;53(RR-12):1-13 [FREE Full text] [Medline: 15385915]
62. Dahlberg L, Toal S, Swahn M, Behrens C. Measuring Violence-Related Attitudes, Behaviors, and Influences among Youths: A Compendium of Assessment Tools. Second Edition. Education Resources Information Center. 2005. URL: https://eric.ed.gov/?id=ED486261 [accessed 2020-10-28]
63. Espelage DL, Holt MK. Bullying and victimization during early adolescence. J Emotion Abuse 2001 Mar;2(2-3):123-142. [doi: 10.1300/j135v02n02_08]
64. Smith J, Firth J. Qualitative data analysis: application of the framework approach. Nurse Res 2011;18(2):52-62 [FREE Full text] [doi: 10.7748/nr2011.01.18.2.52.c8284]
65. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol 2013 Sep 18;13:117 [FREE Full text] [doi: 10.1186/1471-2288-13-117] [Medline: 24047204]
66. Arigo D, Pagoto S, Carter-Harris L, Lillie S, Nebeker C. Using social media for health research: methodological and ethical considerations for recruitment and intervention delivery. Digit Health 2018;4:2055207618771757 [FREE Full text] [doi: 10.1177/2055207618771757] [Medline: 29942634]
67. Hoermann S, McCabe KL, Milne DN, Calvo RA. Application of synchronous text-based dialogue systems in mental health interventions: systematic review. J Med Internet Res 2017 Jul 21;19(8):e267 [FREE Full text] [doi: 10.2196/jmir.7023] [Medline: 28784594]
68. Bruehlman-Senecal E, Hook C, Pfeifer J, FitzGerald C, Davis B, Delucchi K, et al. Smartphone app to address loneliness among college students: pilot randomized controlled trial. JMIR Ment Health 2020 Oct 20;7(10):e21496 [FREE Full text] [doi: 10.2196/21496] [Medline: 33079071]

Abbreviations

CBT: cognitive behavioral therapy
CONSORT: Consolidated Standards of Reporting Trials
IMPACT: Intervention Media to Prevent Adolescent Cyber-Conflict Through Technology
MI: motivational interviewing
PROMIS: Patient-Reported Outcomes Measurement Information System
RA: research assistant
REDCap: Research Electronic Data Capture
SUS: System Usability Scale

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Original Paper

Automated Monitoring of Suicidal Adolescents' Digital Media Use: Qualitative Study Exploring Acceptability Within Clinical Care

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Abstract

Background: Monitoring linguistic cues from adolescents' digital media use (DMU; ie, digital content transmitted on the web, such as through text messages or social media) that could denote suicidal risk offers a unique opportunity to protect adolescents vulnerable to suicide, the second leading cause of death among youth. Adolescents communicate through digital media in high volumes and frequently express emotionality. In fact, web-based disclosures of suicidality are more common than in-person disclosures. The use of automated methods of digital media monitoring triggered by a natural language processing algorithm offers the potential to detect suicidal risk from subtle linguistic units (eg, negatively valanced words, phrases, or emoticons known to be associated with suicidality) present within adolescents' digital media content and to use this information to respond to alerts of suicidal risk. Critical to the implementation of such an approach is the consideration of its acceptability in the clinical care of adolescents at high risk of suicide.

Objective: Through data collection among recently suicidal adolescents, parents, and clinicians, this study examines the current context of digital media monitoring for suicidal adolescents seeking clinical care to inform the need for automated monitoring and the factors that influence the acceptance of automated monitoring of suicidal adolescents' DMU within clinical care.

Methods: A total of 15 recently suicidal adolescents (aged 13-17 years), 12 parents, and 10 clinicians participated in focus groups, qualitative interviews, and a group discussion, respectively. Data were recorded, transcribed, and analyzed using thematic analysis.

Results: Participants described important challenges to the current strategies for monitoring the DMU of suicidal youth. They felt that automated monitoring would have advantages over current monitoring approaches, namely, by protecting web-based environments and aiding adolescent disclosure and support seeking about web-based suicidal risk communication, which may otherwise go unnoticed. However, they identified barriers that could impede implementation within clinical care, namely, adolescents' and parents' concerns about unintended consequences of automated monitoring, that is, the potential for loss of privacy or false alerts, and clinicians' concerns about liability to respond to alerts of suicidal risk. On the basis of the needs and preferences of adolescents, parents, and clinicians, a model for automated digital media monitoring is presented that aims to optimize acceptability within clinical care for suicidal youth.

Conclusions: Automated digital media monitoring offers a promising means to augment detection and response to suicidal risk within the clinical care of suicidal youth when strategies that address the preferences of adolescents, parents, and clinicians are in place.

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KEYWORDS

adolescents; parents; digital media; social media; technology; monitoring; suicide prevention; implementation in clinical care; natural language processing; qualitative

Introduction

Background

There is growing public health interest in strategies for monitoring the digital media use (DMU) of youth at risk for suicide, the second leading cause of death among adolescents [1]. DMU, which we define as digitized content transmitted on the web, for example, through social media or text messages, can offer adolescents a number of important benefits, such as social support and connectedness [2,3]. However, youth at risk for suicide may be especially vulnerable to negative digital media experiences that can contribute to changes in mood and mental state [4,5]. Compared with youth in the general population, adolescents facing mental health challenges are more likely to be exposed to explicit or triggering content such as images or descriptions of self-harm behavior through their DMU [3], report negative experiences such as cyberbullying [6], and engage in problematic internet use (ie, difficulty in controlling use that has negative consequences in daily life) [7,8]. Although there is potential for greater vulnerability to negative digital media experiences, there are currently no evidence-based approaches for monitoring the DMU of youth at risk for suicide.

Monitoring linguistic cues on DMU that could denote suicidal risk could prove especially advantageous in clinical care of suicidal adolescents. Suicidal disclosures are frequent within web-based spaces, perhaps even more so than through in-person communication [9]. Typical assessment practices within clinical settings rely heavily on the subjective reporting of suicidal thoughts and behaviors [10]. Patient self-report, although useful, is limited in predicting suicidal risk [10]. Patients vary in their ability and willingness to provide information about suicidal intent based on a variety of factors, including lack of insight, a wish to avoid more restrictive treatment, or a desire to thwart detection to carry out suicidal plans [10]. The use of algorithms to guide clinicians' conceptualization of risk is recommended to advance the current methods of suicide risk assessment [11]. Given the high rate of adolescent DMU [12], an algorithm that identifies language indicative of suicidal risk from adolescents' DMU could be a beneficial supplement to the available assessment methods.

Advances in computer science and language analytic methods, such as natural language processing (NLP), allow for large amounts of textual data to be collected and analyzed [13], such as the high volume of web-based content produced by adolescents. Using a variety of analytic methods, NLP can evaluate the frequency and structure of linguistic units, features of interpersonal awareness, and emotional and psychological states [13]. NLP has shown the capacity to detect subtle indicators of suicidal risk within digital media content over time [14,15], highlighting its potential to enable an automated approach for monitoring suicidal risk.

Objectives

A critical issue for the implementation of an automated digital media monitoring approach to detect suicidal risk is its acceptability within clinical care of youth identified to be at high risk for suicidal behavior, who have unique and acute needs for monitoring. Through data collection among youth who have experienced recent suicidal thoughts or behaviors, parents, and clinicians, this study examined (1) the current context of digital media monitoring for recently suicidal adolescents and (2) the factors that influence the acceptance of automated monitoring of suicidal adolescents' DMU within clinical care.

Methods

Sample

A purposive sample [16] of adolescents aged 13-18 years in treatment for recent suicidal thoughts or behaviors, parents of adolescent patients, and mental health clinicians from an intensive outpatient program (IOP) at an academic medical center in Pennsylvania were invited to participate in this study. Of 254 youth within the patient population, 202 (79.5%) reported their biological sex as female and 52 (20.5%) as male. Of 244 patients who offered information on their race and ethnicity, 199 (81.6%) reported being White, 24 (9.8%) Black, 8 (3.3%) Asian, 8 (3.3%) Multi-racial, and 5 (2%) Hispanic. Of 217 patients who reported their sexual identity, 95 (43.8%) identified as 100% heterosexual and 122 (56.2%) as bisexual, mostly gay, 100% gay, or they did not know. Of 210 patients who reported their gender identity, 26 (12.4%) identified as transgender, genderqueer, nonbinary, or other gender identity.

Data Collection

The first and second authors were introduced to adolescents and parents by clinicians to discuss the study. Adolescents and parents were not recruited as dyads, although 9 parents also had children who participated in the study. Interested adolescents participated in 3 focus groups (n=15). Focus groups ranged in size from 3 to 6 members, based on the patients enrolled within the IOP at the time of enrollment. Interested parents participated in interviews (n=12). Research visits were conducted separately for youth and parent participants. Parents provided informed consent, and the adolescents provided assent. Clinicians (n=10) were recruited via an email invitation and consented to participate in a group discussion, a form of qualitative data collection that derives shared meanings from people who have common experiences [17]. This study was approved by the University of Pittsburgh Institutional Review Board.

Data collection for patients and parents occurred between January and July 2018, and subsequent data collection for clinicians was conducted in January 2020. Appointments were conducted in person at research staff offices for adolescents and clinicians and either in person or via phone for parents based on their availability. All participants received an incentive of US $25. Data collection focused on experiences with digital media monitoring and perspectives on an automated approach to monitoring. To aid the recollection of mediation strategies deployed, parents completed a brief questionnaire via Qualtrics (version XM of Qualtrics) of selected items from the survey on Teens, Parents, and Digital Monitoring by the Pew Research Center [18]; subsequently, they were asked to expand upon the strategies they reported during interviews.

Guides were developed to facilitate semistructured discussion. The conversations remained open to topics most salient to the participants, which facilitated the spontaneous generation of themes. This approach increases the validity of experiential data collection [19]. The first and second authors conducted focus groups and the group discussion, and the first author conducted parent interviews. The inclusion of participants continued until saturation was reached [20].

Data Analysis

Focus groups, interviews, and the group discussion were audiotaped, transcribed, and coded using NVivo, version 12 (QSR International) [21]. Data were analyzed using a thematic analysis approach designed by Braun and Clark [22], a recommended approach for applied health research [23]. Data were reviewed independently by the first and second authors using a codebook, which was created by the first author based on the interview script and revised to include emergent codes. Additions of new codes, changes in code definitions, and coding discrepancies were reviewed by consensus among the research team. Responses to the parent questionnaire were used to conceptualize the interview themes.

Results

Context for Digital Media Monitoring

Adolescent Focus Groups

Focus groups were conducted with 15 youth aged 13-17 years (mean 15.1, SD 1.6), 7 of whom were female, 5 of whom were male, and 2 of whom reported other gender identities. During the focus groups, adolescents acknowledged that DMU had positive influences but also mentioned that DMU negatively impacted their mental health and contributed to suicidal thoughts. However, most adolescents had mixed feelings toward the monitoring of their DMU, that is, they believed there should be a balance between their need for protection and for free expression and privacy. Some adolescents expressed moral opposition to monitoring, noting that it was an infringement of their personal freedoms. Likening it to having personal phone conversations endlessly recorded, they felt that monitoring was an invasion of privacy. Although others did not take a moral stance to monitoring, they reported valuing the ability to autonomously identify with a group of like-minded others on digital media. Some described having “Finstas” or secondary Instagram accounts. Although they often presented an idealized version of themselves on their primary accounts (eg, depicting a happy or successful persona), they used these secondary accounts to authentically express themselves to a limited number of trusted friends. They felt that monitoring these private conversations would diminish their ability to be themselves and limit their opportunities for peer support. All youth, even those who expressed a high degree of hesitance toward monitoring, agreed that monitoring of DMU is necessary when safety is a concern, for example, when self-harm is disclosed. They agreed that monitoring is especially important for younger children, who are more easily influenced and have a greater need for protection from negative experiences with DMU than adolescents.

Most adolescents said their parents did not monitor their DMU, and those who were monitored were strongly dissatisfied with their parents’ chosen monitoring methods. Adolescents consistently reported that they had never or infrequently discussed their DMU with their therapist, although they felt doing so would be helpful. Some youth were concerned about burdening their therapist with issues that felt inconsequential, such as getting enough *likes* or followers. They described apprehension in initiating these conversations and wanted prompting from therapists:

> *I think if it bothered me a lot, I wouldn’t be able to tell him...at all. Like I would have to be asked a question pertaining to it. I probably wouldn’t talk about it out of the blue.*

Parent Interviews

Interviews were conducted with 12 parents, three-quarters of whom were mothers (N=9) and one-quarter were fathers (N=3). The parents’ mean age was 49.3 years (SD 4.2). During interviews, parents universally reported engaging in monitoring to protect their children. Parents reported feeling a strong obligation to monitor because they felt that negative digital media experiences (eg, cybervictimization) could trigger their children to have depressed or suicidal thoughts. Parents used a variety of strategies to mediate their children’s DMU (Table 1). Parents desired help in mediating their at-risk adolescents’ DMU, which they consistently reported took an emotional toll on them. They found it challenging to weigh the perceived benefit of mediation against the consequences of parent-child conflict and reducing prosocial digital interactions, which contributed to a sense of powerlessness:

> *I feel like, oh my gosh, it’s going to be my fault if she gets suicidal...So, I hate her phone, and I’m really frustrated at the lack of being able to truly control what she does.*

Table 1. Parents' strategies for mediating adolescents' digital media use (N=12).

Mediation strategies and strategies parents used	Parents, n (%)	Successes	Challenges	Quote from a parent
Co-use: parents engaging in DMU[a] with their child		Offered unique insights into adolescents' emotional state and successful when other family members (eg, adult siblings) were engaged	Limited by adolescents' use of multiple accounts that are not known to the parent	"It started out with- we said we had to have access to- we had to be not blocked. We had to be friends with her, so that we could see when she did post things. Then we noticed that she was having more than one account and we were friends with her on one account, but we were not friends with her on another account even though it existed. And, the school district actually called us and said that there were some things on there that were disturbing."
Friends with child on Facebook	4 (33)			
Friends with child on Twitter	1 (8)			
Friends with child on other social media platforms	5 (42)			
Restriction: restriction of an adolescents' DMU using social rules or technical means		Removing phones from their child's possession before bed was viewed as helpful to adolescents' sleep, and blocking or filtering was considered useful for reducing content for mature audiences	Resulted in parent-child conflict, contributed to use behind parents' back, restricted access to supportive friends, limited digital literacy impacted parents' ability to use technical restrictions, and youth circumvented parental controls	"Like, I put parental controls on her phone, and she knows how to break into them and change them, and I feel very powerless a lot that all the monitoring that I know how to do I feel like she still circumvents that. And it's very frustrating to me."
Removed child's phone from their possession as punishment	7 (58)			
Limited the time or times of the day their child can use the internet	8 (67)			
Used parental controls to block certain content	7 (58)			
Used parental controls to restrict phone use	4 (33)			
Monitoring: covert or overt review of an adolescents' DMU		Open dialog about DMU builds or sustains trust in the parent-child relationship	Monitoring DMU was viewed as exhausting and only done when there was a reason for concern	"I have a program that when I asked them for their phones, I could plug it in to my computer, and I could get all their information on their phones. What I was really interested in was their text messages and their notes because in their notes is where they would write things that were revealing about their safety and also what websites they go to."
Checked which websites the child visited	9 (75)			
Checked child's profile on social media	10 (83)			
Used monitoring tools to track location	9 (75)			
Discussed appropriate web-based behavior	11 (92)			

[a] DMU: digital media use.

Clinician Group Discussion

A group discussion was conducted with 10 clinicians from different disciplines (6 mental health counselors, 2 clinical social workers, and 2 psychiatric nurses). Participants were predominantly female (7/10, 70%) and ranged in age from 27 to 63 years (mean 32.8, SD 11.8). During the group discussion, clinicians described having a role in discussing DMU with parents and adolescents. To reduce adolescents' negative experiences with DMU, clinicians helped patients consider reducing access to upsetting, triggering, or bullying content, and omitting use during sleep times. Further, they promoted healthy digital expression by suggesting privately contacting a support person rather than publicly broadcasting suicidal thoughts. Clinicians who incorporated positive experiences with DMU as part of the treatment primarily discussed the use of DMU for distraction and social support. Clinicians felt that their role with parents involves education about DMU and its influence on youth mental health as well as helping both parents and adolescents navigate compromises with monitoring:

> *We often have to talk to families about finding that middle path, because they—parents want their children to go to them. But their kids aren't gonna go to them if they know that their cell phone is gonna be taken away.*

Perceptions on Automated Digital Media Monitoring

Proposed Strategy for Automated Digital Media Monitoring

We described our idea for a 3-step process for the automated monitoring of adolescents' DMU to participants and asked them to offer feedback. In step 1, adolescents and parents are securely connected to a website on which their permission would be requested to release the adolescents' digital media content from several platforms. In step 2, the software automatically detects language indicative of suicidal risk from the adolescents' digital media data. Finally, in step 3, when risk is detected, an alert is automatically sent to the adolescents' clinician for response, as deemed necessary.

Parent and Adolescent Perspectives

Parents and adolescents identified facilitators and barriers associated with automated monitoring.

Protection From Harm

Parents and adolescents reflected that the chief facilitator is the potential for automated monitoring to protect digital media environments. Parents reflected on their capacity to identify suicidal risks. Despite their existing monitoring strategies, some parents felt that it was difficult to know when their child had suicidal thoughts. They believed that the automated detection of risk could aid their ability to maintain their child's safety. Several adolescents felt that automated monitoring could protect them from harm, particularly on anonymous sites where they felt victimization is more frequent. Furthermore, some youth described that more adolescents are inclined to disclose suicidal thinking on digital media, who may not do so in person to a key support person who could act to prevent a crisis. They felt that automated monitoring has the potential to detect youth who reach out for help through digital media when their comments may otherwise go unnoticed:

> *I'm sure that a lot of kids turn to social media, because they don't know how to turn to the people in real life. And sometimes it's easier hiding behind a screen.* [adolescent]

Automated Risk Detection

Adolescents and parents were generally accepting of monitoring strategies that used software to detect suicidal risk. Adolescents consistently found the use of software acceptable because automation would reduce the private information received by clinicians to only content indicative of suicidal risk. Several parents appreciated that the automated detection of risk would decrease the burden associated with the manual review of their child's digital media content. They also felt that the use of software would result in a greater reach than what they were capable of on their own:

> *That's an awesome idea...if you had a way to monitor it sort of automatically then I feel like that would be more instrumental in finding out what's really going on. You know? Like, I can only do what I can see, what she'll let me see on her phone.* [parent]

Involvement of Clinicians

Parents and adolescents appreciated that automated monitoring would prompt conversations with clinicians about the risk of DMU. All parents saw the involvement of a trained mental health professional as a benefit. They felt that clinicians are likely to be effective because they regularly engage with their children and know their circumstances well. Some parents had experience working with clinicians who addressed DMU during treatment, which they felt helped their child gain insight. Although adolescents agreed that these conversations may be difficult, they acknowledged that being directly asked about risk language would help them engage with their clinician about their digital environments:

> *Yeah, especially for like the people that post on social media stuff like they post about their self-harm. I think that is really good to refer that to a therapist because not only is it somebody like looking this up out of curiosity or speculating that this person needs help, because it's like proof that they do.* [adolescent]

Loss of Digital Privacy

Parents and adolescents agreed that their primary concern is the loss of privacy associated with releasing DMU for automated monitoring. Most adolescent and parent participants feared the release of personal communications on digital media, particularly sensitive text messages:

> *You know, I guess with social media I would be a little more comfortable just because it's...already out there anyway. I think I [feel] more adversely at the text side.* [parent]

Potential for False Labeling

Due to the complicated ways in which adolescents communicate through DMU, many did not fully trust the ability of software to detect risk. Adolescents were concerned about whether a machine could effectively interpret sarcasm pertaining to suicidal communication:

> *Some people are serious, some people are just joking, some people are suicidal and joking. But there are so many jokes about wanting to kill yourself, that it would be too hard to actually pinpoint the actual people who are at risk.* [adolescent]

Tendency to Alter Behavior

When adolescents became aware that their DMU was being monitored, some adolescents suggested that they may alter their behavior. They suspected that some may change their behavior to negate the potential for risk alerts to be generated:

> *It would make people go off of it. They'd find their way around it. Or it'd be completely fake people trying to be happy so that they wouldn't get monitored. But, at the same time, no monitoring is also kind of an issue.* [adolescent]

Communication With Parents About Risk

Most parents trusted their child's therapist to gauge when they need to be made aware of risk alerts but acknowledged the need for a protocol to alert parents to safety risks:

> *I would hope that they would at least send a text message and let me know that there's possibly a problem...I mean, if my child's in danger, yeah...I want to know.* [parent]

Clinicians' Perspectives

Through the group discussion, clinicians worked together to find a consensus on the risks and benefits of the proposed automated monitoring approach.

Potential Risks

Clinicians' chief concern was their liability to respond when receiving risk alerts. Clinicians were concerned about not having the capacity to respond at all hours. They felt it was critical to have a feasible safety protocol in place and to assure patient and parent buy-in before proceeding with this monitoring approach. In addition, clinicians acknowledged the concerns that automated monitoring may not be compatible with all patients, specifically those who may have deficits in communication. One clinician considered potential challenges in identifying the risk in patients with autism:

> *I've had three different kids over the years who have been autistic. They would say something, and then they were done with it. But then all these fire alarms went off, metaphorically. [Mobile crisis support] was called...and the kid says "uh, I'm fine."*

Accommodations

Clinicians suggested accommodations to the automated monitoring strategy to reduce liability. They considered the potential for parents to be alerted to risk language instead of clinicians. However, some clinicians felt that this could result in less buy-in from adolescents who may not want their parents to have that level of information and access to their DMU. Consensus was reached upon an alternative in which adolescents themselves receive alerts when risk is detected and are automatically provided with feedback on how to respond based on their safety plan:

> *I think that would almost be the best way to do this because then you're creating the awareness for them in the moment, that, "oh wait, hey, I'm at higher risk right now," or "I'm feeling worse, and I'm saying these things, this might be a great time for me to utilize coping skills or reach out for support."*

In addition to youth receiving in-the-moment alerts, clinicians wanted to be informed of trends regarding risk detected through adolescents' DMU. They suggested one option would be to provide an index of suicide risk severity over time, that they could review with youth during therapy sessions.

Potential Benefits

If the automated monitoring strategy was revised to meet their needs, clinicians felt it could have advantages both for them and their patients. Clinicians felt that this would aid their ability to monitor patients' symptoms over time. Furthermore, clinicians felt that an approach alerting adolescents to the potential for risk would allow autonomy in managing their mental health, similar to how patients manage their physical health:

> *I think it kinda reminds me...of someone who has diabetes and is like checking your blood sugar to say like, "Oh, I need to take my insulin." It lets them have control.*

Discussion

Principal Findings

This study offers insights from parents, adolescents, and mental health clinicians to inform the development of an automated method for digital media monitoring aimed at detecting and responding to adolescent suicidal risk. All participants reported challenges to the current monitoring approaches. Although adolescents perceived the negative consequences of DMU on their mental health, they were displeased by parental monitoring and experienced discomfort in starting a conversation with their therapists about DMU. Parents expressed challenges in monitoring their children's DMU, which left them feeling powerless. Clinicians felt that they had a role in managing parent-child relationship dynamics pertaining to digital media monitoring. Participants perceived that automated monitoring has a potential for advantage beyond the current monitoring approaches but had concerns that could act as barriers to implementation.

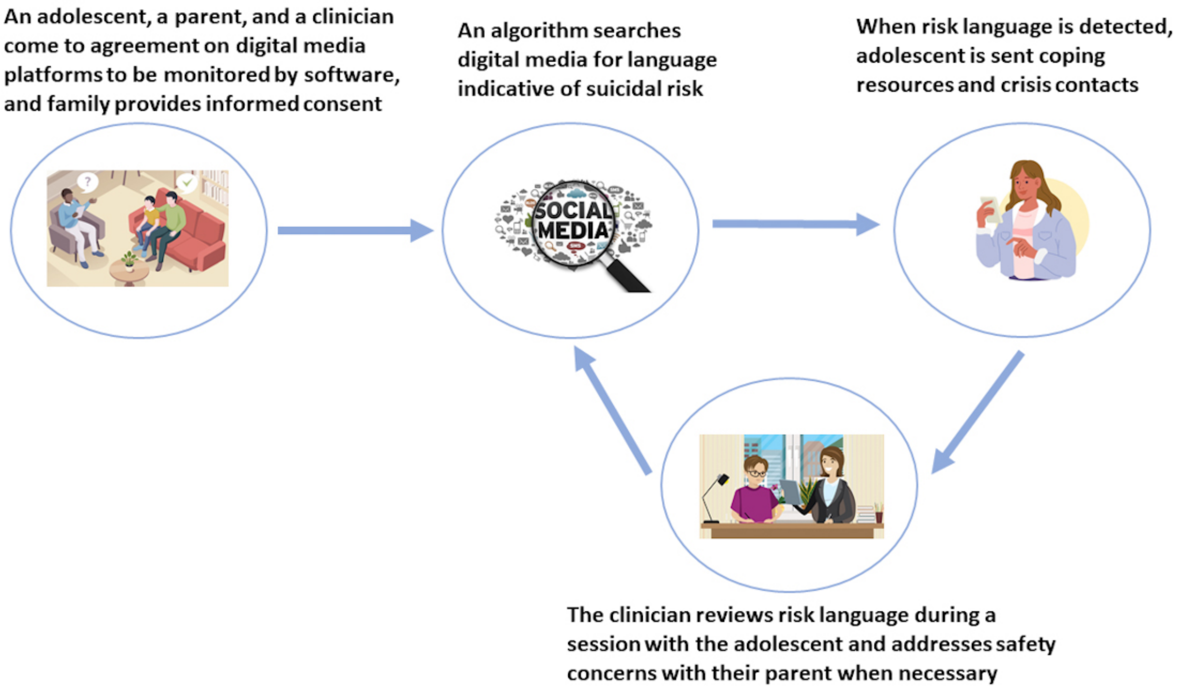
The results of this study suggest a need to honor adolescents' desires for free and private expression that could aid engagement with supportive peers, while also honoring parents' need to protect adolescents' safety. Clinicians and adolescents reported that younger children, in particular, require protection. Their assertions are consistent with recommendations from UNICEF (United Nations International Children's Emergency Fund), which suggests the need to temper approaches to monitoring based on a child's developmental capacity [24], and the American Association of Suicidology [25], which suggests determining a monitoring approach based on adolescents' individual vulnerability to the harmful aspects of digital media as well as its benefits. When adolescents are suicidal, monitoring intensity should be consistent with their level of maturity, acuity, and risk of self-harm.

The results from this study also suggest the need to screen for DMU as part of clinical care. Exemplifying this point, clinicians in this study felt that they openly discussed DMU with their adolescent patients, whereas adolescents rarely reported talking about DMU with their clinicians. Although it is possible that these differences in report may have been influenced by the 1.5-year gap in data collection between adolescents or parents and clinicians, the clinical care and management of concerns related to DMU in this setting remained stable within this period. Furthermore, other data have shown adolescents' hesitance in discussing DMU with trusted adults. For example, only 11% of adolescents reported disclosing incidents of cyberbullying [26]. Using a validated questionnaire, such as the Problematic and Risky Internet Use Screening Scale [27,28], as part of the clinical assessment could aid adolescents' discomfort in initiating a discussion on DMU and support an open line of communication that will aid informed suicide risk management.

Participants' perceptions of the facilitators and barriers of automated monitoring suggest the need for an approach that is responsive to their preferences. This approach could leverage adolescents' and parents' desires for a protected digital environment to garner interest. To mitigate hesitance toward the release of private information, flexibility is recommended whereby adolescents and parents can decide what information they are willing to share. The role of clinicians is critical in explaining the potential risks before proceeding. Discussion regarding risks should recognize the potential for false alerts, that is, the possibility that automated analysis could misinterpret ambiguous language as risky or that indications of risk could be missed, while also recognizing NLP's potential to detect subtle communications of suicidal risk [14,15]. Furthermore, clinicians requested accommodations to the proposed method of automated monitoring. They desired alerts of risk language to be delivered to adolescents, alongside coping resources and crisis contacts from adolescents' safety plans. This approach could innovatively address the guidance by the American Association of Suicidology to incorporate the positive and negative aspects of DMU into safety planning for youth at risk for suicide [25] through novel automated methods. A revised strategy that consolidates the participants' recommendations is shown in Figure 1. Although this revised approach should be further reviewed with adolescents and parents, it is likely to offer adolescents autonomy in their communication through DMU, a key need that they identified for digital media monitoring. Furthermore, this revised approach would retain clinician involvement in monitoring through the adolescents' clinical care, which was desirable to parents.

Next steps will include the use of human-centered design, a methodology known to enhance the implementation of digital mental health interventions [29], to develop prototypes of a clinician dashboard and interface to provide youth with coping and crisis resources when risk is indicated. Subsequently, we will test this approach using an evidence-based NLP algorithm. This design and testing process will also include additional iterative steps with adolescents and parents to optimally address the barriers they have identified, namely, those related to privacy and the risk of false positives, while harnessing facilitators toward engagement in automated monitoring.

Figure 1. Final strategy for automated digital media monitoring based on participant feedback.



An adolescent, a parent, and a clinician come to agreement on digital media platforms to be monitored by software, and family provides informed consent

An algorithm searches digital media for language indicative of suicidal risk

When risk language is detected, adolescent is sent coping resources and crisis contacts

The clinician reviews risk language during a session with the adolescent and addresses safety concerns with their parent when necessary

Strengths and Limitations

This study had several limitations. First, the use of a convenience sample, the small sample size, and the exploratory nature of this study limit our ability to generalize our results to a larger population. Participants were part of an IOP at an academic medical center; therefore, our results may differ from those obtained from other settings and may not be representative of adolescents who do not seek mental health care. Additional perspectives are necessary to generalize to settings with differing levels of resources or for adolescents and families who do not seek clinical care. Furthermore, there was a lag in data collection of adolescents and parents in 2018 and clinicians in 2020. When interpreting clinicians' perspectives in the context of parents' and adolescents' reports, readers should acknowledge the potential that clinicians' awareness of digital media's influence on adolescents may have changed within this period. Despite these limitations, this study offers insights into the current context of monitoring of suicidal adolescents' DMU and provides a breadth of information that will fuel an acceptable approach to the automated monitoring of high-risk youth, thereby strengthening its feasibility for implementation in clinical practice.

Conclusions

Our findings provide valuable insights into the development of a feasible automated monitoring intervention that can be implemented in the clinical care of suicidal youth. Involving adolescents, parents, and clinicians in the development of approaches for automated monitoring is likely to result in a more widely accepted, understood, and effective monitoring strategy and a greater capacity to protect adolescents from harmful DMU experiences.

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Conflicts of Interest

None declared.

References

1. Hedegaard H, Curtin SC, Warner M. Suicide mortality in the United States, 1999-2017. NCHS Data Brief 2018 Nov(330):1-8 [FREE Full text] [Medline: 30500324]
2. Marchant A, Hawton K, Stewart A, Montgomery P, Singaravelu V, Lloyd K, et al. A systematic review of the relationship between internet use, self-harm and suicidal behaviour in young people: the good, the bad and the unknown. PLoS One 2017;12(8):e0181722. [doi: 10.1371/journal.pone.0181722] [Medline: 28813437]
3. Dyson MP, Hartling L, Shulhan J, Chisholm A, Milne A, Sundar P, et al. A systematic review of social media use to discuss and view deliberate self-harm acts. PLoS One 2016;11(5):e0155813 [FREE Full text] [doi: 10.1371/journal.pone.0155813] [Medline: 27191728]
4. Viner RM, Gireesh A, Stiglic N, Hudson LD, Goddings A, Ward JL, et al. Roles of cyberbullying, sleep, and physical activity in mediating the effects of social media use on mental health and wellbeing among young people in England: a secondary analysis of longitudinal data. Lancet Child Adolesc Health 2019 Oct;3(10):685-696. [doi: 10.1016/S2352-4642(19)30186-5] [Medline: 31420213]
5. Biernesser C, Bear T, Brent D, Mair C, Trauth J. Social media and adolescent suicide: exploring risks, benefits, and opportunities for prevention. University of Pittsburgh, PhD Dissertation. 2019. URL: http://d-scholarship.pitt.edu/36205/ [accessed 2021-06-22]
6. Hamm MP, Newton AS, Chisholm A, Shulhan J, Milne A, Sundar P, et al. Prevalence and effect of cyberbullying on children and young people: a scoping review of social media studies. JAMA Pediatr 2015 Aug;169(8):770-777. [doi: 10.1001/jamapediatrics.2015.0944] [Medline: 26098362]
7. Spada MM. An overview of problematic internet use. Addict Behav 2014 Jan;39(1):3-6. [doi: 10.1016/j.addbeh.2013.09.007] [Medline: 24126206]
8. Liu H, Liu S, Tjung J, Sun F, Huang H, Fang C. Self-harm and its association with internet addiction and internet exposure to suicidal thought in adolescents. J Formos Med Assoc 2017 Mar;116(3):153-160 [FREE Full text] [doi: 10.1016/j.jfma.2016.03.010] [Medline: 27146126]
9. Belfort EL, Miller L. Relationship between adolescent suicidality, self-injury, and media habits. Child Adolesc Psychiatr Clin N Am 2018 Apr;27(2):159-169. [doi: 10.1016/j.chc.2017.11.004] [Medline: 29502743]

10. Jacobs D, Baldessarini R, Conwell Y, Fawcett J, Horton L, Meltzer H, et al. Practice guidelines for the assessment and treatment of patients with suicidal behaviors. American Psychiatric Association. 2010. URL: https://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/suicide.pdf [accessed 2021-06-22]
11. Franklin JC, Ribeiro JD, Fox KR, Bentley KH, Kleiman EM, Huang X, et al. Risk factors for suicidal thoughts and behaviors: a meta-analysis of 50 years of research. Psychol Bull 2017 Feb;143(2):187-232. [doi: 10.1037/bul0000084] [Medline: 27841450]
12. Rideout VR, Robb MB. Social media, social life: teens reveal their experiences. Common Sense Media. 2018. URL: https://tinyurl.com/yjw69s6r [accessed 2021-06-22]
13. Nadkarni PM, Ohno-Machado L, Chapman WW. Natural language processing: an introduction. J Am Med Inform Assoc 2011 Oct;18(5):544-551 [FREE Full text] [doi: 10.1136/amiajnl-2011-000464] [Medline: 21846786]
14. Coppersmith G, Leary R, Crutchley P, Fine A. Natural Language Processing of Social Media as Screening for Suicide Risk. Biomed Inform Insights 2018;10:1178222618792860 [FREE Full text] [doi: 10.1177/1178222618792860] [Medline: 30158822]
15. De Choudhury M, Kiciman E, Dredze M, Coppersmith G, Kumar M. Discovering shifts to suicidal ideation from mental health content in social media. Proc SIGCHI Conf Hum Factor Comput Syst 2016 May;2016:2098-2110 [FREE Full text] [doi: 10.1145/2858036.2858207] [Medline: 29082385]
16. Patton MQ. Qualitative Research & Evaluation Methods. 3rd Ed. Thousand Oaks, California, United States: SAGE Publications, Inc; 2001:1-688.
17. Payne G, Payne J. Group Discussions/Focus Groups. London: Sage Publications; 2004.
18. Anderson M. Parents, teens and digital monitoring. Pew Research Center. 2016. URL: http://www.pewinternet.org/2016/01/07/parents-teens-and-digital-monitoring [accessed 2020-11-24]
19. Clandinin D, Connelly F. Personal experience methods. In: Denzin N, Lincoln Y, editors. Handbook of Qualitative Research. Thousand Oaks, CA: Sage Publications; 1994:1-784.
20. Morse JM. The significance of saturation. Qual Health Res 2016 Jul 01;5(2):147-149. [doi: 10.1177/104973239500500201]
21. NVivo qualitative data analysis software, version 12. QSR International Pty Ltd. 2018. URL: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home [accessed 2021-06-22]
22. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
23. Braun V, Clarke V. What can "thematic analysis" offer health and wellbeing researchers? Int J Qual Stud Health Well-being 2014;9:26152 [FREE Full text] [doi: 10.3402/qhw.v9.26152] [Medline: 25326092]
24. Children's online privacy and freedom of expression. UNICEF. 2018. URL: https://www.unicef.org/csr/files/UNICEF_Childrens_Online_Privacy_and_Freedom_of_Expression(1).pdf [accessed 2020-11-24]
25. Suicide and social media. American Association of Suicidology. 2019. URL: https://suicidology.org/wp-content/uploads/2019/07/SUICIDE-SOCIAL-MEDIA.pdf [accessed 2020-11-24]
26. Stop cyberbullying before it starts. National Crime Prevention Council. 2010. URL: http://archive.ncpc.org/resources/files/pdf/bullying/cyberbullying.pdf [accessed 2021-06-22]
27. Moreno MA, Arseniev-Koehler A, Selkie E. Development and testing of a 3-item screening tool for problematic internet use. J Pediatr 2016 Sep;176:167-172 [FREE Full text] [doi: 10.1016/j.jpeds.2016.05.067] [Medline: 27395768]
28. Jelenchick LA, Eickhoff J, Christakis DA, Brown RL, Zhang C, Benson M, et al. The Problematic and Risky Internet Use Screening Scale (PRIUSS) for adolescents and young adults: scale development and refinement. Comput Human Behav 2014 Jun 01;35:171-178 [FREE Full text] [doi: 10.1016/j.chb.2014.01.035] [Medline: 24882938]
29. Mohr DC, Lyon AR, Lattie EG, Reddy M, Schueller SM. Accelerating digital mental health research from early design and creation to successful implementation and sustainment. J Med Internet Res 2017 May 10;19(5):e153 [FREE Full text] [doi: 10.2196/jmir.7725] [Medline: 28490417]

Abbreviations

DMU: digital media use
IOP: intensive outpatient program
NLP: natural language processing
UNICEF: United Nations International Children’s Emergency Fund

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Original Paper

Perceived Facilitators of and Barriers to Implementation of a Decision Support Tool for Adolescent Depression and Suicidality Screening: Focus Group and Interview Study

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Abstract

Background: Screening Wizard (SW) is a technology-based decision support tool aimed at guiding primary care providers (PCPs) to respond to depression and suicidality screens in adolescents. Separate screens assess adolescents’ and parents’ reports on mental health symptoms, treatment preferences, and potential treatment barriers. A detailed summary is provided to PCPs, also identifying adolescent-parent discrepancies. The goal of SW is to enhance decision-making to increase the utilization of evidence-based treatments.

Objective: This qualitative study aims to describe multi-stakeholder perspectives of adolescents, parents, and providers to understand the potential barriers to the implementation of SW.

Methods: We interviewed 11 parents and 11 adolescents and conducted two focus groups with 18 health care providers (PCPs, nurses, therapists, and staff) across 2 pediatric practices. Participants described previous experiences with screening for depression and were shown a mock-up of SW and asked for feedback. Interviews and focus groups were transcribed verbatim, and codebooks were inductively developed based on content. Transcripts were double coded, and disagreements were adjudicated to full agreement. Completed coding was used to produce thematic analyses of the interviews and focus groups.

Results: We identified five main themes across the interviews and focus groups: parents, adolescents, and pediatric PCPs agree that depression screening should occur in pediatric primary care; there is concern that accurate self-disclosure does not always occur during depression screening; SW is viewed as a tool that could facilitate depression screening and that might encourage more honesty in screening responses; parents, adolescents, and providers do not want SW to replace mental health discussions with providers; and providers want to maintain autonomy in treatment decisions.

Conclusions: We identified that providers, parents, and adolescents are all concerned with current screening practices, mainly regarding inaccurate self-disclosure. They recognized value in SW as a computerized tool that may elicit more honest responses and identify adolescent-parent discrepancies. Surprisingly, providers did not want the SW report to include treatment recommendations, and all groups did not want the SW report to replace conversations with the PCP about depression. Although SW was originally developed as a treatment decision algorithm, this qualitative study has led us to remove this component, and instead, SW focuses on aspects identified as most useful by all groups. We hope that this initial qualitative work will improve the future implementation of SW.

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KEYWORDS

depression; adolescent; suicidality; screening

Introduction

Adolescent suicide rates have increased by 20% in the past decade and are now the second leading cause of death for ages 10 to 24 years in the United States [1,2].

Screening for Depression and Suicidality

As depression and suicidal ideation are strong risk factors for adolescent suicidal behavior [3], screening for depression and suicidality have become national priorities, with depression screening being a billable International Classification of Diseases, Tenth Revision, diagnosis code and a covered preventive service often used as a quality measure in pediatric quality initiatives [4]. The United States Preventive Services Task Force recommendations highlight that screening programs *alone* are unlikely to improve care for depression or have a measurable impact on reducing suicide rates among adolescents. In fact, despite routine screening in primary care settings, initiation of depression treatment following a positive screening has been as low as 17% [5,6].

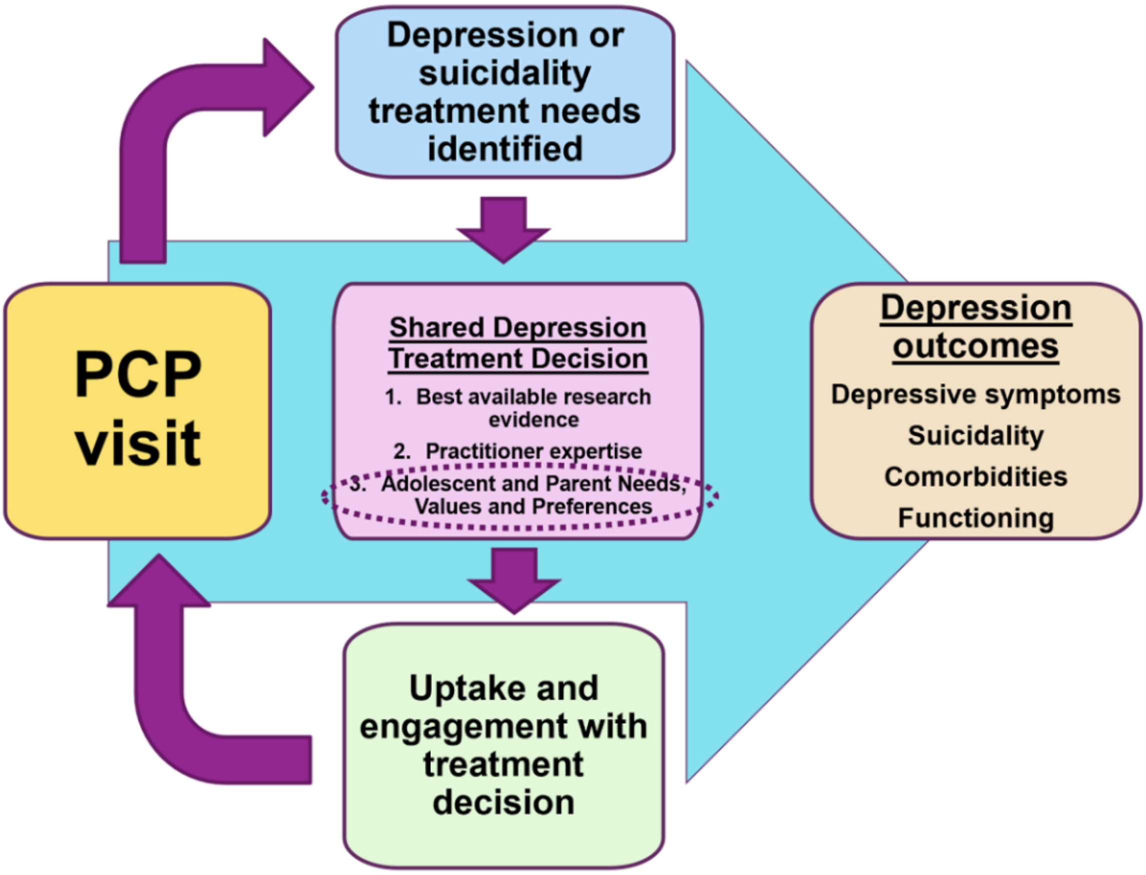
Barriers to Treatment Initiation Despite Screening

The reasons include primary care providers' (PCPs) unfamiliarity and variability in the interpretation of screening results [7], failure to assess and address patients' and parents' barriers to treatment [8], failure to factor in patients' and parents' preferences [9,10], and low motivation for treatment among patients who screen positive for depression. The revised Guidelines for Adolescent Depression in Primary Care (GLAD-PC) recommends that PCPs assess and integrate information about patient beliefs, preferences, and barriers to guide their management decisions; however, further research is needed to implement these guidelines [11]. Although the adolescent age group may be defined as ages 12 to 26 years, in this manuscript, we refer to early and middle adolescence (ages 12-17 years), considering that earlier access to mental health treatment may improve long-term health outcomes.

Shared Decision-making and Comorbidity Assessment to Address Barriers to Screening

As presented in Figure 1, identifying the need for depression treatment triggers a complex decision-making process. Optimally, this process incorporates a triad of perspectives to reach a treatment decision: (1) the PCPs' clinical experience and knowledge of diagnostic and treatment evidence and (2) the adolescents' and (3) the parents' personal expertise in their values, beliefs, and preferences, which may or may not be aligned [12]. Although routine screens offer identification of depressive symptomatology, the PCP must also consider potential comorbidities and ask separately about suicide when making their management decision. Anxiety [13] and mania are important to consider, especially when considering antidepressant prescribing for depression, which may induce a switch to mania for those at risk for bipolar disorder [14]. Not asking about substance use may lead to treatment failure and is associated with a higher risk of suicide attempt [15]. Suicidality may be missed if not assessed independently. For example, when the short Patient Health Questionnaire (PHQ)-2 version of the PHQ-9 is asked, 20% of youth with suicidal ideation may be missed [16,17]. After formulating a diagnostic and management decision based on clinical data, the PCP will need to align their recommendations with patient preferences [18]. Although in some states, adolescents may confidentially consent for mental health care, a parent or guardian is typically involved in medical decision-making and provides the instrumental support needed to obtain treatment. Similarly, barriers to treatment are common and differ between adolescents and their parents [10], which PCPs may not be aware of [19], unless they elicit them. Shared decision-making (SDM) interventions that assess treatment preferences and barriers in the context of clinical decision-making tend to improve decisional quality by reducing conflict around decision-making [20,21] and have proven to be more successful than non-SDM interventions for depression and other chronic illnesses [22,23], as evidenced by systematic reviews conducted globally. SDM is recommended for PCPs assessing adolescent depression in the current GLAD-PC guidelines, specifically that "the patient and family should be active team members and approve the roles of the PCP and mental health clinicians" [11]. However, busy PCPs tend to engage in few SDM behaviors for depression [24], even when they possess knowledge and resources to recommend evidence-based care [25]. This process of eliciting, interpreting, and addressing the previously stated information is quite complex and may lead to prolonged visits for a busy PCP, especially those practicing in busy community pediatric primary care settings.

Figure 1. Primary care provider depression treatment decision-making. PCP: primary care provider.



Opportunities for Technology to Enhance Routine Depression Screening

Advances in technology that assist PCPs (eg, decision support tools) with interpreting screening results and then provide personalized treatment recommendations may improve treatment outcomes for mental health [26]. Specifically, in pediatric primary care, computerized screens with associated decision support have promoted provider utilization of depression screening results [27] and identification of and assessment for suicidality [28]. Most caregivers are comfortable with adolescents independently completing computerized screening [29]. Adolescents also find that computerized tools, especially those that provide personalized feedback, may enhance their interaction with their health care providers [30].

The Screening Wizard Tool

The aim of this study is to develop a technology-based decision support tool, *Screening Wizard* (SW), aimed at guiding PCPs in responding to positive depression and suicidality screens in adolescents. SW was developed as an iPad (Apple Inc) app to include both an adolescent screen and a parent screen. Each screen would include a series of questions that would ask about adolescents' mental health—including anxiety, mania, and suicidality comorbidities—and substance use symptoms and parents' perception of their adolescent's symptoms; adolescents' mental health treatment preferences and readiness if treatment is recommended that day as well as the parent's readiness and preferences on behalf of their child; and both adolescents' and parents' potential barriers to mental health treatment. The results of this screen and accompanying patient handouts (with referral information and psychoeducation) would then be summarized in a report that highlights adolescent-parent discrepancies to share with the health care provider. Our goal is to facilitate SDM between adolescents, parents, and PCPs and to increase uptake of depression treatment in the primary care setting.

This Study

Despite its anticipated benefits, the potential challenges of integrating new technology interventions in busy community primary care settings may be numerous. This manuscript describes a multi-stakeholder qualitative study conducted with adolescents, parents, and providers to evaluate the usability of a prototype of the SW and understand the acceptability of and potential barriers to future implementation of SW.

Methods

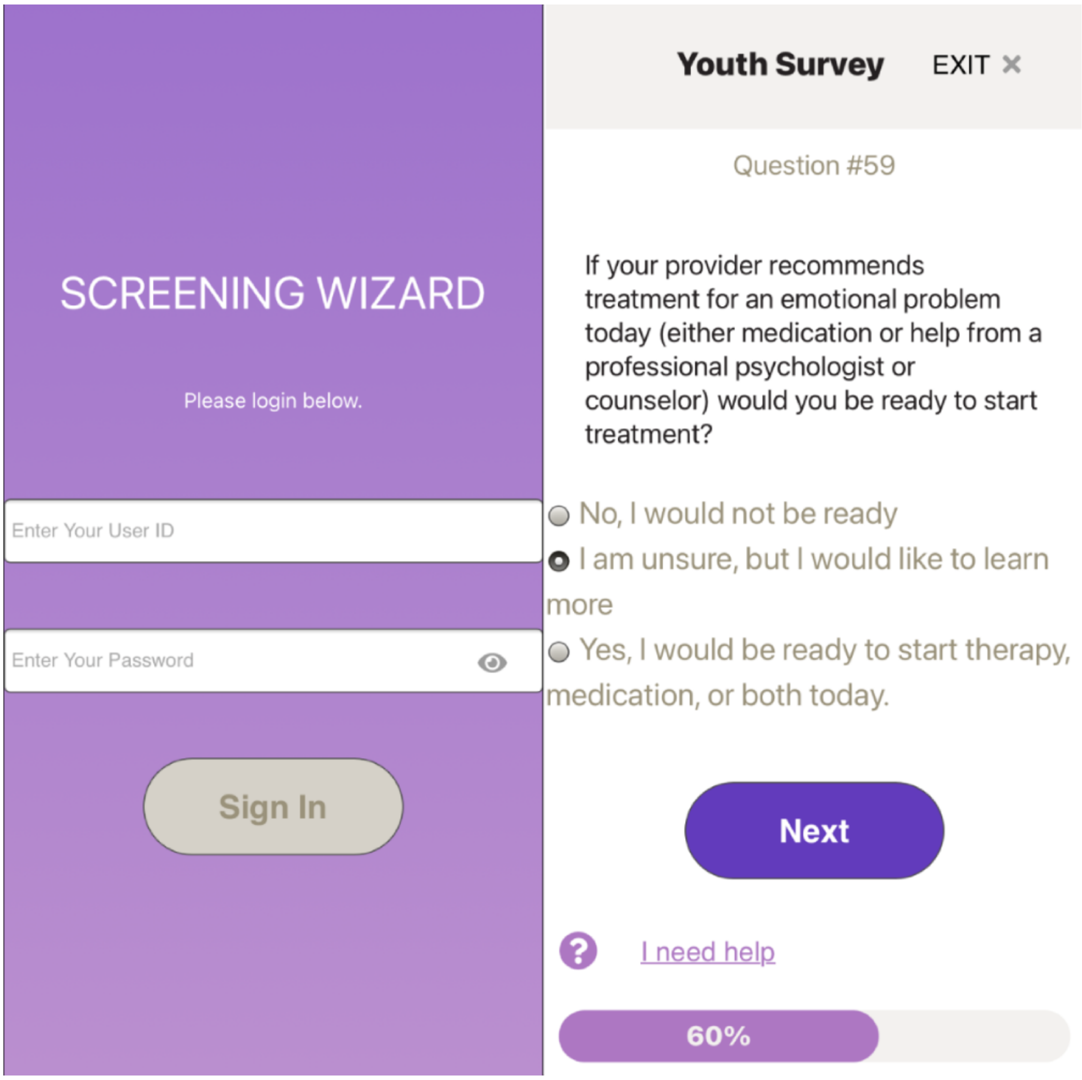
This qualitative study was conducted as part of a larger study meant to refine the already-developed SW technology in a prototype form before implementation.

SW Prototype

The initial SW prototype was developed iteratively by the first and last authors, starting with low-fidelity mock-ups (Figures 2 and 3). Content was selected for each domain by choosing measures that are *free, brief, and validated* to maximize the likelihood of uptake [31]. Measures with as few items as possible, but with adequate reliability and validity, were selected from the public domain or made available at no cost (Table 1).

The initial algorithms were iteratively refined through expert consultations. The concept and initial design were based on an earlier decision support tool designed to balance symptom severity with child and parent preferences when making treatment recommendations for childhood anxiety [32].

Figure 2. Example screenshots from the Screening Wizard interface for adolescents.



SCREENING WIZARD

Please login below.

Youth Survey

Question #59

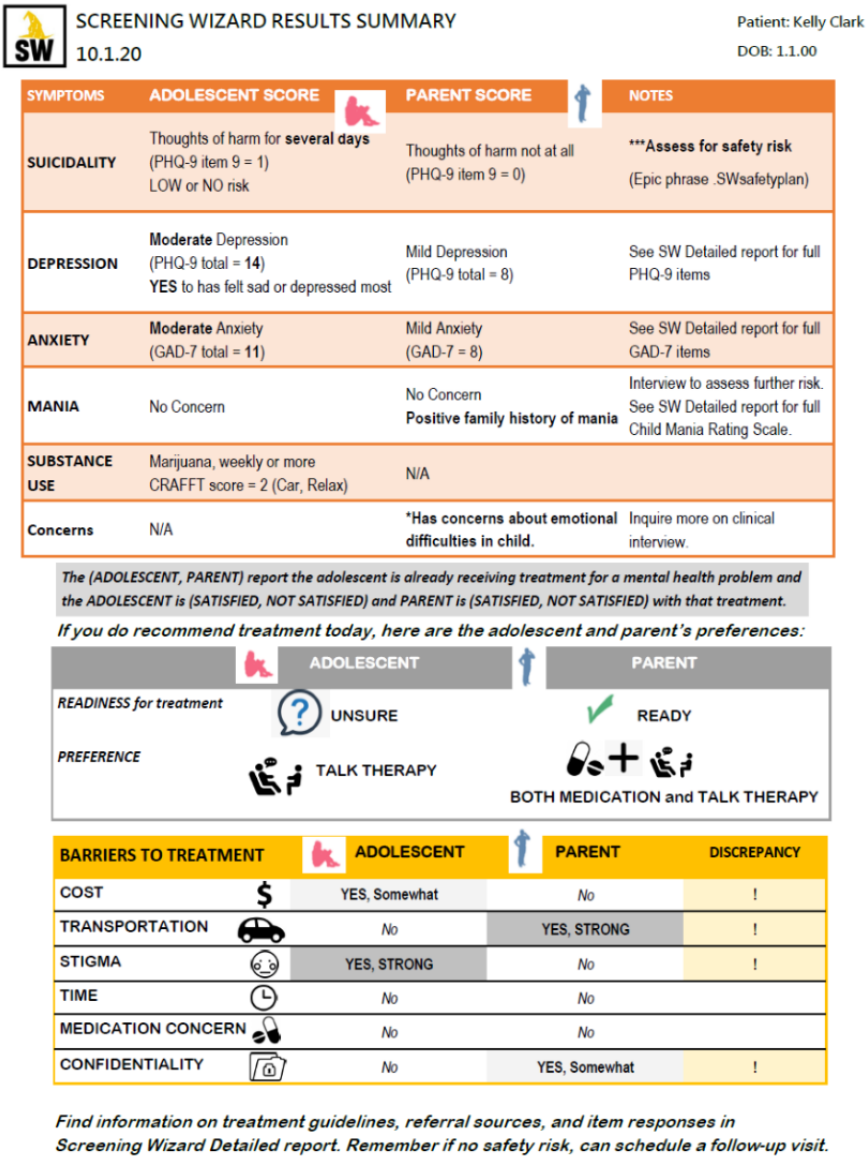
If your provider recommends treatment for an emotional problem today (either medication or help from a professional psychologist or counselor) would you be ready to start treatment?

○ No, I would not be ready

● I am unsure, but I would like to learn more

○ Yes, I would be ready to start therapy, medication, or both today.

Figure 3. Mock-up of the Screening Wizard report for providers. CRAFFT: Car, Relax, Alone, Forget, Friends, Trouble; GAD-7: Generalized Anxiety Disorder-7; N/A: not applicable; PHQ-9: Patient Health Questionnaire-9; SW: Screening Wizard.



SCREENING WIZARD RESULTS SUMMARY
10.1.20

Patient: Kelly Clark
DOB: 1.1.00

SYMPTOMS	ADOLESCENT SCORE	PARENT SCORE	NOTES
SUICIDALITY	Thoughts of harm for **several days** (PHQ-9 item 9 = 1) LOW or NO risk	Thoughts of harm not at all (PHQ-9 item 9 = 0)	*****Assess for safety risk** (Epic phrase .SWsafetyplan)
DEPRESSION	**Moderate** Depression (PHQ-9 total = **14**) **YES** to has felt sad or depressed most	Mild Depression (PHQ-9 total = 8)	See SW Detailed report for full PHQ-9 items
ANXIETY	**Moderate** Anxiety (GAD-7 total = **11**)	Mild Anxiety (GAD-7 = 8)	See SW Detailed report for full GAD-7 items
MANIA	No Concern	No Concern **Positive family history of mania**	Interview to assess further risk. See SW Detailed report for full Child Mania Rating Scale.
SUBSTANCE USE	Marijuana, weekly or more CRAFFT score = 2 (Car, Relax)	N/A	
Concerns	N/A	***Has concerns about emotional difficulties in child.**	Inquire more on clinical interview.

The (ADOLESCENT, PARENT) report the adolescent is already receiving treatment for a mental health problem and the ADOLESCENT is (SATISFIED, NOT SATISFIED) and PARENT is (SATISFIED, NOT SATISFIED) with that treatment.

If you do recommend treatment today, here are the adolescent and parent's preferences:

	ADOLESCENT	PARENT
READINESS for treatment	? UNSURE	✓ READY
PREFERENCE	TALK THERAPY	+ BOTH MEDICATION and TALK THERAPY

BARRIERS TO TREATMENT		ADOLESCENT	PARENT	DISCREPANCY
COST	$	YES, Somewhat	*No*	!
TRANSPORTATION		*No*	YES, STRONG	!
STIGMA		YES, STRONG	*No*	!
TIME		*No*	*No*	
MEDICATION CONCERN		*No*	*No*	
CONFIDENTIALITY		*No*	YES, Somewhat	!

Find information on treatment guidelines, referral sources, and item responses in Screening Wizard Detailed report. Remember if no safety risk, can schedule a follow-up visit.

Table 1. Screening Wizard constructs and measures (total time=7 minutes).

Construct	Measure or instrument	Adolescent version	Parent version (reporting on their child's symptoms)	Time per construct (minutes)
Depression severity	PHQ-9[a] (11-item adolescent version, 9-item parent about adolescent) [33]	✓[b]	✓	1
Suicidality	Y-CAT[c] Static Suicidality [34] (12 items); item 9 on PHQ-9	✓	✓[d]	1
Anxiety	GAD-7[e] (8 items) [35,36]	✓	✓	1
Mania	CMRS[f] brief [37] (12 items), family history	✓	✓	1
Substance use screen	Past year frequency of substance use (tobacco, alcohol, marijuana, prescription drugs not prescribed to them, illegal drugs, inhalants, and herbs or synthetic drugs; 7 items) and CRAFFT[g] [38] (6 items)	✓	N/A[h]	1
Concern about impairment or functioning	Single item (concern about child's social or emotional functioning)	N/A	✓	<1
Treatment history and satisfaction	Currently in treatment? Satisfied with your care? (2 items)	✓	✓	<1
Readiness for treatment	Single item about readiness to start treatment if recommended that day	✓	✓	<1
Treatment preferences	Single item (medication, talk therapy, both, no preference, or not interested in treatment)	✓	✓	<1
Potential barriers	Cost, time, stigma, confidentiality, medication side effect concern, and transportation (6 items) adapted from abbreviated measure of Barriers To Adolescents Seeking Help Scale [39,40], Parental Barriers to Help Seeking Scale [41], and Antidepressant Meaning Scale [42]	✓	✓	<1

[a] PHQ-9: Patient Health Questionnaire-9.

[b] Construct present.

[c] Y-CAT: Youth-Computerized Adaptive Screen (Static Version).

[d] Only item 9.

[e] GAD-7: Generalized Anxiety Disorder-7.

[f] CMRS: Child Mania Rating Scale.

[g] CRAFFT: Car, Relax, Alone, Forget, Friends, Trouble.

[h] N/A: not applicable.

Study Design

Participants

To elicit feedback from the populations that would ultimately use SW, we conducted interviews with adolescents who had a history of depression and their parents (parents and adolescents were interviewed separately). In addition, we conducted focus groups with health care providers. These providers were included if they were part of the day-to-day clinical staff, which could include physicians, advanced practice practitioners (Certified Registered Nurse Practitioners and physician assistants), nurses, patient care technicians, patient service representatives, embedded mental health therapists, or administrative staff such as practice managers at a pediatric practice. The practices chosen were participating in a pediatric practice-based research network, Pediatric PittNet, that was considering (but had not yet begun) implementing SW as part of a proposed trial to evaluate SW compared with treatment-as-usual. These providers, as well as adolescents and parents who were recruited, were located in the state of Pennsylvania. We conducted interviews with parents and adolescents to gain their individual perspectives and to ensure their confidentiality as they talked about sensitive mental health topics. We conducted focus groups with providers within the same practice to benefit from group interactions in response to questions about practice-level experiences and opinions on SW implementation. Interviews and focus groups were conducted until the study principal investigators felt that they had sufficient information to move forward with implementation.

Recruitment

Participants were recruited through primary care clinics and flyers posted in clinical settings; clinics were selected for flyering based on the study teams' previous experience with those clinics and confidence in those clinics' depression diagnosis. Interested individuals could self-refer through these means. Research assistants also received referrals from the same clinical settings and approached families after they expressed interest in participating in the research. Eligible families were included if the child was aged between 12 and 17 years and screened positive for depressive symptoms or suicidal behavior at their pediatric primary care office. Individuals were excluded if they did not undergo screening in a pediatric primary care setting and were not referred as a result of a positive depression or suicide screening. Health care providers needed to be employed in a pediatric primary care setting to participate in the focus groups.

Procedure

At a scheduled visit occurring in the research offices, parents and youth were provided with a verbal consent script, and research assistants reviewed it before completing the interviews. Health care provider focus groups took place during a scheduled break at the pediatric primary care offices, and all providers underwent a verbal informed consent process. Interviews and focus groups were conducted by a member of the research team with deep knowledge of SW and previous experience conducting qualitative interviews (BGM). Data collection was performed by a qualitative methodologist (MH). All interviews and focus groups were audio recorded and transcribed.

Interview Guide

All participants were asked to describe previous experiences with screening for depression in primary care, following which they were shown a mock-up of the SW tool and asked for their feedback on it. In the first part of the interview, both adolescents and parents were asked if they or their child had ever been screened before; details of where, when, and how that screening occurred; what the results of the screening had been and how results indicating depression were handled; and whether and how they had been referred to mental health services as a result of the screening. They were also asked whether and how depression screening should occur in primary care. In the focus groups, the first portion of the focus group included questions about how depression screening is currently done in their practice as well as how positive screenings and referrals are handled. In the second part of the interviews and focus groups, participants were shown a mock-up of the SW provider decision tool paper report. The interviewer explained each component of the report and provided a low-fidelity version of the SW tool through Adobe software on an iPad (as it would be administered in a pediatric primary care setting). Participants responded with their reactions and thoughts on the appropriateness of the types and amount of information included in the provider decision tool. Participants explained out loud using a think-aloud approach [43] as they completed the low-fidelity SW tool. They were asked to review what they thought each question meant and how relevant the questions would be for their health care provider to provide advice on mental health treatment. The interview and focus group guides are included in Multimedia Appendix 1.

Data Analysis

Interviews and focus groups were transcribed verbatim, and codebooks were inductively developed based on the content. In total, 2 qualitative analysts (BGM and MH) independently coded 10 interview transcripts to establish intercoder reliability. Cohen κ scores were calculated for each code; the average score was 0.76, indicating substantial agreement [44]. The remaining 12 interview transcripts were coded by the primary coder. Both focus group transcripts were cocoded, and coding disagreements were adjudicated to full agreement. Completed coding was used to produce thematic analyses of the interviews and focus groups [45]. The resulting themes were shared with and agreed upon by the secondary coder and interviewers as a form of investigator triangulation. All study procedures were approved by the institutional review board of the University of Pittsburgh.

Results

Overview

Demographics of the sample are summarized in Table 2.

Table 2. Participant demographics.

Demographic characteristics	Adolescents (n=11)	Parents (n=11)	Health care providers (n=18)[a]
Age (years)			
Value, mean (SD)	15 (0.6)	41 (8.2)	45 (12.8)
Value, range	15-17	32-61	28-69
Sex at birth, n (%)			
Female	5 (45)	9 (82)	15 (83)
Male	6 (55)	2 (18)	2 (11)
Provider type, n (%)			
Physician	N/A[b]	N/A	4 (22)
Certified registered nurse practitioner	N/A	N/A	1 (6)
Administrator	N/A	N/A	2 (11)
Professional staff nurse or nurse coordinator	N/A	N/A	5 (28)
Patient care technician	N/A	N/A	1 (6)
Patient services representative (front desk staff)	N/A	N/A	3 (17)
Behavioral health therapist	N/A	N/A	1 (6)

[a] One health care provider has missing data, as they only partially participated in the focus group because of clinical care needs and did not provide demographic data.

[b] N/A: not applicable.

We conducted interviews with 11 parents and 11 adolescents and conducted two focus groups with 18 health care providers (physicians, Certified Registered Nurse Practitioners, nurses, behavioral health providers, and support staff) at 2 pediatric practices participating in a pediatric practice-based research network, Pediatric PittNet, which were in the process of considering implementing SW as part of a proposed trial to evaluate SW compared with treatment-as-usual. We identified five main themes across the interviews and focus groups: (1) parents, adolescents, and pediatric PCPs and support staff believe that depression screening should occur in pediatric primary care; (2) there is concern that accurate self-disclosure does not always occur during depression screening; (3) SW is viewed as a tool that could facilitate depression screening and that might encourage more honesty in screening responses; (4) parents, adolescents, and providers do not want SW to replace mental health discussions with providers; and (5) providers want to maintain autonomy in treatment decisions. Each of these themes will be discussed below with select quotations from participants presented in Textbox 1.

Textbox 1. Selected quotes from adolescents, parents, and providers.

Themes and Quotes

Parents, adolescents, and pediatric primary care providers and support staff believe that depression screening should occur in pediatric primary care

- Q1. “A lot of the time maybe people are suffering from mental health problems may not want to talk about it outright and may not bring it up, so if they give you like a survey or something that might help kind of encourage them to talk about it more.” [adolescent]
- Q2. “I mean catching it earlier on is better than catching it when [...] they’ve already suffered for 4 or 5 years, you know, [with] kind of underlying issues building up, getting worse.” [parent]
- Q3. “It would just seem more helpful and useful to like know what the person goes through before you try to do something. You know what I mean?” [adolescent]
- Q4. “I think that [primary care] should be where it should come from. I mean that’s where we go when we’re sick, that’s where we go for guidance.” [parent]
- Q5. “I feel like it’s easier to talk to a doctor about it rather than talking to like your family [...] because it seems—they’ve dealt with it before, they kind of already know, they’ve seen it, it’s easier for them to understand it rather than someone who doesn’t have any experience with it.” [adolescent]
- Q6. “Once you start screening then the doctor—if the doctor posits a question and the children will like yeah, so it’s a double edge sword on that. Um—I think if there’s—if they have any types of symptoms maybe they should [screen] but other than that I-I would say uh—no I guess.” [parent]
- Q7. “[the PCP] is supposed to help me out with like with something like if like—if I have like a broken leg or something.” [adolescent]

There is concern that accurate self-disclosure does not always occur during depression screening

- Q8. “I just don’t have the confidence that they understand the questions. [...] So we have to navigate that you know: ‘[Do] you understand why we’re asking this? Do you understand what these questions are?’, and you know I feel like there’s probably kids that slipped through the cracks that don’t screen positive that would probably benefit from a more intensive review, and that puts us in a difficult position ‘cause ‘Oh yeah, your screen is negative’ but we’re in the room and we know it’s a chaotic situation or we can tell [from] the kids affect or from other you know just red flags. That always scares me, and you feel like you’re gonna miss something.” [provider]
- Q9. “I wasn’t completely honest when I first filled out like the tablet [...] because I didn’t want to get treatment. [...] Like if they asked me if my mood was like 1 through 10, say it was like a 1 I said it was like a 3 or 4.” [adolescent]
- Q10. “fear of it getting out, like if their parents were to find out. I know that it’s harder to open up if you think more people are going to know about it ‘cause it feels like people are judging you.” [adolescent on why adolescents may be dishonest in screening]

Screening Wizard is viewed as a tool that could facilitate depression screening and that might encourage more honesty in screening responses

- Q11. “When you’re talking to a person, you’re thinking about what they’re thinking, but when you’re talking to a computer, you know it’s not, like, judging you or having any thoughts of its own. It’s just recording what you’re inputting.” [adolescent]
- Q12. “I think having both the teen and the parent do them separately of course um has the benefit of getting a more accurate picture for the same reasons, like the teenager might be embarrassed to admit uh sort of things but the parent will have noticed things the they’ll be honest about it, vice versa the parent might be embarrassed to admit that their teenager has some problems but the teenager might be willing to admit it um and so having these two perspectives you’re just a lot more likely to actually catch something that needs attention.” [parent]
- Q13. “So that [discrepancies between parent and child] is useful to know about beforehand so I can address it, and address it in a way that is immediate. So, [pretends they are talking to a patient] ‘Let me show you the handout and, this is what you guys told me.’ I don’t know makes it more natural to just bring it up in conversation.” [provider]

Parents, adolescents, and providers do not want the Screening Wizard to replace mental health discussions with providers

- Q14. “I wouldn’t want it [Screening Wizard] to replace dialogue but obviously you know a screen that’s positive or issues will lead to dialogue but a negative screen doesn’t mean there’s no issues you know? So I think that it can’t really replace dialogue. [Even if the screening is negative] I think that the provider can follow up with dialogue that just says you know the-the screening that you did um seems like you guys are doing really well which is pretty unusual for teenagers...” [parent]
- Q15. “I think you’re delegating a lot of important conversations to, just the use of handouts and these screener questionnaires and then yeah it is depersonalized. But if you kind of use it in a way that prompts important conversations, then it doesn’t have to be [depersonalized].” [provider]
- Q16. “[Screening Wizard should be used] when you go in for like a checkup or something, see like um how the person’s feeling and if they are feeling bad maybe you can um talk to them about it during the checkup or something like that.” [adolescent]

Providers want to maintain autonomy in treatment decisions

- Q17. “If you give me a recommendation it might work the vast majority of the time but I think a lot of us especially with gray hair are going to say my clinical judgment would probably trump the decision support rarely but just enough that I don’t want you to take it away, you know I’m going to use it but I want that final veto power.” [provider]
- Q18. “There might be situations where I don’t always agree with the decision support and now I’m like ‘Well, that’s not really what I wanna do’ and-and that, that makes me a little less comfortable.” [provider]

- Q19. “How are we supposed to reconcile the difference between the decision support that could spit out versus the parent who really wants something else [...] ‘cause I can tell you that it’s going to happen and I just, I with our-our population I know that’s going to happen.” [provider]
- Q20. “If a tool like this gives me decisions support, makes me feel like I’m making the right decision that it is okay to wait then I’m really glad about that. But on the other hand if your decision support sets the bar so low because of medical legal fear issues that everyone has to be referred, right now if I don’t get that referral done now you’re making me feel like I’m at risk, you know not only for the kid which of course is the primary issue but now medically, legally you’re telling me I should do something I don’t do it if something bad happens and that’s on the chart I feel like some lawyers going to find that and I’m now you know, ‘Why didn’t you do that?’ So the standard of care, best support kind of decision making really has to be very carefully thought out because you know it’s obviously the goal is to keep the kid safe but at the same time you’ve got to protect us a little. If you tell me to do something and I don’t do it am I liable? I’m worried about that, which is I’m going to be honest.” [provider]

Theme 1: Parents, Adolescents, and Pediatric PCPs and Support Staff Believe That Depression Screening Should Occur in Pediatric Primary Care

Parents and adolescents were nearly unanimous in believing that universal depression screening should occur and that pediatric primary care was an appropriate place for it. Depression screening was regarded as appropriate because it might identify adolescents struggling with depression who, for any number of reasons, might not know that they were experiencing depression or who might not be comfortable bringing the topic up unless asked. Adolescents, in particular, thought that they and their peers would be unlikely to bring it up on their own but might disclose if asked (Q1; Textbox 1). Some adolescents and parents regarded the PCP as a more neutral person to talk to about depressive symptoms than a parent. The possibility of identifying depression earlier, as well, was regarded as a benefit by all groups of participants (Q2 and Q3; Textbox 1). In addition to depression screening itself being a good thing, pediatric primary care was regarded as a good place to do it (Q4 and Q5; Textbox 1).

Health care providers were also in favor of routine depression screening in primary care, and the PCPs who participated in the two focus groups described routine depression screening as part of their practice. In one case, a health care provider described their experience as a parent, as well, who wished that the practice they took their child to would universally screen for depression. Providers’ reasoning for why screening should take place coincided with the reasoning described by adolescents and parents in terms of the importance of detecting mental health problems early and PCPs being able to help families with follow-up.

Only 1 parent and 1 adolescent (their child) felt that universal depression screening should not occur in primary care. The parent felt that pediatricians should screen for depression in the presence of symptoms, but that to do so otherwise might somehow draw an adolescent’s attention to depression such that they might become depressed when they were not before (Q6; Textbox 1). The adolescent did not think that their pediatrician should handle mental health concerns and instead thought that depression screening was the purview of a therapist (Q7; Textbox 1).

Theme 2: There Is Concern That Accurate Self-disclosure Does Not Always Occur During Depression Screening

Although pediatricians were in favor of and described routinely conducting depression screening, they noted that they did not treat screening results as accurate, meaning they often perceived a high rate of false-negative results for screening. A positive depression screen was likely to be regarded as accurate and acted upon with referral to mental health services or prescription of antidepressants (depending on patients’ and PCPs’ comfort and preference), but a negative screening did not indicate to pediatricians that there was no cause for concern (Q8; Textbox 1). One pediatrician described checking in with his patients using open-ended questions even following a negative screening to try to prevent patients who actually have depressive symptoms from being missed.

Adolescents and parents were additionally concerned that adolescents might not answer screening questions honestly. Some adolescents described not filling out depression screenings accurately in the past out of a desire to avoid treatment (Q9; Textbox 1). In addition to a desire to avoid treatment, adolescents sometimes described not wanting to be honest in screening for fear of others finding out that they have mental health problems (Q10; Textbox 1). Parents also expressed concern that their children might lie during screenings, either exaggerating or downplaying how they were really feeling out of a desire for *attention* or because they were in denial about symptoms. Thus, although screening was valued, it was not regarded as perfect in its ability to identify adolescents with depression.

Theme 3: SW Is Viewed as a Tool That Could Facilitate Depression Screening and That Might Encourage More Honesty in Screening Responses

When presented with the SW tool, nearly all interviewees and focus group participants had a positive reaction to the screening tool. One adolescent had a negative reaction but indicated that he would not have wanted to do any screening, and so his sentiment was around screening in general, not SW in particular. The fact that the screening was delivered via tablet was regarded as a major selling point by adolescents and by their parents reporting on what adolescents would like. Parents noted that their children were extremely comfortable interacting with the technology. Both parents and adolescents felt that the lack of a paper hardcopy that could be misplaced made them feel more secure in the confidentiality of their responses. They were aware that the provider would receive a printout of results, but this did not impair their perception of confidentiality. Adolescents sometimes described feeling more comfortable disclosing depression in a computerized screening (Q11; Textbox 1), and parents loved the idea of filling out their own evaluation of their child’s depressive state on the tablet (Q12; Textbox 1). Furthermore, one primary point of difference in opinion between parents and adolescents in these interviews was the extent to which the parents should be involved in their child's screening, with parents expressing a greater desire to participate and be present for it than children desiring to have their parents present for their screening. Giving the parents an opportunity to fill out the screening as well was regarded by them as helpful and giving them a voice in their child's care.

Providers in the focus groups were comfortable with the administration of screening on a tablet and supportive of other features of SW (resource sheets for adolescents and families, the screening of parents, and feedback to clinicians regarding whether parents and children are on the same page with regard to symptoms and treatment). They were particularly supportive of seeing both parent and child screening responses and of seeing discrepancies between the parent and child responses highlighted on the SW report. One provider described how they would use such a report to guide discussion with the parent and child (Q13; Textbox 1).

Theme 4: Parents, Adolescents, and Providers Do Not Want SW to Replace Mental Health Discussions With Providers

As noted previously in theme 2, depression screening was not regarded as always accurate, and as such, despite strongly positive feedback on SW, parents, adolescents, or providers did not want SW to replace face-to-face discussions of screening results and mental health between providers and patients. One parent shared that they envisioned a provider following up on a negative screening by having a more open-ended conversation that confirmed (or perhaps refuted) the original negative screening (Q14; Textbox 1). Adolescents and providers also often envisioned SW as operating best in a context in which the screening is followed up with a conversation with a provider (Q15 and Q16; Textbox 1). As long as SW was a tool that helped facilitate these sorts of discussions rather than something that replaced them, participants felt that it would prove beneficial.

Theme 5: Providers Want to Maintain Autonomy in Treatment Decisions

In addition, providers expressed concern about the idea of SW making treatment recommendations. Providers were concerned that they might think a recommendation should not be followed (Q17; Textbox 1), contributed to by the concern for false-negative results based on an adolescent's willingness to be honest on the screen. Although they were personally interested in seeing recommendations so that, as one provider put it, "old dogs could be shown new tricks," they were opposed to those recommendations being either requirements (as part of an SW trial studying efficacy; Q18; Textbox 1) or shown to parents and adolescents via an SW output sheet. Their concerns about recommendations being shared with patients stemmed from wanting to avoid conflict if they disagreed with the recommendation (Q19; Textbox 1). Providers also expressed concern about avoiding legal liability in the event that they did not follow a recommendation and there was a bad outcome (Q20; Textbox 1).

Discussion

Principal Findings

In this qualitative study, we elicited feedback from parents, adolescents, and health care providers in pediatric primary care regarding the process of screening adolescents for depression and suicidality and their opinion about a technology-based decision support tool—SW—aimed at guiding PCPs in responding to positive depression and suicidality screens in adolescents. Although most groups felt that depression screening should occur in pediatric primary care, the most salient concerns raised were around nondisclosure on the screen, which may impede the identification of depressed or suicidal adolescents. Respondents felt that the SW tool could elicit more honest responses than routine screening and that it adds value of contrasting parent and adolescent barriers and preferences, but they did not want SW to replace mental health discussions or treatment decision-making.

The benefits of depression screening in primary care were seen in identifying symptoms earlier, comfort with the pediatric PCP, and disclosure to a safe supportive adult such as the PCP being more likely than the adolescent's parent. This aligns with formative literature on depression screening in pediatric primary care, which found that parents, adolescents, and PCPs find depression screening acceptable [46]. This literature contributed to informing the United States Preventive Services Task Force guidelines [47] as well as guidance from organizations such as the American Academy of Pediatrics [48,49] to recommend routine depression screening. Interestingly, 1 parent and their child expressed concern that depression screening may lead to depression in the child and that screening should be done by a mental health professional. Although clinicians are generally familiar with the literature that asking about suicide and self-harm does not lead to an increase in these behaviors [50], parents and adolescents may be less familiar, warranting the addition of reassurance within the introduction to a screen. Similar to this dyad, some parents and adolescents may have the opinion that their PCP office should not provide mental health care because of a lack of expertise. Although pediatric PCP offices continue to expand depression screening, some may lack messaging that reduces stigma and enhances confidence in their capacity to manage mental health concerns. Including antistigma messaging, such as that promoted by the Healthcare Equality Index [51], for sexual and gender minorities with regard to mental health within a PCP office's marketing, signage, and within the screen itself may help increase parent and adolescent comfort with screening and enhance trust in the PCP practices' competence to address mental health concerns.

All participant groups shared a concern that adolescents may not be honest during the screening process. In studies evaluating the validity of the PHQ-9 in the adolescent population, Richardson et al [33] found a 10% false-negative rate in the screen when compared with the Diagnostic Interview Schedule for Children Version IV *gold standard* diagnostic tool. As this study was conducted in a research population, actual clinical populations may have even higher false-negative rates because of active nondisclosure to their clinician, which may occur because of the perceived consequences of disclosure. Adolescents may worry that the PCP will share sensitive answers or results with their parents, be unwilling or embarrassed to discuss symptoms with their PCP, or be unwilling to engage in treatment and therefore obscure symptoms. A 2014 systematic review found that screens administered in pediatric primary care are more likely to be seen as acceptable when there are clear statements made to adolescents and parents that the screens are confidential and being applied universally [52]. Although the rates of screen positivity for depression in pediatric primary care are approximately 12% [33,53], approximately one-third (32%) of high school students say they have felt sad or hopeless every day for 2 weeks or more in the past year on the 2019 Youth Risk Behavior Surveillance System survey [1], which is anonymous, thereby increasing the likelihood of honesty. Although one factor contributing to lower positivity on screens may be because of universal screening occurring during well-child visits, which adolescents with depression are less likely to present for compared with acute or emergency visits [54-56], another modifiable factor is a lack of honesty.

Adolescents, parents, and providers held the opinion that the SW tool may encourage more honesty and thereby facilitate depression screening. This is partially because of it being an electronic screen [57], as adolescents shared that they would feel less judged by a computer, and it is something they are already comfortable interacting with. A study asking 115 adolescents about their comfort with screening found that only 70 (60.9%) agreed that they were honest on paper screens compared with 102 (88.7%) who were honest when completing electronic screens [57]. In addition, providers thought there would be less of a chance of missing positive symptoms if both parents and adolescents completed the screen, as opposed to just adolescents alone, as is commonly practiced. The GLAD-PC guidelines recommend soliciting information from both adolescents and parents independently [48]. Providers may not be aware of the discrepancies between adolescents and parents regarding mental health treatment preferences or barriers to treatment [10,19]. If parents and adolescents disagree on the presence of symptoms, adolescents may be less likely to receive care [58,59]. SW specifically highlights symptoms, preferences, and barriers from both adolescent and parent perspectives, as in Figure 1, thereby offering an opportunity for providers to facilitate SDM between all parties, which may lead to increased uptake and engagement with the treatment decision.

Although adolescents, parents, and providers saw value in SW, they did not want the technology to replace discussions about mental health or management decisions. Although providers anticipated that SW may enhance honest symptom reporting by the adolescent, they also hesitated to rely completely on the screen if they had clinical suspicion for mental illness not revealed by the screen. Other studies have shown that PCPs tend to not use screens as intended, using individual items to inform treatment as opposed to severity symptom scores [7]. In addition, because pediatric PCP comfort varies in managing mental health diagnoses [60] and the ability to follow recommendations is dependent on the setting and available resources, providers may feel a one-size-fits-all PCP management approach is not warranted. Although the treatment decision algorithm was a major component of the initial SW tool, we concluded that the providers', adolescents', and parents' discomfort with this portion of the report may preclude future implementation. Nonetheless, measurement-based care may improve depression outcomes [61] and is facilitated by computerized decision support, which may enhance compliance with clinical guidelines [62] and result in small to moderate improvements in quality of care [63]. Future iterations of SW will, instead of providing specific treatment recommendations (eg, refer for substance use treatment or follow-up in 6 weeks), gather and display information in a user-friendly way to the provider while highlighting the severity score of symptoms and discrepancies between adolescents and parents and providing reference to the current clinical guidelines to enhance clinical decision-making without being overly prescriptive.

Limitations

This provider sample was recruited from a well-resourced setting with regard to access to mental health services and is likely not representative of all pediatric primary care settings. For our purposes, we were interested in developing a technology to assist PCPs in mental health care management. Therefore, a sample having some familiarity with the mental health care system was helpful in facilitating discussions. Future iterations of SW will likely need to be adapted for other settings, but we feel that most potential acceptability concerns were identified in this process. The adolescent age range was small, and much younger adolescents and older young adults may have different opinions about the SW tool. Another limitation is that we did not collect information about gender or sexual minority status, which is important because of the elevated risk of depression, or about individually reported race or ethnicity. These important demographic data will be collected in future interviews. Owing to the limitations of this study population, we do not feel that thematic saturation was reached regarding all possible responses to or opinions on SW. However, the opinions expressed in the interviews and focus groups were saturated for the purposes of this study population—that is, with the exception of one parent-child dyad with responses that differed from the others, responses were consistent across the interviews and in the two focus groups. Additional interviews with respondents from different settings may have yielded different opinions or themes.

Conclusions

By providing the PCP with (1) both adolescents' reports and parents' reports of depression, (2) reports of potential mental health and substance use comorbidities, (3) an additional screen for suicidality alone, (4) both adolescents' and parents' treatment preferences, (5) adolescents' and parents' potential barriers to treatment, and (6) an overview of discrepancies between the adolescents and parents, our aim is for SW to address the potential gaps in routine screening and facilitate the SDM process between adolescents, parents, and PCPs. In this formative study evaluating the initial design of SW, we learned that providers, parents, and adolescents are concerned that there are limitations to the current efforts to routinely screen adolescents for depression, mainly because screens may miss some adolescents who are unwilling to disclose symptoms. They recognized value in SW as a computerized tool may elicit more honest responses and that asking both adolescents and parents about symptoms and summarizing discrepancies may be useful. None of the groups wanted the tool to replace treatment discussions, and providers did not want it to replace their clinical judgment.

Future Implications

Although SW was originally developed as a treatment decision algorithm, this qualitative study informed us to remove this component and instead focus on aspects identified as most useful by all groups: identifying discrepancies between adolescents and parents and efficiently presenting treatment barriers and preferences to health care providers. This formative work guides the iterative development of the SW tool, which will then be evaluated in a future effectiveness trial to understand whether it facilitates SDM and enhances treatment uptake for adolescent mental health concerns in the primary care office.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Screening Wizard interview guide.
[DOCX File , 28 KB - mental_v8i9e26035_app1.docx]

References

1. 1991-2019 High School Youth Risk Behavior Survey Data. Centers for Disease Control and Prevention. 2020 Nov 25. URL: http://nccd.cdc.gov/youthonline/ [accessed 2020-11-25]
2. WISQARS™ — Web-based Injury Statistics Query and Reporting System. Centers for Disease Control and Prevention. 2020. URL: https://www.cdc.gov/injury/wisqars/index.html [accessed 2021-02-26]
3. Nrugham L, Larsson B, Sund AM. Specific depressive symptoms and disorders as associates and predictors of suicidal acts across adolescence. J Affect Disord 2008 Nov;111(1):83-93. [doi: 10.1016/j.jad.2008.02.010] [Medline: 18395267]
4. Hughes C. Getting Paid for Screening and Assessment Services. Fam Pract Manag 2017;24(6):25-29 [FREE Full text] [Medline: 29160676]
5. Hacker K, Arsenault L, Franco I, Shaligram D, Sidor M, Olfson M, et al. Referral and follow-up after mental health screening in commercially insured adolescents. J Adolesc Health 2014 Jul;55(1):17-23. [doi: 10.1016/j.jadohealth.2013.12.012] [Medline: 24525226]
6. Breland DJ, McCarty CA, Zhou C, McCauley E, Rockhill C, Katon W, et al. Determinants of mental health service use among depressed adolescents. Gen Hosp Psychiatry 2014;36(3):296-301 [FREE Full text] [doi: 10.1016/j.genhosppsych.2013.12.003] [Medline: 24417955]
7. Hacker K, Goldstein J, Link D, Sengupta N, Bowers R, Tendulkar S, et al. Pediatric provider processes for behavioral health screening, decision making, and referral in sites with colocated mental health services. J Dev Behav Pediatr 2013;34(9):680-687. [doi: 10.1097/01.DBP.0000437831.04723.6f] [Medline: 24247911]
8. Radovic A, Farris C, Reynolds KA, Miller E, Stein B. Primary Care Clinicians' Beliefs About Teen and Parent Barriers for Depression Care. J Adolesc Health 2013 Feb;52(2):S80-S88 [FREE Full text] [doi: 10.1016/j.jadohealth.2012.10.186]
9. Tanielian T, Jaycox LH, Paddock SM, Chandra A, Meredith LS, Burnam MA. Improving treatment seeking among adolescents with depression: understanding readiness for treatment. J Adolesc Health 2009 Nov;45(5):490-498. [doi: 10.1016/j.jadohealth.2009.03.005] [Medline: 19837356]
10. Meredith LS, Stein BD, Paddock SM, Jaycox LH, Quinn VP, Chandra A, et al. Perceived barriers to treatment for adolescent depression. Med Care 2009 Jun;47(6):677-685. [doi: 10.1097/MLR.0b013e318190d46b] [Medline: 19434001]
11. Cheung AH, Zuckerbrot RA, Jensen PS, Laraque D, Stein RE, GLAD-PC Steering Group. Guidelines for adolescent depression in primary care (GLAD-PC): part ii. Treatment and ongoing management. Pediatrics 2018 Mar;141(3) [FREE Full text] [doi: 10.1542/peds.2017-4082] [Medline: 29483201]

12. Satterfield JM, Spring B, Brownson RC, Mullen EJ, Newhouse RP, Walker BB, et al. Toward a transdisciplinary model of evidence-based practice. Milbank Q 2009 Jun;87(2):368-390 [FREE Full text] [doi: 10.1111/j.1468-0009.2009.00561.x] [Medline: 19523122]
13. Kroenke K, Spitzer RL, Williams JB, Monahan PO, Löwe B. Anxiety disorders in primary care: prevalence, impairment, comorbidity, and detection. Ann Intern Med 2007 Mar 6;146(5):317-325. [doi: 10.7326/0003-4819-146-5-200703060-00004] [Medline: 17339617]
14. Craney J, Geller B. Clinical implications of antidepressant and stimulant use on switching from depression to mania in children. J Child Adolesc Psychopharmacol 2003;13(2):201-204. [doi: 10.1089/104454603322163925] [Medline: 12880514]
15. Brent DA, Perper JA, Moritz G, Allman C, Friend A, Roth C, et al. Psychiatric risk factors for adolescent suicide: a case-control study. J Am Acad Child Adolesc Psychiatry 1993 May;32(3):521-529. [doi: 10.1097/00004583-199305000-00006] [Medline: 8496115]
16. Richardson LP, Rockhill C, Russo JE, Grossman DC, Richards J, McCarty C, et al. Evaluation of the PHQ-2 as a brief screen for detecting major depression among adolescents. Pediatrics 2010 May;125(5):e1097-e1103 [FREE Full text] [doi: 10.1542/peds.2009-2712] [Medline: 20368315]
17. Horowitz LM, Bridge JA, Pao M, Boudreaux ED. Screening youth for suicide risk in medical settings: time to ask questions. Am J Prev Med 2014 Sep;47(3 Suppl 2):S170-S175. [doi: 10.1016/j.amepre.2014.06.002] [Medline: 25145735]
18. Lindhiem O, Bennett CB, Trentacosta CJ, McLear C. Client preferences affect treatment satisfaction, completion, and clinical outcome: a meta-analysis. Clin Psychol Rev 2014 Aug;34(6):506-517 [FREE Full text] [doi: 10.1016/j.cpr.2014.06.002] [Medline: 25189522]
19. Radovic A, Farris C, Reynolds K, Reis EC, Miller E, Stein BD. Primary care providers' beliefs about teen and parent barriers to depression care. J Dev Behav Pediatr 2014 Oct;35(8):534-538 [FREE Full text] [doi: 10.1097/DBP.0000000000000089] [Medline: 25098692]
20. Stacey D, Légaré F, Col NF, Bennett CL, Barry MJ, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev 2014 Jan 28(1):CD001431. [doi: 10.1002/14651858.CD001431.pub4] [Medline: 24470076]
21. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev 2011 Oct 5(10):CD001431. [doi: 10.1002/14651858.CD001431.pub3] [Medline: 21975733]
22. Joosten EA, DeFuentes-Merillas L, de Weert GH, Sensky T, van der Staak CP, de Jong CA. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. Psychother Psychosom 2008;77(4):219-226. [doi: 10.1159/000126073] [Medline: 18418028]
23. Patel SR, Bakken S, Ruland C. Recent advances in shared decision making for mental health. Curr Opin Psychiatry 2008 Nov;21(6):606-612 [FREE Full text] [doi: 10.1097/YCO.0b013e32830eb6b4] [Medline: 18852569]
24. Young HN, Bell RA, Epstein RM, Feldman MD, Kravitz RL. Physicians' shared decision-making behaviors in depression care. Arch Intern Med 2008 Jul 14;168(13):1404-1408 [FREE Full text] [doi: 10.1001/archinte.168.13.1404] [Medline: 18625920]
25. Radovic A, Reynolds K, McCauley HL, Sucato GS, Stein BD, Miller E. Parents' role in adolescent depression care: primary care provider perspectives. J Pediatr 2015 Oct;167(4):911-918 [FREE Full text] [doi: 10.1016/j.jpeds.2015.05.049] [Medline: 26143382]
26. Epstein JN, Kelleher KJ, Baum R, Brinkman WB, Peugh J, Gardner W, et al. Impact of a web-portal intervention on community ADHD care and outcomes. Pediatrics 2016 Aug;138(2) [FREE Full text] [doi: 10.1542/peds.2015-4240] [Medline: 27462065]
27. Aalsma MC, Zerr AM, Etter DJ, Ouyang F, Gilbert AL, Williams RL, et al. Physician intervention to positive depression screens among adolescents in primary care. J Adolesc Health 2018 Feb;62(2):212-218 [FREE Full text] [doi: 10.1016/j.jadohealth.2017.08.023] [Medline: 29174939]
28. Etter DJ, McCord A, Ouyang F, Gilbert AL, Williams RL, Hall JA, et al. Suicide screening in primary care: use of an electronic screener to assess suicidality and improve provider follow-up for adolescents. J Adolesc Health 2018 Feb;62(2):191-197 [FREE Full text] [doi: 10.1016/j.jadohealth.2017.08.026] [Medline: 29195764]
29. Ferrin SN, Grout RW, Gilbert AL, Wilkinson TA, Cheng ER, Downs SM, et al. Caregiver comfort in adolescents independently completing screening tablet-based questionnaires at primary care visits. J Adolesc Health 2019 Dec;65(6):799-804 [FREE Full text] [doi: 10.1016/j.jadohealth.2019.07.008] [Medline: 31522906]
30. Zieve GG, Richardson LP, Katzman K, Spielvogle H, Whitehouse S, McCarty CA. Adolescents' perspectives on personalized E-feedback in the context of health risk behavior screening for primary care: qualitative study. J Med Internet Res 2017 Jul 20;19(7):e261 [FREE Full text] [doi: 10.2196/jmir.7474] [Medline: 28729236]
31. Beidas RS, Stewart RE, Walsh L, Lucas S, Downey MM, Jackson K, et al. Free, brief, and validated: standardized instruments for low-resource mental health settings. Cogn Behav Pract 2015 Feb 1;22(1):5-19 [FREE Full text] [doi: 10.1016/j.cbpra.2014.02.002] [Medline: 25642130]

32. Lindhiem O, Bennett CB, Beidas R, Grasso DJ, Sakolsky DJ, Druzdzel MJ. Development and preliminary feasibility testing of a decision support tool for childhood anxiety treatment. Cogn Behav Pract 2018 May;25(2):199-207 [FREE Full text] [doi: 10.1016/j.cbpra.2017.07.002] [Medline: 32982138]
33. Richardson LP, McCauley E, Grossman DC, McCarty CA, Richards J, Russo JE, et al. Evaluation of the patient health questionnaire-9 item for detecting major depression among adolescents. Pediatrics 2010 Dec;126(6):1117-1123 [FREE Full text] [doi: 10.1542/peds.2010-0852] [Medline: 21041282]
34. Gibbons RD, Kupfer D, Frank E, Moore T, Beiser DG, Boudreaux ED. Development of a computerized adaptive test suicide scale-the CAT-SS. J Clin Psychiatry 2017;78(9):1376-1382. [doi: 10.4088/JCP.16m10922] [Medline: 28493655]
35. Mossman SA, Luft MJ, Schroeder HK, Varney ST, Fleck DE, Barzman DH, et al. The generalized anxiety disorder 7-item scale in adolescents with generalized anxiety disorder: signal detection and validation. Ann Clin Psychiatry 2017 Nov;29(4):227-34A [FREE Full text] [Medline: 29069107]
36. Spitzer RL, Kroenke K, Williams JB, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med 2006 May 22;166(10):1092-1097. [doi: 10.1001/archinte.166.10.1092] [Medline: 16717171]
37. Henry DB, Pavuluri MN, Youngstrom E, Birmaher B. Accuracy of brief and full forms of the child mania rating scale. J Clin Psychol 2008 Apr;64(4):368-381. [doi: 10.1002/jclp.20464] [Medline: 18302291]
38. Dhalla S, Zumbo BD, Poole G. A review of the psychometric properties of the CRAFFT instrument: 1999-2010. Curr Drug Abuse Rev 2011 Mar;4(1):57-64. [doi: 10.2174/1874473711104010057] [Medline: 21466499]
39. Kuhl J, Jarkon-Horlick L, Morrissey RF. Measuring barriers to help-seeking behavior in adolescents. J Youth Adolesc 1997 Dec;26(6):637-650. [doi: 10.1023/a:1022367807715]
40. Wilson CJ, Deane FP, Ciarrochi J. Can hopelessness and adolescents' beliefs and attitudes about seeking help account for help negation? J Clin Psychol 2005 Dec;61(12):1525-1539. [doi: 10.1002/jclp.20206] [Medline: 16173086]
41. Hall S. Electronic theses and dissertations. Sci Technol Libr 2008 Sep 21;22(3-4):51-58. [doi: 10.1300/j122v22n03_06]
42. Cohane G. Psychological Barriers to Antidepressant Use in Adolescents Doctoral dissertation. Semantic Scholar. 2008. URL: https://www.semanticscholar.org/paper/Psychological-barriers-to-antidepressant-use-in-Cohane/fea6f1e1c185af7d6c30fbbb192274216cea7ee2#citing-papers [accessed 2021-07-14]
43. Hartson R. The UX Book: Process and Guidelines for Ensuring a Quality User Experience. Waltham, MA, USA: Morgan Kaufman; 2012.
44. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977 Mar;33(1):159-174. [Medline: 843571]
45. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
46. Zuckerbrot RA, Maxon L, Pagar D, Davies M, Fisher PW, Shaffer D. Adolescent depression screening in primary care: feasibility and acceptability. Pediatrics 2007 Jan;119(1):101-108. [doi: 10.1542/peds.2005-2965] [Medline: 17200276]
47. US Preventive Services Task Force. Screening and treatment for major depressive disorder in children and adolescents: US preventive services task force recommendation statement. Pediatrics 2009 Apr;123(4):1223-1228. [doi: 10.1542/peds.2008-2381] [Medline: 19336383]
48. Zuckerbrot RA, Cheung A, Jensen PS, Stein RE, Laraque D, GLAD-PC Steering Group. Guidelines for adolescent depression in primary care (GLAD-PC): part I. Practice preparation, identification, assessment, and initial management. Pediatrics 2018 Mar;141(3) [FREE Full text] [doi: 10.1542/peds.2017-4081] [Medline: 29483200]
49. Foy JM, Perrin J, American Academy of Pediatrics Task Force on Mental Health. Enhancing pediatric mental health care: strategies for preparing a community. Pediatrics 2010 Jun;125(Suppl 3):S75-S86. [doi: 10.1542/peds.2010-0788D] [Medline: 20519565]
50. Polihronis C, Cloutier P, Kaur J, Skinner R, Cappelli M. What's the harm in asking? A systematic review and meta-analysis on the risks of asking about suicide-related behaviors and self-harm with quality appraisal. Arch Suicide Res 2020 Jul 25:1-23. [doi: 10.1080/13811118.2020.1793857] [Medline: 32715986]
51. Healthcare Equality Index 2020. Human Rights Campaign. 2020. URL: https://www.hrc.org/resources/healthcare-equality-index [accessed 2020-11-25]
52. Wissow LS, Brown J, Fothergill KE, Gadomski A, Hacker K, Salmon P, et al. Universal mental health screening in pediatric primary care: a systematic review. J Am Acad Child Adolesc Psychiatry 2013 Nov;52(11):1134-47.e23 [FREE Full text] [doi: 10.1016/j.jaac.2013.08.013] [Medline: 24157388]
53. Hacker KA, Penfold R, Arsenault L, Zhang F, Murphy M, Wissow L. Screening for behavioral health issues in children enrolled in Massachusetts medicaid. Pediatrics 2014 Jan;133(1):46-54 [FREE Full text] [doi: 10.1542/peds.2013-1180] [Medline: 24298005]
54. Borowsky IW, Mozayeny S, Ireland M. Brief psychosocial screening at health supervision and acute care visits. Pediatrics 2003 Jul;112(1 Pt 1):129-133. [doi: 10.1542/peds.112.1.129] [Medline: 12837878]
55. Wilson KM, Klein JD. Adolescents who use the emergency department as their usual source of care. Arch Pediatr Adolesc Med 2000 Apr;154(4):361-365. [doi: 10.1001/archpedi.154.4.361] [Medline: 10768673]

56. King CA, O'Mara RM, Hayward CN, Cunningham RM. Adolescent suicide risk screening in the emergency department. Acad Emerg Med 2009 Nov;16(11):1234-1241 [FREE Full text] [doi: 10.1111/j.1553-2712.2009.00500.x] [Medline: 19845554]
57. Jasik CB, Berna M, Martin M, Ozer EM. Teen preferences for clinic-based behavior screens: who, where, when, and how? J Adolesc Health 2016 Dec;59(6):722-724. [doi: 10.1016/j.jadohealth.2016.08.009] [Medline: 27884300]
58. Williams KA, Chapman MV. Unmet health and mental health need among adolescents: the roles of sexual minority status and child-parent connectedness. Am J Orthopsychiatry 2012 Oct;82(4):473-481. [doi: 10.1111/j.1939-0025.2012.01182.x] [Medline: 23039345]
59. Logan DE, King CA. Parental identification of depression and mental health service use among depressed adolescents. J Am Acad Child Adolesc Psychiatry 2002 Mar;41(3):296-304. [doi: 10.1097/00004583-200203000-00009] [Medline: 11886024]
60. Radovic A, Farris C, Reynolds K, Reis EC, Miller E, Stein BD. Primary care providers' initial treatment decisions and antidepressant prescribing for adolescent depression. J Dev Behav Pediatr 2014 Jan;35(1):28-37 [FREE Full text] [doi: 10.1097/DBP.0000000000000008] [Medline: 24336091]
61. Trivedi MH, Daly EJ. Measurement-based care for refractory depression: a clinical decision support model for clinical research and practice. Drug Alcohol Depend 2007 May;88(Suppl 2):S61-S71 [FREE Full text] [doi: 10.1016/j.drugalcdep.2007.01.007] [Medline: 17320312]
62. Moghadam ST, Sadoughi F, Velayati F, Ehsanzadeh SJ, Poursharif S. The effects of clinical decision support system for prescribing medication on patient outcomes and physician practice performance: a systematic review and meta-analysis. BMC Med Inform Decis Mak 2021 Mar 10;21(1):98 [FREE Full text] [doi: 10.1186/s12911-020-01376-8] [Medline: 33691690]
63. Kwan JL, Lo L, Ferguson J, Goldberg H, Diaz-Martinez JP, Tomlinson G, et al. Computerised clinical decision support systems and absolute improvements in care: meta-analysis of controlled clinical trials. Br Med J 2020 Sep 17;370:m3216 [FREE Full text] [doi: 10.1136/bmj.m3216] [Medline: 32943437]

Abbreviations

GLAD-PC: Guidelines for Adolescent Depression in Primary Care
PCP: primary care provider
PHQ: Patient Health Questionnaire
SDM: shared decision-making
SW: Screening Wizard

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Original Paper

Social Media Use, Physical Activity, and Internalizing Symptoms in Adolescence: Cross-sectional Analysis

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Abstract

Background: Most American adolescents have access to smartphones, and recent estimates suggest that they spend considerable time on social media compared with other physical and leisure activities. A large body of literature has established that social media use is related to poor mental health, but the complicated relationship between social media and symptoms of depression and anxiety in adolescents is yet to be fully understood.

Objective: We aim to investigate the relationship between social media use and depression and anxiety symptoms in adolescents by exploring physical activity as a mediator.

Methods: A Qualtrics survey manager recruited adult panel participants between February and March 2019, who indicated that they had adolescent children who spoke English. A total of 4592 adolescent-parent dyads completed the survey that took approximately 39 minutes. The survey entailed completing web-based questionnaires assessing various aspects of social media use, psychological symptoms, and psychosocial factors. The average age of the adolescent participants was 14.62 (SD 1.68; range 12-17) years, and the majority of the adolescent sample was male (2392/4592, 52.09%).

Results: Total social media use was associated with more depressive symptoms (multiple R^2=0.12; $F_{3,4480}$=207.1; P<.001), anxiety (multiple R^2=0.09; $F_{3,4477}$=145.6; P<.001), and loneliness (multiple R^2=0.06; $F_{3,4512}$=98.06; P<.001), controlling for age and gender. Physical activity was associated with decreased depression and anxiety symptoms after controlling for other extracurricular activities and social media use (multiple R^2=0.24; $F_{5,4290}$=266.0; P<.001). There were significant differences in symptoms based on gender: female adolescents reported higher rates of social media use and males reported higher rates of depression. Nonbinary and transgender adolescents had higher rates of depression, anxiety, and loneliness than the female and male adolescents in the sample.

Conclusions: In a nationally representative sample of adolescents, more social media use was associated with more severe symptoms of depression, anxiety, and loneliness. Increased physical activity was associated with decreased depression and anxiety symptoms. Physical activity partially mediated the relationship between social media use and depression and anxiety. As this was a cross-sectional study, we cannot conclude that social media use causes internalizing symptoms or that physical activity leads to decreased internalizing symptoms—there may be additional confounding variables producing the relationships we observed. Physical activity may protect against the potentially harmful effect of social media on some adolescents. The effect sizes were small to medium, and the results should be interpreted with caution. Other limitations of this study include our reliance on self-reporting. Future work should examine social media use beyond how much time adolescents spend using social media and instead focus on the nature of social media activity.

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KEYWORDS

social media; depression; anxiety; physical activity; adolescence; mobile phone

Introduction

Background

Social media refers to web-based networks that enable users to interact with each other visually and verbally [1] via a public or semipublic profile within a bounded system [2]. Social media is ubiquitous, and its use continues to rise, especially among adolescents and young adults. Over a span of 6 years, the number of adolescents with smartphones grew from 4 in 10 adolescents to 9 in 10 adolescents [3]. In the same span of time, the percentage of adolescents using social media more than once a day doubled from 34% to 70%. A 2018 study conducted by the Pew Research Center found that 45% of teenagers reported being online on a "near-constant" basis [3,4]. Thus, it is important to understand the associations between social media use and adolescents' developmental and mental health outcomes, while also considering alternative activities (physical activities and extracurricular activities) intended to promote adolescent health. Moreover, although there is substantial evidence that physical activity is a protective factor against the development of internalizing disorders (depression and anxiety disorders) in adults with clinical and nonclinical levels of depression and anxiety [5], less is known about the connection between physical activity, other extracurricular activities, social media use, and internalizing symptoms (depression and anxiety) during adolescence.

Physical Activity (Exercise) and Internalizing Symptoms in Adolescence

In a study conducted by Bartels et al [6] to examine the relationship between exercise and internalizing problems in an adolescent cohort of monozygotic twins and nontwin siblings, regular exercise was both cross-sectionally and longitudinally related to fewer internalizing problems and to an increase in subjective well-being. Interestingly, the finding that exercise related to fewer internalizing problems was supported regardless of the amount of exercise [6], meaning that even low amounts of exercise can be protective against depression and anxiety among adolescents. Furthermore, the odds of experiencing elevated anxiety symptoms regardless of anxiety disorder diagnosis were significantly reduced following physical activity [7]. Given the potential value of exercise as a protective factor against symptoms of depression and anxiety in adulthood [8,9], developing these healthy behaviors early during adolescence is advantageous to both short- and long-term mental health. However, the rise of smartphones and social media use might place some youth at risk for engaging in fewer physical activities and thus greater depression and anxiety throughout their life span.

Adolescence as the Age of Vulnerability

As adolescence is an important period of development, with unique changes in physical, cognitive, emotional, and social development [10,11], the effect of social media on an individual may be particularly salient during this developmental stage. Whether the benefits of physical activity may mitigate the potentially harmful effects of social media during adolescence remains to be tested. Emotional distress, marked by symptoms of depression and anxiety, has increased congruently with the rise of social media [12], raising the possibility that the two are causally connected. The many effects of social media include harm to the sense of self, behavior that resembles addiction, self-harm promotion, sleep deprivation, fear of missing out, loneliness [13], depression, and anxiety [14-17]. Moreover, the negative effects of social media may have a dose-response relationship, such that adolescents who use a variety of social media platforms and spend the most time on social media are most affected. In one study, adolescents who engaged in multiple social media platforms had sequentially increased likelihoods for depressive and anxiety symptoms based on the number of platforms [15]. Moreover, adolescents who engaged in social media for longer periods had an increased risk of depression and anxiety symptoms [15]. These findings suggest that both the amount of time and breadth of social media platform use relate to symptoms of depression and anxiety in adolescents.

In addition to the developmental changes that occur during adolescence, it is also the period when many internalizing disorders naturally onset [18,19]. Thus, the relationship between social media use and internalizing symptoms may have a bidirectional association such that social media aggravates internalizing psychopathology, and these increases in depression and anxiety symptoms lead adolescents to social media use more often. Negative cognitive styles common in depression and anxiety, such as brooding and rumination, have been found to exacerbate the negative effects associated with social media [20]. A recent study to determine the effect of the frequency of social media use on children and adolescents found that students in grades 7 through 12 with poor mental health use social media with greater frequency than their healthier peers [21]. In a recent systematic review, Keles et al [22] found that time spent, active (posting) and passive (checking, scrolling) use of social media, investment in social media, and social media addiction were all correlated with depression, anxiety, and psychological distress; however, there were considerable methodological constraints across studies, including sampling and measures. Of the 7 studies and meta-analyses that addressed the relationship between symptoms of internalizing disorders (anxiety, depression, and loneliness or fear of missing out) and social media use, 6 studies found positive correlations [13-17,23] and 1 study did not find a relationship [24]. It is also possible that social media has a positive impact on adolescents, including providing educational resources and support to promote mental well-being [25]. Owing to the inconsistency between and limitations of completed studies, it is important to clarify the risk and protective factors that relate to social media use and its influence on internalizing symptoms in adolescents.

Social Media and Internalizing Symptoms

A better understanding of how social media may be associated with internalizing symptoms differently across adolescence based on gender is also important. The likelihood of adolescent females experiencing depression is 1.5 to 3 times higher than that of adolescent males [18]. Although gender differences in anxiety are not found in childhood, they continue to increase throughout adolescence, with girls experiencing higher levels of anxiety than boys [26]. Furthermore, recent studies have found gender to be a meaningful variable in the relationship between technology use and depressive symptoms. One study showed that the link between technology use and depressive symptoms was stronger for girls than it was for boys, postulating that the negative impacts of self-relevant comparisons might be more threatening to self-worth and therefore more salient to well-being for girls than boys [18]. Importantly, there are also gender differences in physical activity, whereby girls are less active than boys in adolescence [27,28].

This Study

Although studies have addressed the effect of social media use and physical activity on internalizing disorders separately, to our knowledge, no study to date has explored how both are associated with symptoms of depression and anxiety among adolescents. The aim of this study is to investigate how physical activity interacts with social media use and depression and anxiety symptoms during adolescence. We have two primary hypotheses and several exploratory analyses. First, we hypothesize that social media use would be associated with more internalizing symptoms (ie, depression, anxiety, and loneliness) and less physical activity. Although this hypothesis is based on the literature on physical activity, it is also possible that social media use and physical activity are not related or that more physically active adolescents are also more active on social media. Second, we hypothesize that physical activity would be associated with less severe internalizing symptoms. We also explore gender differences in social media use and internalizing symptoms, especially as they relate to physical activity, and examine differences, if any, between active (posting) and passive (checking) social media use. Finally, we believe that the association between social media and depression would be fully or partially explained by the level of physical activity, such that if adolescents were actively engaged in physical activity, social media use would not be strongly associated with depression. We expect physical activity to have this protective buffering relationship both due to its known associations with depression and anxiety symptoms [5,29] and because it represents an alternative behavior to social media use, indicating a range of extracurricular involvement that is associated with physical and emotional health [30].

Methods

Overview

The Institutional Review Boards at the University of Washington and University of Wisconsin approved this study. Data were obtained via a data use agreement between researchers at the University of Wisconsin and Indiana University.

Participants

Participants were a national sample of adolescents aged 12 to 17 years and their parents or caregivers recruited via Qualtrics panels. Qualtrics recruits panelists with advertisements on the web and conducts a background check to verify their identity before participation. A Qualtrics survey manager recruited adult panel participants between February and March 2019, who indicated that they had adolescent children who spoke English. Parents or caregivers who met these criteria provided information about the survey and an opportunity to provide informed consent for their child’s participation. The minor participants provided consent following parental consent. Adolescents were instructed to complete the survey independently and in a private location. Parents or caregivers completed a panel of surveys assessing social media use, social media rules, and demographic variables, whereas adolescents completed surveys assessing social media, rules around social media, and a variety of psychosocial factors. Adolescents and their caregivers took an average of 39 minutes to complete the survey. Qualtrics parameters were set such that our sample was consistent with race or ethnicity data from the US census [31]. Recruitment procedures were modeled based on prior youth and social media studies using Qualtrics [32,33].

Materials

Assessment of Social Media Use

Adolescents reported how often they checked and how often they posted on social media through a single item question about frequency of checking and a single item about frequency of posting. The social media platform that adolescents reported in this study was Facebook. Scores were on a 9-point frequency range representing “Almost constantly” to “Never” and coded, so that lower scores indicated less social media use and higher scores indicated more social media use. A maximum score of 18 indicated near-constant checking and posting on social media. For our analyses, we not only combined checking and posting into total social media use scores but also conducted some analyses with separate scores for checking and posting to examine differences in types of social media behaviors.

Patient Health Questionnaire-9

The Patient Health Questionnaire-9 (PHQ-9) [33] is a widely used screening measure of depression based on *the Diagnostic and Statistical Manual of Mental Disorders* 14 criteria. The nine items are each rated on a 0 (Not at all) to 3 (nearly every day) scale, with higher scores indicating more severe depression symptoms. On the basis of prior research, PHQ-9 scores ≥10 have 88% sensitivity and 88% specificity for major depression. We did not use cutoff scores and viewed depression as a continuous variable, with higher scores representing more severe depression [34]. The internal consistency was excellent (α=.95).

Screen for Child Anxiety Related Emotional Disorders

The Screen for Child Anxiety Related Emotional Disorders (SCARED) [34] is a five-item self-report intended to assess anxiety symptoms in children (eg, “I get really frightened for no reason at all”). Scores on each item range from 0 (Not true or hardly ever true) to 2 (True or often true). The five-item SCARED has similar psychometric properties to the original 41-item version, with a sensitivity of 74% and specificity of 73% [35], and we did not use cutoff scores and viewed anxiety as a continuous variable, with higher scores representing more severe anxiety. The internal consistency was good (α=.83).

Comprehensive Inventory of Thriving

The Comprehensive Inventory of Thriving (CIT) [36] is a measure of psychological well-being comprised of 18 subscales with 54 items in total, measuring a wide array of components of well-being. We used three items from the Loneliness subscale, comprising prompts such as “I feel lonely” that are rated 1 (Strongly disagree) to 5 (Strongly agree). Higher scores indicate greater loneliness. We also used the CIT Social Support subscale to evaluate adolescents’ feelings of social connectedness and support from others. Of note, this scale does not distinguish between peer social support and parental or other support. This scale is comprised of three prompts such as “There are people I can depend on to help me” that are rated 1 (Strongly disagree) to 5 (Strongly agree). Higher scores indicated greater social support in our sample. The CIT has excellent psychometric properties and good convergent validity with existing measures of psychological well-being [37]. Internal consistency was excellent for loneliness (α=.90) and good for social support (α=.88).

Assessment of Physical Activity and Other Extracurricular Activities

Physical activity was assessed with three questions rated on a 1 (Never) to 5 (4 or more times a week) scale, with higher scores indicating more physical activity. Questions assessed how often, outside of school hours, the adolescents exercised to the point of being out of breath or sweating with or without club associations, and as a part of competitive sports. Internal consistency was good (α=.81).

In addition to assessing physical activities, involvement in other extracurricular activities was assessed with four items rated on a 1 (0 hours) to 5 (11 or more hours) point scale. Higher scores indicated more time spent on extracurricular activities. Questions assessed time involvement in music (band, choir, orchestra, lessons, and practicing), clubs outside of school, clubs at school, and time playing sports on a school team. Importantly, the time spent on a school sports team was positively associated with the assessment of total physical activity, as described earlier (r=0.60; P<.001). Thus, as we wanted to examine the relationship between social media use and internalizing psychopathology with physical activity as a potential mediator, we removed the sports items from the other extracurricular items and instead included items assessing the time spent on music, school clubs, and out-of-school clubs. With both the sports item included and the sports item removed, internal consistency was acceptable and did not change (α=.74).

Data Analyses

Analyses were conducted using R Studio [38]. We used the *psych* package to examine the direct relationships between social media use (checking, posting, and total) and internalizing psychopathology (depression, anxiety, and loneliness). Mediation analyses for variables of interest (physical activity and loneliness) were conducted in the *mediation* package [39] using *diagram* to plot results. Of note, this package uses the more recent bootstrapping method of Preacher and Hayes [40] to address the power limitations of the Sobel test. Standardized regression coefficients were determined using the *lm.beta* package. For all analyses, we corrected for multiple comparisons using the Bonferroni method. Effect sizes were interpreted according to Cohen standards [41].

Results

Descriptive Statistics and Correlations

A total of 4592 adolescent-parent dyads completed the survey. The average age of adolescent participants was 14.62 (SD 1.68; range 12-17) years. Most adolescent participants were White (3070/4592, 66.86%), non-Hispanic (3703/4592, 80.73%) with White (3148/4592, 68.55%), and non-Hispanic parents or caregivers (3798/4592, 82.71%). More adolescent males (2392/4592, 52.09%) than adolescent females completed the survey, whereas most parents or caregivers completing the survey were female (2652/4592, 57.75%). Most parents or caregivers identified being biological parents of the adolescent (3934/4592, 85.67%), followed by stepparents (246/4592, 5.36%). On the basis of parents’ self-reported household socioeconomic status, the majority of the sample was above the poverty line (3402/4592, 74.09%). Table 1 presents detailed demographic information.

Table 1. Participant characteristics.

Variable	Parent report, n (%)	Adolescent report, n (%)
Relationship to child in research (n=4581)		
Biological parent	3934 (85.88)	—[a]
Stepparent	246 (5.37)	—
Parent’s partner (living together)	137 (2.99)	—
Adoptive parent	120 (2.61)	—
Foster parent	12 (0.26)	—
Grandparent	106 (2.31)	—
Other relative or guardian	26 (0.57)	—
Number of children (n=4588)		
1	1357 (29.58)	—
2	1745 (38.03)	—
3	872 (19)	—
4	334 (7.27)	—
5	147 (3.2)	—
≥6	133 (2.9)	—
Child participating in research (n=4565)		
Youngest child	1456 (31.89)	—
Middle child	632 (13.84)	—
Oldest child	1584 (34.7)	—
Only child	893 (19.56)	—
Gender (n=4592)		
Female	2652 (57.75)	2130 (46.39)
Male	1877 (40.88)	2392 (52.09)
Nonbinary	26 (0.57)	23 (0.5)
Female to male transgender	20 (0.43)	25 (0.54)
Male to female transgender	5 (0.11)	5 (0.11)
Other	3 (0.07)	0 (0)
Prefer not to answer	9 (0.2)	17 (0.2)
Ethnicity (n=4592)		
Not Hispanic, Latino, or Spanish origin	3798 (82.71)	3707 (80.73)
Mexican American, Chicano	386 (8.41)	439 (9.56)
Puerto Rican	166 (3.61)	178 (3.88)
Cuban	44 (0.96)	50 (1.09)
Another Hispanic, Latino, or Spanish origin	148 (3.22)	152 (3.31)
Prefer not to answer	50 (1.09)	66 (1.44)
Race (n=4592)		
White or Caucasian	3148 (68.55)	3070 (66.86)
Black or African American	674 (14.68)	699 (15.22)
American Indian or Alaska Native	123 (2.68)	116 (2.52)
Asian	230 (5.01)	211 (4.59)
Asian Indian	17 (0.37)	17 (0.37)
Other Asian	7 (0.15)	7 (0.15)

Variable	Parent report, n (%)	Adolescent report, n (%)
Native Hawaiian or other Pacific Islander	42 (0.91)	36 (0.78)
Multiracial	146 (3.18)	221 (4.81)
Other	36 (0.78)	31 (0.68)
Prefer not to answer	72 (1.57)	82 (1.79)
Latino, Hispanic, or Mexican	97 (2.11)	102 (2.22)
Highest completed education (n=4592)		
4th grade	—	1 (0.02)
5th grade	—	19 (0.41)
6th grade	—	489 (10.65)
7th grade	—	644 (14.02)
8th grade	—	747 (16.27)
9th grade	—	776 (16.9)
10th grade	—	828 (18.03)
11th grade	—	681 (14.83)
12th grade	—	361 (7.86)
Other	—	12 (0.26)
Prefer not to answer	—	23 (0.5)
College	—	11 (0.24)
Highest completed education (n=4592)		
High school incomplete or less	292 (6.36)	—
High school graduate or General Educational Development	886 (19.29)	—
Some college	1440 (31.36)	—
Four-year college degree or bachelor's degree	1049 (22.84)	—
Some postgraduate or professional schooling	176 (3.83)	—
Postgraduate or professional degree	718 (15.64)	—
Prefer not to answer	31 (0.66)	—

[a] For some questionnaires, only one party (adolescent or parent) filled it out.

With regard to total social media use, 7.14% (328/4592) of our sample indicated never checking or posting on social media, whereas 11.26% (517/4592) reported being on social media "almost constantly." The mean checking score was closest to "A few times/day," whereas the mean posting score was approximately "Once a day." There was a significant positive relationship between checking and posting (r=0.72; P<.001). The average SCARED score was 2.32 (SD 2.54; range 0-10), which approaches clinical risk for an anxiety disorder. The average PHQ-9 score in our sample was 5.43 (SD 6.90; range 0-27), indicating mild depression.

In our sample, the average physical activity to the point of being out of breath or sweating was about twice a week with noncompetitive physical activities and competitive sports, both averaging about twice a week. Thus, the overall mean for physical activity, calculated by totaling all three items and dividing by three, was approximately 2.93 (SD 3.74), indicating that total physical activity was about twice a week. Of note, this is lower than the national recommendations for physical activity in adolescents [16]. With regard to involvement in extracurricular activities, with the sports item removed, the summed score was 5.94, indicating an average of 3-5 hours per week of extracurricular activities. When we included the sports item with the other three, the summed score was 8.22, also indicating 3-5 hours per week of extracurricular activities on average.

Descriptive statistics of the primary variables of interest, including demographic information, are presented in Table 1. Table 2 presents a correlation matrix.

Table 2. Correlation matrix.

Variable	Age	Depression	Anxiety	Loneliness	Social support	Physical activity	Extracurricular	Social media checking	Social media posting
Age									
r	—[a]	—	—	—	—	—	—	—	—
P value	—	—	—	—	—	—	—	—	—
Depression									
r	−0.08	—	—	—	—	—	—	—	—
P value	<.001	—	—	—	—	—	—	—	—
Anxiety									
r	−0.12	0.73	—	—	—	—	—	—	—
P value	<.001	<.001	—	—	—	—	—	—	—
Loneliness									
r	−0.04	0.67	0.61	—	—	—	—	—	—
P value	.006	<.001	<.001	—	—	—	—	—	—
Social support									
r	0.05	−0.32	−0.22	−0.31	—	—	—	—	—
P value	<.001	<.001	<.001	<.001	—	—	—	—	—
Physical activity									
r	−0.07	0.10	0.09	−0.03	0.06	—	—	—	—
P value	<.001	<.001	<.001	.02	<.001	—	—	—	—
Extracurricular									
r	−0.08	0.43	0.42	0.28	−0.09	0.41	—	—	—
P value	<.001	<.001	<.001	<.001	<.001	<.001	—	—	—
Social media checking									
r	0.12	0.25	0.20	0.19	−0.02	0.12	0.17	—	—
P value	<.001	<.001	<.001	<.001	—	<.001	<.001	—	—
Social media posting									
r	0.06	0.34	0.28	0.24	−0.11	0.17	0.28	0.72	—
P value	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	—
Social media total									
r	0.10	0.32	0.26	0.23	−0.08	0.15	0.25	0.92	0.93
P value	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001

[a] Not applicable.

As expected, there was a significant positive relationship between depression and anxiety in adolescents, such that higher depression scores were associated with higher anxiety scores (r=0.73; P<.001). The relationships between internalizing symptoms and social media behavior were significant, such that higher depression (r=0.32; P<.001) and anxiety (r=0.26; P<.001) scores were associated with more social media use (Table 2).

Social support was inversely related to depression (r=−0.32; P<.001), anxiety (r=−0.22; P<.001), loneliness (r=−0.31; P<.001), and total time spent on social media (r=−0.08; P<.001). When tested on a linear model, social support was a significant predictor of lower depression (multiple R^2=0.18; $F_{2,4466}$=517.20; P<.001; f^2=0.22) and anxiety (multiple R^2=0.11; $F_{2,4459}$=262.30; P<.001; f^2=0.11). These effects were medium and small, respectively; were statistically significant; and survived the Bonferroni correction for multiple comparisons. However, there was no significant interaction between social media checking and social support for depression (P=.30) or anxiety (P=.83). This was also true for the interaction between social media posting and social support for depression (P=.46) and anxiety (P=.25)

Contrary to expectations, there was a significant positive relationship between depression and physical activity scores (r=0.10; P<.001) and depression and other extracurricular activities (r=0.40; P<.001), such that adolescents with higher depression scores reported higher levels of physical activity and extracurricular activities. We proceeded to investigate group differences that may account for this and test mediations as planned, despite the unexpected direction of the relationship between physical activity and internalizing symptoms.

Investigating Group Differences

Age-Related Differences

We conducted a series of regressions to examine the relationships among internalizing symptoms, social media use, and physical activity, controlling for other variables including age and gender. First, we examined the nature of the relationships between depression or anxiety scores and age and social media and age. As was previously shown in correlations (Table 2), there was a significant relationship between age and depression (multiple R^2=0.01; $F_{1,4500}$=25.56; P<.001; f^2=0.01), age and anxiety (multiple R^2=0.01; $F_{1,4500}$=25.56; P<.001; f^2=0.01), and age and social media use (multiple R^2=0.01; $F_{1,4555}$=44.41; P<.001; f^2=0.01), and older adolescents showed more social media use than younger adolescents, and depression and anxiety symptoms decreased with age. Of note, although regression results were statistically significant and survived Bonferroni correction, the effect sizes were small.

Gender Differences

We wanted to characterize gender differences in our sample before controlling for gender as a covariate in our regression analyses. Owing to the nonnormal distribution of the PHQ-9 and SCARED data, we could not compare all genders using analysis of variance. Thus, to further investigate these symptom differences between genders, we first used Kruskal-Wallis tests and found significant differences among all gender categories represented (female, male, nonbinary, female to male transgender, and male to female transgender) for depression (Kruskal-Wallis χ^2_5=42.4; P<.001), anxiety (Kruskal-Wallis χ^2_5=55.0; P<.001), loneliness (Kruskal-Wallis χ^2_5=37.7; P<.001), and total social media use (Kruskal-Wallis χ^2_5=27.2; P<.001). We tested this further by subsetting our data and comparing males to females, and then by grouping males and females into one group and all other gender categories into a second group to conduct a series of Welch two-tailed t tests. There were significant differences in depression scores based on the majority gender, with males reporting significantly higher depression scores (t_{4444}=−4.51; P<.001) and more loneliness (t_{4480}= −2.31; P=.02) than females, but there were no differences in anxiety scores (t_{4443}=0.76; P=.44) between men and women. Women reported significantly more social media use than males (t_{4499}=4.47; P<.001). Males reported more physical activity than females (t_{4397}=−9.89; P<.001). Both males and females (grouped together) showed significantly lower (less severe) internalizing scores than nonbinary gender or transgender adolescents (depression: t50=−6.48, P<.001; anxiety: t_{52}=−6.68, P<.001; loneliness: t_{53}=−6.80, P<.001), with no differences in total physical activity (t_{53}=1.26; P=.21). Interestingly, although there were no significant differences in total social media use between males and females and nonbinary and transgender groups (t_{55}=−0.93; P=.36), male and female adolescents reported significantly more posting (t_{55}=3.80; P<.001), whereas nonbinary and transgender adolescents reported significantly more checking on social media (t_{53}=−2.29; P=.03). Finally, we assessed whether the effects of social media use on internalizing symptoms were moderated by gender (male vs female) and found significant results for all internalizing symptoms, including depression (b=0.28, SE 0.04; P<.001), anxiety (b=0.11, SE 0.02; P<.001), and loneliness (b=0.10, SE 0.02; P<.001). The associations between social media use and internalizing symptom severity were stronger in males than in females.

Controlling for Age and Gender Covariates

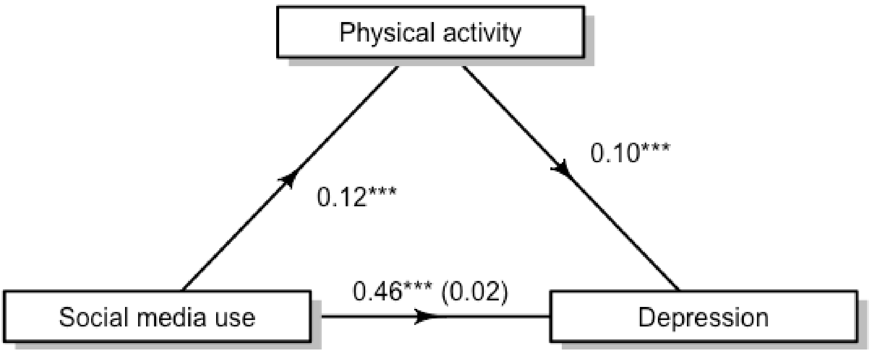
Given the significance of age and gender in our models, we wanted to control for these variables in subsequent analyses. Using gender and age as covariates, we tested the associations between different types of social media use (total, checking, and posting) and internalizing symptoms in linear regressions. The reported R^2 values represent multiple R^2 values for the tested linear model. Total social media use was associated with more depressive symptoms (R^2=0.12; $F_{3,4480}$=207.1; P<.001; f^2=0.14), anxiety (R^2=0.09; $F_{3,4477}$=145.6; P<.001; f^2=0.10), and increased loneliness (R^2=0.06; $F_{3,4512}$=98.06; P<.001; f^2=0.06), controlling for age and gender. Contrary to predictions, total social media use was associated with more physical activity (R^2=0.04; $F_{3,4529}$=67.78; P<.001; f^2=0.04). In examining differences between types of social media behavior, both checking and posting were significantly associated with more depression (checking: R^2=0.08; $F_{3,4492}$=138.1; P<.001; f^2=0.09; posting: R^2=0.13; $F_{3,4485}$=222.6; P<.001; f^2=0.15), more anxiety (checking: R^2=0.06, $F_{3,4489}$=97.74, P<.001, f^2=0.06; posting: R^2=0.10, $F_{3,4482}$=159.6, P<.001, f^2=0.11), and more loneliness (checking: R^2=0.04, $F_{3,4524}$=69.23, P<.001, f^2=0.04; posting: R^2=0.06, $F_{3,4518}$=102.0, P<.001, f^2=0.06), controlling for age and gender and correcting for multiple comparisons using Bonferroni methods. The effect sizes ranged from small to medium. As evidenced by these results and examining β coefficients and effect sizes between regression models, there were no major differences when comparing social media posting versus social media checking. As such, we proceeded by using social media total as our independent variable in the remaining analyses.

Owing to the unexpected findings regarding the relationship between physical activity and depression and anxiety symptoms based on correlations, we wanted to further examine differences related to age and gender that may account for these relationships. We regressed internalizing symptoms (depression, anxiety, and loneliness) on total physical activity, controlling for other extracurricular activities, age, and gender. This was significant in the hypothesized direction: more physical activity predicted decreased depression, anxiety, and loneliness symptoms when controlling for other nonsports-related extracurricular activity, age, and gender (depression: R^2=0.20, $F_{4,4440}$=273.1, P<.001, f^2=0.25; anxiety: R^2=0.19, $F_{4,4437}$=257.6, P<.001, f^2=0.23; loneliness: R^2=0.11, $F_{4,4472}$=134.8, P<.001, f^2=0.22). All the effect sizes were medium. When we controlled for social media use as an additional covariate, the relationship between physical activity and internalizing symptoms became even stronger (depression: R^2=0.25, $F_{5,4421}$=299.0, P<.001, f^2=0.33; anxiety: R^2=0.22, $F_{4,4418}$=251.7, P<.001, f^2=0.28; loneliness: R^2=0.14, $F_{5,4452}$=147.6, P<.001, f^2=0.16). Thus, although the relationship between social media and internalizing remains significant in the model, with more social media use linked to more depression and anxiety symptoms, physical activity showed a significant association in the opposite direction, as our hypotheses and prior research in adults would suggest. The effect sizes were medium and survived the Bonferroni corrections.

Mediation Analyses

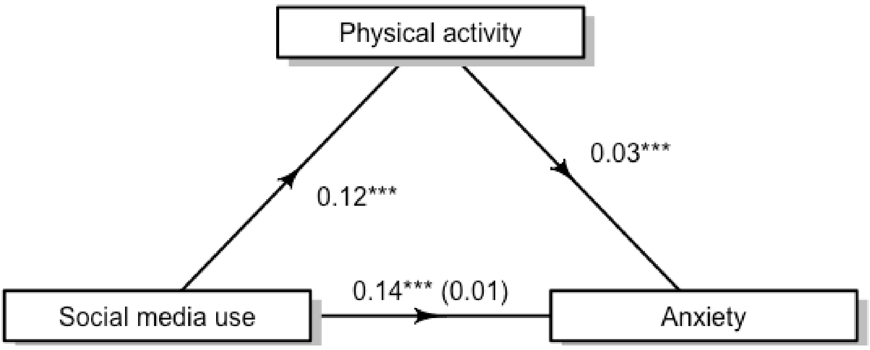
The effect of total social media use on depression is partially mediated by physical activity. As Figure 1 illustrates, the regression coefficient between total social media use and depression severity and the regression coefficient between total physical activity and depression severity were significant. The indirect effect is (0.12) × (0.10) = 0.01. We tested the significance of this indirect effect using bootstrapping. Unstandardized indirect effects were computed for each of the 500 bootstrapped samples, and the 95% CI was computed by determining the indirect effects at the 2.5th and 97.5th percentiles. Thus, the bootstrapped unstandardized indirect effect was 0.01 (95% CI 0.01-0.02). Although small, the indirect effect was statistically significant (P<.001). Here, physical activity accounted for 2.6% (95% CI 1%-4%) of the effect of total social media use on depressive symptoms. Of note, after examining total social media use, we ran mediations with checking and posting behaviors. We observed the same pattern of findings in these mediations; therefore, we report only on total social media use.

Figure 1. The relationship between social media use and depression is partially mediated by physical activity. ***Statistical significance at P<.001.



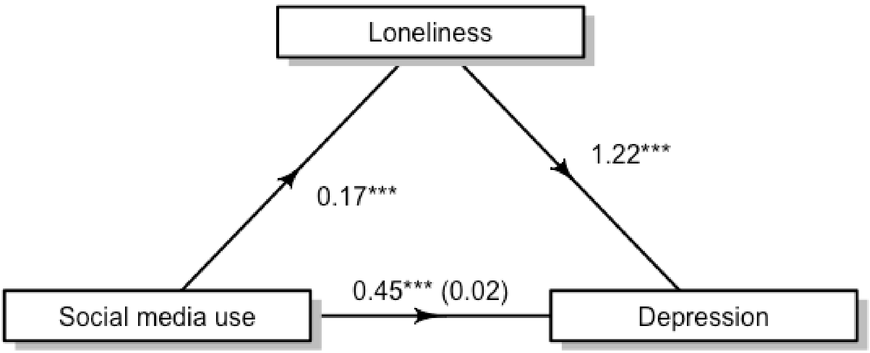
We observed the same pattern of findings in examining the relationship between total social media use, anxiety, and physical activity (Figure 2). The results showed that more social media use was associated with higher anxiety symptoms and that more physical activity was associated with greater anxiety. Physical activity partially mediated the relationship between social media use and anxiety, again using 500 bootstrapped samples. The indirect effect was very small (0.12) × (0.03) = 0.004 (95% CI 0.002-0.01), but statistically significant (P<.001). Here, physical activity accounted for 3% (95% CI 1%-5%) of the effect of total social media use on anxiety symptoms.

Figure 2. The relationship between social media use and anxiety is partially mediated by physical activity. ***Statistical significance at P<.001.



We continued to examine the complex relationship between social media and internalizing by exploring loneliness as a mediator. We hypothesized that feelings of loneliness would account for social media's relationship with increased depression, and indeed, this was true (Figure 3). Using 500 bootstrapped samples, the unstandardized indirect effect of loneliness was (1.22) × (0.17) = 0.21 (95% CI 0.18-0.23; P<.001). Here, loneliness accounted for a large proportion of the effect of total social media use on depressive symptoms (45%; 95% CI 41%-50%).

Figure 3. The relationship between social media use and depression is partially mediated by loneliness. ***Statistical significance at *P*<.001.



Discussion

Principal Findings

Consistent with the current literature [17,42], we found that more social media use was associated with higher levels of internalizing symptoms (depression, anxiety, and loneliness). We also found that more social media use was associated with greater physical activity. Given our cross-sectional design, it is unclear whether social media use leads to more depression, anxiety, and loneliness or if these internalizing symptoms cause individuals to seek out more social media, which could feed into a vicious cycle. As anticipated, depression and anxiety were positively associated with one another in adolescents [5]. There is substantial evidence that physical activity is associated with lowered rates and decreased severity of internalizing symptoms in adults [7-9] and promising evidence that such a relationship exists for adolescents [5]. Our results showed that physical activity was associated with less severe symptoms of depression and anxiety. Our findings regarding physical activity were further explored in the mediation analyses. The results of our mediation analyses suggest a small but significant mediation of physical activity on the relationship between social media use and anxiety and depression. The mediating effects were greater for depression, which could partially be due to the correlation between depression and other variables, including loneliness and gender.

Initially, when examining bivariate correlations in our data, the findings seem to conflict with the existing literature [43-45] and the common sense idea that physical activity is associated with better health outcomes, including reduced anxiety and depression [46]. However, when our model controlled for other variables including age, gender, and extracurricular activities, which all independently had significant associations with depression, our findings were in line with our hypotheses. The various reasons adolescents in our sample engaged in physical activity remain unknown. Adolescents with depression and anxiety may have been trying to exercise more to improve their mood, and we expected that social media (likely a sedentary behavior) would replace physical activity. However, in some adolescents and teenagers, physical activity may not be driven by health benefits but instead fueled by social media itself: comparison to others and using social media as fitness inspiration (*fitspo*). Indeed, fitspo in adults has been linked to negative mental health outcomes, including poor appearance-based self-perception in some studies [47,48] but not all [49,50], but less is known about this trend in adolescents and young adults. Adolescence is also a time of many physical changes (ie, higher fat-to-muscle ratio among girls), along with the development of social-cognitive processes from others' perspectives. Specifically, adolescents become keenly aware of others' perspectives and their bodies [51]. Moreover, in predicting that physical activity would act as a buffer between potentially harmful social media use and internalizing symptoms, we drew primarily from the adult literature. In adults, physical activity has been used as an intervention for depression and anxiety, but less is known about the use of exercise interventions in depressed and anxious youth. However, a recent meta-analysis suggested that exercise interventions may be associated with decreases in adolescent depression [52]. Although this study was not an exercise intervention study and cannot draw conclusions regarding interventions, it is recommended that future studies investigate exercise interventions in adolescents, particularly given the number of adolescents who are prescribed psychotropic medications [53,54] despite their harmful effects.

Additional implications can be drawn from the mediation results and regression analyses. With regard to physical activity partially mediating the effect of social media on depression and anxiety, we can surmise that it is not simply checking or posting on social media that is linked with depression because there is an indirect effect of physical activity such that more physical activity also accounts for the connection between social media and internalizing symptoms in our sample. This may indicate that the amount of overall activity, physical activity, social media engagement, and extracurricular activity may be added to allostatic load. It is also important to consider the idea that physical activity in the form of competitive sports may increase depression and anxiety, as prior studies have shown that athletes are vulnerable to a range of mental health problems [55]. Although physical activity and extracurricular activities are generally believed to be a positive activity for adolescents at risk for depression and anxiety, this may not be true for all adolescents [56]. Supplementing or replacing physical activity and extracurricular activities with other well-being activities, including socializing in person and making time for leisure, relaxation, or other value-driven behaviors is important to consider. One implication of our findings is that if social media use continues to increase [57,58], doing more physical activity or extracurricular activities cannot entirely mitigate its potentially harmful effect. However, given our finding of the unique link between physical activity and internalizing symptoms when controlling for social media and other activities, physical activity should continue to be researched as a potential intervention in depressed and anxious adolescents, perhaps combined with setting limits on social media and reducing other extracurricular activities.

Our results also have implications for future studies. The gender differences in this study indicate that this is an important area to account for: male adolescents in this study presented higher scores in depression and loneliness, whereas female adolescents checked social media more. Considering the positive relationship between social media use and internalizing symptoms, it is clear that no one size fits all approaches. More research is needed on transgender and nonbinary adolescents. Furthermore, given the relationships between social media, depression, and loneliness, it may be important to target social connectedness beyond social media. A potential method for doing this could encourage adolescents to combine socializing and physical activity. It is also possible and likely that the type of social media platform matters, so continuing to investigate these phenomena across different types of media accounts is important.

This study has several strengths. First, our study used a large, nationally representative sample that allowed the study to be adequately powered to conduct analyses and draw generalizable conclusions. Second, with survey data using brief and reliable measures, we were able to capture a variety of variables in a short period, from social media use (checking and posting) to internalizing symptoms, social support, extracurricular activities, and physical activity. To the best of our knowledge, this is the largest data set capturing adolescent mental health, social media, and physical activity in a nationally representative sample of adolescents.

Limitations

Despite the strengths of this study, including the large sample size and diversity of respondents, there were several limitations. First, there is often concern regarding the validity of adolescent self-report, as adolescents' self-perception and presentation can be influenced by many factors, including social desirability and the sensitivity of items being reported [59]. We attempted to control for this by instructing adolescents to complete the survey independently and in a private location from their parents. Second, physical activity is often overreported due to the perceived social desirability of the activity [60]. Studies have found fallibility in the perception of time, frequency, and intensity of activities such as driving and web-based activities. Similarly, students have been found to overreport social media use by an average of two hours. There is also a significant error in the self-report of social media use in adults. As people spent more time on Facebook, reports of time spent were less accurate [61]. Third, this study is cross-sectional; therefore, causality and directionality of effects cannot be stated. Fourth, it is possible that adolescents use social media while exercising, which could complicate the interpretation of findings. Finally, our effect sizes ranged from small to medium, and replication was recommended.

Conclusions

In conclusion, this study showed that when controlling for social media use, physical activity is associated with decreased internalizing symptoms in a nationally representative sample of adolescents. We did not observe a significant association between physical activity and reduced depression and anxiety until after controlling for social media use and other extracurricular activities, which may imply that if adolescents are involved in multiple activities, the protective mental health benefits of physical activity can decrease. As this was a cross-sectional study and a direct causal relationship between time on social media and internalizing symptoms cannot be established, the type of social media use should be more specifically examined in future work [61]. Perhaps an intervention that promotes physical activity in social groups in person, or social media, is the next step for adolescents with depression and anxiety symptoms. Physical activity that facilitates feelings of connectedness would likely help teenagers at risk for depression, anxiety, and loneliness; however, this is an empirical question that should be tested. Additional future work should use multiple report sampling to learn more about parental physical activity and the modeling of health behaviors. Finally, objective tracking of social media use (through partnerships with industry) and objective physical activity monitoring in adolescents via passive sensors such as a Fitbit is recommended to fully understand these relationships.

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Authors' Contributions

LAR conceived the idea, performed data analyses, and created figures and tables. LAR, TNR, and RDJR were used to design the methodology. JH assisted LAR with data transfer agreements and institutional review board documentation. LAR, HMT, and JH drafted the original draft. All authors reviewed and edited subsequent drafts.

Conflicts of Interest

None declared.

References

1. Carr CT, Hayes RA. Social Media: Defining, developing, and divining. Atlan J Commun 2015 Feb 06;23(1):46-65. [doi: 10.1080/15456870.2015.972282]

2. Boyd DM, Ellison NB. Social Network Sites: Definition, history, and scholarship. J Comput-Med Commun 2007;13(1):210-230. [doi: 10.1111/j.1083-6101.2007.00393.x]
3. Social Media, Social Life: Teens reveal their experiences, 2018. Common Sense Media. URL: https://www.commonsensemedia.org/research/social-media-social-life-2018 [accessed 2020-11-12]
4. Anderson M, Jiang J. Teens, social media and technology 2018. Pew Research Center. URL: https://www.pewresearch.org/internet/2018/05/31/teens-social-media-technology-2018/ [accessed 2020-11-12]
5. Rebar AL, Stanton R, Geard D, Short C, Duncan MJ, Vandelanotte C. A meta-meta-analysis of the effect of physical activity on depression and anxiety in non-clinical adult populations. Health Psychol Rev 2015 Jul 03;9(3):366-378. [doi: 10.1080/17437199.2015.1022901] [Medline: 25739893]
6. Bartels M, de Moor MH, van der Aa N, Boomsma DI, de Geus EJC. Regular exercise, subjective wellbeing, and internalizing problems in adolescence: causality or genetic pleiotropy? Front Genet 2012;3:4 [FREE Full text] [doi: 10.3389/fgene.2012.00004] [Medline: 22303410]
7. McDowell CP, Dishman RK, Gordon BR, Herring MP. Physical activity and anxiety: a systematic review and meta-analysis of prospective Cohort studies. Am J Prev Med 2019 Oct;57(4):545-556. [doi: 10.1016/j.amepre.2019.05.012] [Medline: 31542132]
8. Teychenne M, Ball K, Salmon J. Physical activity and likelihood of depression in adults: a review. Prev Med 2008 May;46(5):397-411. [doi: 10.1016/j.ypmed.2008.01.009] [Medline: 18289655]
9. Kim-Cohen J, Caspi A, Moffitt TE, Harrington H, Milne BJ, Poulton R. Prior juvenile diagnoses in adults with mental disorder: developmental follow-back of a prospective-longitudinal cohort. Arch Gen Psychiatry 2003 Jul;60(7):709-717. [doi: 10.1001/archpsyc.60.7.709] [Medline: 12860775]
10. Sturdevant MS, Spear B. Adolescent psychosocial development. J Am Diet Assoc 2002 Mar;102(3):30-31. [doi: 10.1016/s0002-8223(02)90419-0]
11. Steinberg L, Morris AS. Adolescent development. Annu Rev Psychol 2001;52:83-110. [doi: 10.1146/annurev.psych.52.1.83] [Medline: 11148300]
12. Abi-Jaoude E, Naylor KT, Pignatiello A. Smartphones, social media use and youth mental health. Can Med Assoc J 2020 Feb 10;192(6):136-141. [doi: 10.1503/cmaj.190434] [Medline: 32041697]
13. Barry CT, Sidoti CL, Briggs SM, Reiter SR, Lindsey RA. Adolescent social media use and mental health from adolescent and parent perspectives. J Adolesc 2017 Dec;61:1-11. [doi: 10.1016/j.adolescence.2017.08.005] [Medline: 28886571]
14. Ivie EJ, Pettitt A, Moses LJ, Allen NB. A meta-analysis of the association between adolescent social media use and depressive symptoms. J Affect Disord 2020 Oct 01;275:165-174. [doi: 10.1016/j.jad.2020.06.014] [Medline: 32734903]
15. Primack BA, Shensa A, Escobar-Viera CG, Barrett EL, Sidani JE, Colditz JB, et al. Use of multiple social media platforms and symptoms of depression and anxiety: a nationally-representative study among U.S. young adults. Comput Hum Behav 2017 Apr;69:1-9. [doi: 10.1016/j.chb.2016.11.013]
16. Riehm KE, Feder KA, Tormohlen KN, Crum RM, Young AS, Green KM, et al. Associations between time spent using social media and internalizing and externalizing problems among US youth. JAMA Psychiatry 2019 Dec 01;76(12):1266-1273 [FREE Full text] [doi: 10.1001/jamapsychiatry.2019.2325] [Medline: 31509167]
17. Sarmiento IG, Olson C, Yeo G, Chen YA, Toma CL, Brown BB, et al. How does social media use relate to adolescents' internalizing symptoms? Conclusions from a systematic narrative review. Adolescent Res Rev 2018 Sep 01;5(4):381-404. [doi: 10.1007/s40894-018-0095-2]
18. Kocsis RN. Book review: Diagnostic and statistical manual of mental disorders: Fifth edition (DSM-5). Int J Offender Ther Comp Criminol 2013 Nov 05;57(12):1546-1548. [doi: 10.1177/0306624x13511040]
19. Rosellini AJ, Rutter LA, Bourgeois ML, Emmert-Aronson BO, Brown TA. The relevance of age of onset to the psychopathology of social phobia. J Psychopathol Behav Assess 2013 Sep 01;35(3):356-365 [FREE Full text] [doi: 10.1007/s10862-013-9338-5] [Medline: 23935239]
20. Seabrook EM, Kern ML, Rickard NS. Social networking sites, depression, and anxiety: a systematic review. JMIR Ment Health 2016 Nov 23;3(4):e50 [FREE Full text] [doi: 10.2196/mental.5842] [Medline: 27881357]
21. Sampasa-Kanyinga H, Lewis RF. Frequent use of social networking sites is associated with poor psychological functioning among children and adolescents. Cyberpsychol Behav Soc Netw 2015 Jul;18(7):380-385. [doi: 10.1089/cyber.2015.0055] [Medline: 26167836]
22. Keles B, McCrae N, Grealish A. A systematic review: the influence of social media on depression, anxiety and psychological distress in adolescents. Int J Adolesc Youth 2019 Mar 21;25(1):79-93. [doi: 10.1080/02673843.2019.1590851]
23. Thorisdottir IE, Sigurvinsdottir R, Asgeirsdottir BB, Allegrante JP, Sigfusdottir ID. Active and passive social media use and symptoms of anxiety and depressed mood among icelandic adolescents. Cyberpsychol Behav Soc Netw 2019 Aug;22(8):535-542. [doi: 10.1089/cyber.2019.0079] [Medline: 31361508]
24. Jelenchick LA, Eickhoff JC, Moreno MA. "Facebook depression?" social networking site use and depression in older adolescents. J Adolesc Health 2013 Jan;52(1):128-130. [doi: 10.1016/j.jadohealth.2012.05.008] [Medline: 23260846]
25. O'Reilly M, Dogra N, Hughes J, Reilly P, George R, Whiteman N. Potential of social media in promoting mental health in adolescents. Health Promot Int 2019 Oct 01;34(5):981-991 [FREE Full text] [doi: 10.1093/heapro/day056] [Medline: 30060043]

26. Letcher P, Sanson A, Smart D, Toumbourou JW. Precursors and correlates of anxiety trajectories from late childhood to late adolescence. J Clin Child Adolesc Psychol 2012 Jul;41(4):417-432. [doi: 10.1080/15374416.2012.680189] [Medline: 22551395]
27. Trost SG, Pate RR, Sallis JF, Freedson PS, Taylor WC, Dowda M, et al. Age and gender differences in objectively measured physical activity in youth. Med Sci Sports Exerc 2002 Feb;34(2):350-355. [doi: 10.1097/00005768-200202000-00025] [Medline: 11828247]
28. Hallal PC, Andersen LB, Bull FC, Guthold R, Haskell W, Ekelund U. Global physical activity levels: surveillance progress, pitfalls, and prospects. Lancet 2012 Jul;380(9838):247-257. [doi: 10.1016/S0140-6736(12)60646-1]
29. Ströhle A. Physical activity, exercise, depression and anxiety disorders. J Neural Transm (Vienna) 2009 Jun;116(6):777-784. [doi: 10.1007/s00702-008-0092-x] [Medline: 18726137]
30. Hanson MD, Chen E. Socioeconomic status and health behaviors in adolescence: a review of the literature. J Behav Med 2007 Jun 20;30(3):263-285. [doi: 10.1007/s10865-007-9098-3] [Medline: 17514418]
31. Heen MS, Lieberman JD, Miethe TD. A comparison of different online sampling approaches for generating national samples. Center For Crime and Justice Policy. 2014. URL: https://www.unlv.edu/sites/default/files/page_files/27/ComparisonDifferentOnlineSampling.pdf [accessed 2020-11-12]
32. Len-Ríos ME, Hughes HE, McKee LG, Young HN. Early adolescents as publics: a national survey of teens with social media accounts, their media use preferences, parental mediation, and perceived Internet literacy. Public Relat Rev 2016 Mar;42(1):101-108. [doi: 10.1016/j.pubrev.2015.10.003]
33. Moreno MA, Binger K, Zhao Q, Eickhoff J. Measuring Interests Not Minutes: Development and validation of the adolescents' digital technology interactions and importance scale (ADTI). J Med Internet Res 2020 Feb 12;22(2):e16736 [FREE Full text] [doi: 10.2196/16736] [Medline: 32049068]
34. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med 2001 Sep;16(9):606-613 [FREE Full text] [doi: 10.1046/j.1525-1497.2001.016009606.x] [Medline: 11556941]
35. Birmaher B, Brent DA, Chiappetta L, Bridge J, Monga S, Baugher M. Psychometric properties of the Screen for Child Anxiety Related Emotional Disorders (SCARED): a replication study. J Am Acad Child Adolesc Psychiatry 1999 Oct;38(10):1230-1236. [doi: 10.1097/00004583-199910000-00011] [Medline: 10517055]
36. Su R, Tay L, Diener E. The development and validation of the Comprehensive Inventory of Thriving (CIT) and the Brief Inventory of Thriving (BIT). Appl Psychol Health Well Being 2014 Nov 12;6(3):251-279. [doi: 10.1111/aphw.12027] [Medline: 24919454]
37. Causal mediation analysis. CRAN - Package Mediation. URL: https://cran.r-project.org/web/packages/mediation/index.html [accessed 2021-06-21]
38. RStudio Team. RStudio: Integrated development for R. RStudio, PBC, Boston, MA. 2020. URL: http://www.rstudio.com/ [accessed 2021-03-30]
39. Preacher KJ, Hayes AF. SPSS and SAS procedures for estimating indirect effects in simple mediation models. Behav Res Methods Instrum Comput 2004 Nov;36(4):717-731. [doi: 10.3758/BF03206553]
40. Physical activity guidelines for Americans 2nd edition. U.S. Department of Health and Human Services. URL: https://whish.stanford.edu/wp-content/uploads/2019/01/2018-Physical_Activity_Guidelines_2nd_edition.pdf [accessed 2020-11-12]
41. Cohen J. Statistical Power Analysis for the Behavioral Sciences. Cambridge, Massachusetts, United States: Academic Press; 1977:1-474.
42. Melton TH, Croarkin PE, Strawn JR, McClintock SM. Comorbid anxiety and depressive symptoms in children and adolescents: a systematic review and analysis. J Psychiatr Pract 2016 Mar;22(2):84-98 [FREE Full text] [doi: 10.1097/PRA.0000000000000132] [Medline: 27138077]
43. North TC, McCullagh P, Tran ZV. Effect of exercise on depression. Exerc Sport Sci Rev 1990;18(1):379-415. [doi: 10.1249/00003677-199001000-00016]
44. Carek PJ, Laibstain SE, Carek SM. Exercise for the treatment of depression and anxiety. Int J Psychiatry Med 2011;41(1):15-28. [doi: 10.2190/PM.41.1.c] [Medline: 21495519]
45. Larun L, Nordheim LV, Ekeland E, Hagen KB, Heian F. Exercise in prevention and treatment of anxiety and depression among children and young people. Cochrane Database Syst Rev 2006 Jul 19(3):CD004691. [doi: 10.1002/14651858.CD004691.pub2] [Medline: 16856055]
46. Sherlock M, Wagstaff DL. Exploring the relationship between frequency of Instagram use, exposure to idealized images, and psychological well-being in women. Psychol Pop Media Cult 2019 Oct;8(4):482-490. [doi: 10.1037/ppm0000182]
47. Sumter SR, Cingel DP, Antonis D. “To be able to change, you have to take risks #fitspo”: Exploring correlates of fitspirational social media use among young women. Telemat Inform 2018 Aug;35(5):1166-1175. [doi: 10.1016/j.tele.2018.01.013]
48. Slater A, Varsani N, Diedrichs PC. #fitspo or #loveyourself? The impact of fitspiration and self-compassion Instagram images on women's body image, self-compassion, and mood. Body Image 2017 Sep;22:87-96. [doi: 10.1016/j.bodyim.2017.06.004] [Medline: 28689104]
49. Jones DC. Social comparison and body image: attractiveness comparisons to models and peers among adolescent girls and boys. Sex Roles 2001;45(9):645-664. [doi: 10.1023/A:1014815725852]

50. Morrison TG, Kalin R, Morrison MA. Body-image evaluation and body-image investment among adolescents: a test of sociocultural and social comparison theories. Adolescence 2004;39(155):571-592. [Medline: 15673231]
51. Olfson M, Marcus SC, Weissman MM, Jensen PS. National trends in the use of psychotropic medications by children. J Am Acad Child Adolesc Psychiatry 2002 May;41(5):514-521. [doi: 10.1097/00004583-200205000-00008] [Medline: 12014783]
52. Axelsdóttir B, Biedilae S, Sagatun A, Nordheim LV, Larun L. Review: Exercise for depression in children and adolescents - a systematic review and meta-analysis. Child Adolesc Ment Health 2020 Dec 05:12438. [doi: 10.1111/camh.12438] [Medline: 33277972]
53. Morris J, Stone G. Children and psychotropic medication: a cautionary note. J Marital Fam Ther 2011 Jul;37(3):299-306. [doi: 10.1111/j.1752-0606.2009.00178.x] [Medline: 21745232]
54. Cortese S, Holtmann M, Banaschewski T, Buitelaar J, Coghill D, Danckaerts M, European ADHD Guidelines Group. Practitioner review: current best practice in the management of adverse events during treatment with ADHD medications in children and adolescents. J Child Psychol Psychiatry 2013 Mar;54(3):227-246. [doi: 10.1111/jcpp.12036] [Medline: 23294014]
55. Rice SM, Purcell R, De Silva S, Mawren D, McGorry PD, Parker AG. The mental health of elite athletes: a narrative systematic review. Sports Med 2016 Sep 20;46(9):1333-1353 [FREE Full text] [doi: 10.1007/s40279-016-0492-2] [Medline: 26896951]
56. Twenge JM, Martin GN, Spitzberg BH. Trends in U.S. Adolescents’ media use, 1976–2016: The rise of digital media, the decline of TV, and the (near) demise of print. Psychol Pop Media Cult 2019 Oct;8(4):329-345. [doi: 10.1037/ppm0000203]
57. Spirrison CL, Gordy CC, Henley TB. After-class versus in-class data collection: validity issues. J Psychol 1996 Nov;130(6):635-644. [doi: 10.1080/00223980.1996.9915037]
58. Fan X, Miller BC, Park K, Winward BW, Christensen M, Grotevant HD, et al. An exploratory study about inaccuracy and invalidity in adolescent self-report surveys. Field Methods 2016 Jul 21;18(3):223-244. [doi: 10.1177/152822x06289161]
59. Warnecke RB, Johnson TP, Chávez N, Sudman S, O'Rourke DP, Lacey L, et al. Improving question wording in surveys of culturally diverse populations. Ann Epidemiol 1997 Jul;7(5):334-342. [doi: 10.1016/s1047-2797(97)00030-6]
60. Ernala SK, Burke M, Leavitt A, Ellison NB. How well do people report time spent on Facebook?: an evaluation of established survey questions with recommendations. In: Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems. 2020 Presented at: CHI '20: CHI Conference on Human Factors in Computing Systems; April 25-30, 2020; Honolulu HI USA p. 1-14. [doi: 10.1145/3313831.3376435]
61. Prinstein MJ, Nesi J, Telzer EH. J Child Psychol Psychiatry 2020 Mar 16;61(3):349-352. [doi: 10.1111/jcpp.13219] [Medline: 32064633]

Abbreviations

CIT: Comprehensive Inventory of Thriving
PHQ-9: Patient Health Questionnaire-9
SCARED: Screen for Child Anxiety Related Emotional Disorders

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Commentary

How Our Technology Use Changed in 2020: Perspectives From Three Youths

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Abstract

The Technology and Adolescent Mental Wellness program (TAM) is a research program with the primary goals of promoting research on the topic of adolescent technology use and mental wellness, creatively disseminating that research, and fostering community among stakeholders. Our foundational question is this: How can technology support adolescent mental wellness? Youth are key stakeholders in pursuit of this foundational question. In this commentary, we invited 3 members of TAM's youth advisory board to respond to the following question: "How did your technology use change in 2020?" Jessica, Jared, and Babayosimi describe their technology use during COVID-19 as dynamic, and neither uniformly positive nor negative. Further, these 3 youths differ in their perceptions of the same technologies—social media and online school, for example—as well as their perceived ability to self-regulate use of those technologies. We invite you to weigh these perspectives just as we do at TAM—not as empirical findings in themselves, but as examples of youth ideas for future empirical investigation.

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KEYWORDS

mental health; social media; digital technology; youth; adolescent; commentary; technology; wellness

Introduction

The Technology and Adolescent Mental Wellness program (TAM) is a national, United States–based research program with 3 primary goals. These goals include, first, to promote new research on adolescent technology use and mental wellness, through both project funding and the development of a data repository; second, to creatively disseminate that research through traditional academic means, such as the present theme issue, and nontraditional means, such as social media and industry-facing reports; and, third, to foster community and collaboration among diverse stakeholders. Our stakeholders include adult professionals at the intersection of youth, mental health, and digital technology, such as health care providers, therapists, educators, technology industry professionals, and parents. Furthermore—and perhaps most importantly—our stakeholders are youth themselves. The foundational question driving our program is this: How can technology promote adolescent mental wellness?

Youth are key stakeholders in pursuit of this foundational question. Recent systematic reviews on youth participatory action research (YPAR) [1-3] have evaluated the outcomes of engaging youth in "identifying, researching, and addressing social problems" [1]. These reviews find that youth engagement is associated with heightened youth agency, leadership, and the development of positive academic, social, and critical consciousness skills (eg, writing, belonging, and the ability to recognize social injustice) [1,3]. For communities, the benefit of youth engagement is just as positive; youth involvement in research has been associated with changes to organizational culture toward youth inclusivity and programs and policies that are more responsive to youth needs [2,3]. Importantly, however, one systematic review of YPAR found that youth are rarely involved in the early phases of the research process, such as needs assessment and the development of research questions [1]. Another systematic review found that none of the manuscripts were authored by youth [3]. In short, while the benefits of youth inclusion in academic processes are increasingly clear, the inclusion of youth as the authors of manuscripts and guides for the research agenda remains relatively unexplored.

There are key considerations when inviting youth to academic conversations. First, as investigators and scientists accustomed to seeking perfection in our own projects, papers, and processes, we must be receptive to adolescents' developmental stage and degree of familiarity with academic processes. As with adults, writing abilities inevitably vary. And, as with adults, the availability of authorship opportunities for youth is not equally distributed; instead, it is a function of social determinants that are largely outside of youth's control such as access to academic institutions or adult mentors. In this commentary, we do not claim to "fix" these issues, but merely to acknowledge them, and invite readers to consider for themselves if and how they could be addressed. We present the perspectives of 3 youths whose lives and, specifically, whose technology use were affected by the COVID-19 pandemic, including quarantine, virtual school, and social disruption. Our purpose is, first, to provide an example of empowering youth to be commentators in the academic space. Second, we hope that the perspectives shared will encourage others to include youth in every aspect of the research process—not just in the collection, interpretation, and dissemination of data, but also in the identification of unmet needs and catalysts of research questions.

In order to ensure that the TAM research program is responsive to youth needs, TAM is informed by a youth advisory board (YAB). Members of the TAM YAB are adolescents and young adults (ages 15-18) from around the United States who have a strong interest in the intersection between technology use and mental wellness. In November 2020, 3 members of the TAM YAB volunteered to contribute the following commentary to the academic conversation on adolescent technology use and mental health. Under the supervision of author AJ (who contributed the "Introduction" and "Discussion" sections), the youth authors—JaL, JeL, and BF—collaborated to identify a question of shared interest: "How did your technology use change in 2020?" The youth then created and revised their responses based on feedback from the theme issue co-editor and reviewers, and their final work is presented verbatim below.

Jared Lemminger (Age 17, Grade 11)

In March 2020, the beginning of "quarantine" felt more like a vacation from school, but quickly became a period of boredom, loneliness, and oftentimes, frustration. Even with access to a seemingly infinite selection of entertainment and activities, these too became redundant. Once remote instruction finally started, it was very difficult to find the motivation to actually do it, as it was based on a work-at-your-own-pace platform, with a voluntary pacing guide and a deadline of June 1 to have everything completed. In September 2020, with the consent and direction of the county health department, my school district in Chippewa Falls, Wisconsin, began its first semester in-person, with various modifications to minimize the risk of COVID-19 transmission. Nearly 3 months in, we have, once again, temporarily transitioned back to a remote learning environment due to the incursion of COVID-19-related deaths in our community, with the intent to return to in-person learning once it is safe to do so.

Given this dynamic environment, I have gained insights into the effects these respective learning platforms have on my mental health. I can attest with absolute certainty that in-person learning has benefited my mental health substantially. Not only does it offer an opportunity for true camaraderie, but it also helps to restore a sense of normalcy amidst all that is uncertain about our modern world. I have found that while at home in remote learning, I wake up minutes before class begins, and conduct the rest of the day in Christmas-themed pajama pants, a graphic tee, and my retainer still tacked to my teeth. I can assure you that this is not a recommended habit. Most days, I would continually feel drained and unmotivated. This pattern of despondent behavior led to loneliness and diminished self-efficacy.

In addition, motivation to complete assignments and actively participate in class during remote learning has significantly diminished. Real-time remote instruction, for me, has been almost useless due to the fact that there is no obligation to engage, other than one's own intrinsic motivation. The phrase "I will do it later" has become more prevalent while learning from home, when generally, I would consider myself a productive individual. This contributes to greater undue stress as I have to reteach myself that material through online resources and complete the accompanying assignments. I have fabricated a vicious cycle that can only be interrupted by solemnly attending class, but as I previously mentioned, that can only be achieved through intrinsic motivation (which I do not have).

Finally, the term "virtual" has become rather pervasive given that almost everything has become virtual. As a State Officer for a Career and Technical Student Organization, we have been forced to transition all in-person events and conferences to a virtual format. Our biggest obstacle has been discovering a level of engagement that continues to attract members to virtual events. I have a rather unique lens in this situation, because not only have I been experiencing the virtual fatigue myself, but I also have to plan appealing virtual conferences.

Interestingly enough, as a result of the increasingly virtual environment, my dependence on technology for entertainment purposes and social interaction has decreased. I less often feel pressure to be in constant communication and I do not seek satisfaction from superficial acquaintances. I have been much more authentic and have learned to live the way I am, and meant to be.

Jessica Lee (Age 16, Grade 11)

When COVID-19 hit, I had no clue what technologies such as Zoom, Google Meet, and so many other amazing communication technologies were. The lockdown has forced me, like many others, to shift quickly. At first, it was a struggle to adapt—not to the increased technology use, but to the new technologies such as online conferencing and remote school that I had never truly experienced before. Similar to Jared's experience, procrastination came easily to me. My sleep was affected because virtual school deadlines were often at midnight. I dealt with a lot of stress while adjusting. However, eventually, my mental and physical lifestyle benefitted from increased comfort with virtual technologies. Technology gave me the ability to multitask virtually anywhere. I could be taking a walk, and be learning about factoring polynomials at the same time. The versatility really improved my productivity in remote learning, and I quickly began to prefer being online.

However, with no mental break from technology, I also became much more aware of my constant use of technology. I had to begin shifting my phone usage to apps that were more beneficial to my mental health. Honestly, I still catch myself stuck and staring at my phone, feeling that I need to put it down and do something else, and being unable to even as I am beating myself up for it.

Around the beginning of the quarantine, one of my best friends went through an extremely rough time with her anxiety and depression, and I could not be there for her physically because of the lockdown. The only way I could communicate was through technology and texting, which can be known to not convey emotions well. It was really mentally taxing on me as I learned to interpret and understand what she was really trying to tell me. Because of this, I began having a more conscientious way of interacting with my friends through technology. I had to rethink how I communicated with those around me to be aware and considerate of how they might feel or interpret what I say. In-person, I could read people's body language and tone of voice, I could offer a hug or nod of encouragement, but not in our current virtual age. Quarantine, social distancing, and my friends have helped me fathom just how much we all hide in text and how much those around me may be struggling.

I have now adapted my technology use so that I can better convey my emotions and understand those of others. I began spending less time staring at words and more looking at pictures, videos, memes or gifs, and my friend's face through Zoom or FaceTime. Movement, sound, and motion seemed to reach people more than words. In my way of supporting my friend, I began something I like to call a Daily Tidbit: I send a meme, gif, or something I believe is worth sharing as a once-daily check-in. This was my way of saying, "I may not actually know what you are thinking, or how you feel now, but I will be there for you to stop those negative thoughts when they come." These Daily Tidbits are how I virtually change her mindset and make her feel better. The things we do on our phones, behind our little screens, are important and they do have an impact.

Babayosimi Fadiran (Age 17, Grade 12)

Unlike most teenagers, social media has not been an integral part of my life. I have had a smartphone since eighth grade but never downloaded a social media app until the tenth grade when my soccer team created a group chat on Snapchat to communicate practice and game information. However, when COVID-19 hit, most of my activities were canceled, leaving me isolated from close friends and bored at home for the summer of my senior year. I was left to look for other activities to do, including exploring the features on Snapchat. I soon learned how to view and create stories, which became part of my daily routine. Some of my friends have had multiple negative experiences with Snapchat due to political disagreements and high-school drama. However, for me, looking at stories showcasing my friends' daily lives has made the limited human interaction bearable, and in fact more enjoyable in some cases.

In addition to using Snapchat, YouTube has become a bigger part of my life. Originally I only used YouTube to view entertaining satire or amazing feats. However, with quarantine, I started to "lose it" staying cooped up inside, so I decided on biking every day. But there was one problem: My bike required major repairs and I had little knowledge of the bike anatomy. Luckily, I could rely on YouTube to educate myself on lubrication, gear tension, and more. Ironically, YouTube caused me to get outside more.

Besides incorporating social media in my life during 2020, I also became accustomed to using video call apps, mostly Zoom. I am more of an introvert, so the first few Zoom school classes consisted of me turning off both my camera and sound. However, my Zoom habits changed when I had to switch from in-person cello lessons to virtual ones. Although the lag was troublesome for playing duets, I got more comfortable communicating via Zoom. I started leaving my camera on and contributing to school class discussions more. Similar to Snapchat, I explored the features Zoom had and used them to make video calls more engaging for others. For example, I am the president of a club called HOSA (Health Occupation Students of America) and have struggled to get others to engage in discussions. To combat this, we used the private chat of Zoom to play the game Taboo which has helped members get more comfortable speaking on Zoom.

Although quarantine has prevented me from participating in my normal activities during the year, it has also allowed me to discover new activities to engage in. In addition, it has helped learn the true capabilities of technology that I will be able to use in the future.

Conclusion

"How did your technology use change in 2020?" The perspectives above represent just 3 possible responses to this question. Consistent with recent research on adolescent technology use during COVID-19, Jared, Jessica, and Babayosimi all experienced changes in their technology use in 2020 [4]. Their relationships with technology in 2020 were dynamic, neither uniformly positive nor negative, and the youth varied in both their perception of technology as having a positive or negative effect on their mental health, and their purported abilities to regulate their own technology use. Their personal accounts align with prepandemic findings, namely, that a population-level effect of technology use on mental health is difficult to detect [5]; that technology's effects, positive of negative, may hinge on individual and social factors [6]; and that adolescents vary with respect to how well they regulate technology use [7]. We invite you to weigh these perspectives just as we do at TAM—not as empirical findings in themselves, but as examples of youth ideas for future empirical investigation.

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Conflicts of Interest

None declared.

References

1. Anyon Y, Bender K, Kennedy H, Dechants J. A Systematic Review of Youth Participatory Action Research (YPAR) in the United States: Methodologies, Youth Outcomes, and Future Directions. Health Educ Behav 2018 Dec 11;45(6):865-878. [doi: 10.1177/1090198118769357] [Medline: 29749267]
2. Kennedy H, DeChants J, Bender K, Anyon Y. More than Data Collectors: A Systematic Review of the Environmental Outcomes of Youth Inquiry Approaches in the United States. Am J Community Psychol 2019 Mar 06;63(1-2):208-226. [doi: 10.1002/ajcp.12321] [Medline: 30843254]
3. Shamrova DP, Cummings CE. Participatory action research (PAR) with children and youth: An integrative review of methodology and PAR outcomes for participants, organizations, and communities. Children and Youth Services Review 2017 Oct;81:400-412. [doi: 10.1016/j.childyouth.2017.08.022]
4. Li SH, Beames JR, Newby JM, Maston K, Christensen H, Werner-Seidler A. The impact of COVID-19 on the lives and mental health of Australian adolescents. Eur Child Adolesc Psychiatry 2021 Apr 28:1-13 [FREE Full text] [doi: 10.1007/s00787-021-01790-x] [Medline: 33913036]
5. Odgers CL, Jensen MR. Annual Research Review: Adolescent mental health in the digital age: facts, fears, and future directions. J Child Psychol Psychiatry 2020 Mar 17;61(3):336-348 [FREE Full text] [doi: 10.1111/jcpp.13190] [Medline: 31951670]
6. Seabrook EM, Kern ML, Rickard NS. Social Networking Sites, Depression, and Anxiety: A Systematic Review. JMIR Ment Health 2016 Nov 23;3(4):e50 [FREE Full text] [doi: 10.2196/mental.5842] [Medline: 27881357]
7. Scott H, Biello SM, Woods HC. Identifying drivers for bedtime social media use despite sleep costs: The adolescent perspective. Sleep Health 2019 Dec;5(6):539-545 [FREE Full text] [doi: 10.1016/j.sleh.2019.07.006] [Medline: 31523005]

Abbreviations

HOSA: Health Occupation Students of America
TAM: Technology and Adolescent Mental Wellness program
YAB: youth advisory board
YPAR: youth participatory action research

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Original Paper

Efficacy of an mHealth Intervention (BRAVE) to Promote Mental Wellness for American Indian and Alaska Native Teenagers and Young Adults: Randomized Controlled Trial

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Abstract

Background: Culturally relevant interventions are needed to help American Indian and Alaska Native (AI/AN) teenagers and young adults navigate common risky situations involving family and friends, including drug and alcohol misuse, dating violence, and suicidality. Leveraging *We R Native*, a multimedia health resource for Native teenagers and young adults, staff of the Northwest Portland Area Indian Health Board designed the BRAVE intervention for Native youth. The program is delivered via SMS text messaging and includes role model videos, mental wellness strategies, links to culturally relevant resources, and social support from family and friends.

Objective: We aim to conduct a randomized controlled trial of the BRAVE intervention among AI/AN teenagers and young adults (aged 15-24 years) to assess its impact on their physical, mental, and spiritual health; their resilience and self-esteem; and their coping and help-seeking skills.

Methods: From October to December 2019, we recruited 2334 AI/AN teenagers and young adults nationwide via social media channels and SMS text messages and enrolled 1044 participants. AI/AN teenagers and young adults enrolled in the study received either BRAVE SMS text messages, designed to improve mental health, help-seeking skills, and cultural resilience, or 8 weeks of science, technology, engineering, and math (STEM) SMS text messages, designed to elevate and reaffirm Native voices in STEM and medicine and then received the BRAVE SMS text messages. The impacts of the BRAVE intervention were tested using linear mixed-effect models and linear regressions.

Results: A total of 833 AI/AN teenagers and young adults were included in the analysis. Individuals in the BRAVE and STEM arms showed significant positive trends over the course of the study for all outcomes, except cultural identity and help-seeking behavior. Mean scores were significantly different for health (*P*<.001), resilience (*P*<.001), negative coping (*P*=.03), positive coping (*P*<.001), self-efficacy (*P*=.02), and self-esteem (*P*<.001). Changes in help-seeking self-efficacy were significant in those exhibiting risky behaviors at baseline to exit (*P*=.01). Those who reported positive coping scores at baseline also reported better health on average; however, no difference was found in risky drug and alcohol use (*P*<.001). The number of participants who used SMS text messages to help themselves increased from 69.1% (427/618) at 3 months to 76% (381/501; *P*<.001) at 8 months. Similarly, the number of participants who used SMS text messages to help friends or family members increased from 22.4% (138/616) at 3 months to 54.6% (272/498) at 8 months.

Conclusions: This is the first national randomized controlled trial of a mobile health intervention among AI/AN teenagers and young adults to test the efficacy of a mental wellness intervention in relation to STEM career messages. This study provides new insights for supporting the next generation of AI/AN changemakers.

Trial Registration: ClinicalTrials.gov NCT04979481; https://clinicaltrials.gov/ct2/show/NCT04979481

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KEYWORDS

American Indian; Alaska Native; adolescent; mental health; help-seeking skills, text messaging; mHealth, behavioral intervention; Indian health; mobile phone

Introduction

Background

There are 1.6 million youth aged ≤18 years in the United States who self-identify as American Indian and Alaska Native (AI/AN) [1]. With 573 federally recognized tribes throughout the United States, AI/AN populations are culturally diverse with distinct languages, cultural practices, ceremonies, traditions, and histories. Despite their immense cultural resilience and pride, AI/AN teenagers and young adults are disproportionally affected by stress, depression, and suicide [2]. As a population, AI/AN individuals experience substantial behavioral health needs that are compounded by limited access to mental health professionals and services [3]. Differences in risk behavior and health outcomes among AI/AN teenagers and young adults have been linked to poor economic and social conditions and historical trauma stemming from colonization [4]. Combined with chronic underfunding of the Indian Health Service, these conditions mean that many AI/AN teenagers and young adults do not have sufficient access to needed health services while living in medically underserved communities [3,5].

Mobile Health Interventions

Mobile health (mHealth) technologies, including mobile devices, tablets, PDAs, and computers, are increasingly being used to address unmet health needs because they are cost-effective, developmentally responsive, and have the potential to reach large groups of AI/AN people living across the United States [6]. A recent analysis conducted by MarketCast found that AI/AN teenagers and young adults are open to social media about their mental health and coping strategies. From January to March 2020, participants mentioned mental health, stress, anxiety, and depression more than 1500 times on public social media channels [7]. A recent article by Around Him et al [8] underscored the relevance of social media outlets such as Twitter, Facebook, and Instagram. These platforms offer unique opportunities to address health disparities by building social connections, cultural advocacy, and supportive peer networks [8]. In recent surveys assessing the accessibility and acceptability of technologies to promote health, 93% of AI/AN youth reported having regular access to a smartphone and accessing the internet from their phones daily and 38% reported spending an average of 3-4 hours on social media per day [9].

SMS text messaging interventions are another example of how mHealth technologies are being used to fill the gaps in existing health delivery systems to improve health behavior. Mobile phones are nearly ubiquitous across age groups, socioeconomic classes, and language preferences. A meta-analysis of SMS text messaging to improve diverse health outcomes showed that interventions with tailored and personalized messages have greater effects than interventions without unique messages. However, questions remain about the best strategies for designing message content, the impact of generic versus more tailored SMS text messages, the optimal message timing and dose, and whether unidirectional or bidirectional messaging is important [10-13]. This study is the first to leverage SMS text messaging to promote mental health among AI/AN teenagers and young adults.

Designing Interventions for AI/AN Teenagers and Young Adults

Culturally tailored and user-centered interventions are critically needed to increase the degree by which health messages are perceived as personally relevant by AI/AN youth, thus inspiring and supporting behavior change [6,14,15]. Although mHealth interventions (delivered via SMS text messaging and social media) have been used to improve multiple health outcomes [16], the extent to which mHealth can promote mental health for AI/AN teenagers and young adults is not yet known.

From 2015 to 2018, the Northwest Portland Area Indian Health Board (NPAIHB) carried out formative research involving youth as co-designers to create a behavioral intervention addressing alcohol misuse, intimate partner violence, and suicidality among AI/AN teenagers and young adults living across the United States. In 2015, we conducted key informant interviews with 10 Native young men to better understand their perceptions on alcohol misuse and the context of violence in their communities [17]. In 2016, we designed a series of theoretically informed, culturally relevant SMS text messages and a role model script to demonstrate and reinforce the skills described in the SMS text messages. In 2017, we pilot-tested the messages with Native youth and topical experts to assess the tone, content, and frequency of planned SMS text messages and video episodes.

Grounded in the principles of inclusion, equity, belonging, and diversity, the NPAIHB confirmed that the intervention could reflect the rich cultural diversity of tribes and urban youth living throughout the United States, and multiple phases of youth-driven research informed the design of the BRAVE intervention, the first mHealth intervention delivered via SMS text messages that uses culturally relevant images, narrative role model videos, and help-seeking resources [17].

This study has two aims: (1) to test the BRAVE intervention and (2) to test secondary associations, including self-efficacy, self-esteem, resilience, coping strategies, substance use, and cultural identity.

Research Partners

Overview

The BRAVE intervention was designed and evaluated over 5 years through a series of community-based participatory research activities led by the NPAIHB (Multimedia Appendix 1). The first phase was carried out in collaboration with the Harvard School of Public Health and focused on better understanding alcohol misuse and the context of violence among Native males between the ages of 18 and 24 years using key informant interviews.

The second phase was carried out in collaboration with the NPAIHB's *Tribal Health: Reaching out InVolves Everyone* project and *We R Native*. The NPAIHB is a regional, tribal nonprofit organization that represents 43 federally recognized tribes in Washington, Oregon, and Idaho. The Northwest Tribal Epidemiology Center is housed under NPAIHB and provides support through research, surveillance, and public health capacity building in partnership with the Northwest tribes. During the second phase of the study, the team designed and pilot-tested the intervention with AI/AN young men with a history of alcohol use and violence and 8 topical experts in alcohol prevention, alcohol treatment, violence prevention, health communication, and adolescent health.

During the efficacy phase of the study, the NPAIHB partnered with the mHealth Impact Lab at the Colorado School of Public Health. The lab works to facilitate the rapid and rigorous development, implementation, and evaluation of mobile and digital technology for health promotion and disease prevention to address inequalities in health outcomes. During this phase of the project, the NPAIHB recruited study participants and delivered SMS text messages, and mHealth led the design of data collection tools, data collection, and analysis. The partnership was supported by the Technology & Adolescent Mental Wellness (TAM) program, run by the Social Media and Adolescent Health Research Team and housed within the Department of Pediatrics at the University of Wisconsin-Madison.

We R Native

To reach AI/AN teenagers and young adults with culturally relevant health messages, the NPAIHB built *We R Native*—a holistic, multimedia health resource that reaches over 5000 viewers per day across its messaging channels. *We R Native* was designed using a youth-centered approach, in which youth were actively involved in selecting, writing, and designing their content. The service includes a website, an Ask Auntie Q&A service, an SMS text messaging service (text NATIVE to 97779), a YouTube channel, and social media accounts (ie, Facebook, Instagram, and Twitter). Given the widespread use of mobile phones by Native youth, mHealth interventions provide a promising tool to reach AI/AN youth who live across vast geographies in urban and rural communities.

We R Native regularly engages users to ensure that its tools and messages are relevant, timely, and culturally appropriate. In 2019, the team interviewed 13 AI/AN teenagers and young adults who regularly viewed *We R Native* channels (website, SMS text message, or social media). Participants shared ways in which *We R Native* messages had improved their mental health, cultural connectedness, sense of self-worth, and access to health resources, both for themselves and their loved ones. When asked to reflect on their own mental health concerns, participants mentioned grief and depression as the most common topics, followed by stress and mental wellness skills (eg, coping mechanisms).

These interviews also informed the final design of the BRAVE intervention, highlighting common coping strategies (ie, alcohol and drug misuse), preferred wellness strategies (ie, goal setting and self-care), help-seeking skills (ie, reaching out for help for themselves or a friend), and related protective factors, including cultural resilience, identity, and cultural pride [17]. Participants and key informants recommended expanding the inclusion criteria for BRAVE to females and expanding the age group to 15-24 years. Research is needed to test the efficacy of the BRAVE intervention using the expanded inclusion criteria.

Study Design and Objectives

To evaluate its efficacy, we conducted a randomized controlled trial (RCT) of the BRAVE intervention among AI/AN teenagers and young adults (15-24 years old) living across the United States and assessed its impact on their physical, mental, and spiritual health; their resilience and self-esteem; and their coping and help-seeking skills. Participants were surveyed at four time points (Multimedia Appendix 2 presents the primary and secondary hypotheses).

The use of RCTs in AI/AN communities is often considered an inappropriate study design, given its culture of inclusion that values shared benefits [18]. The NPAIHB used an attention control design to ensure that all participants could receive the same benefits from the study. An alternative study design offers superior methodological rigor compared with a no-intervention control arm [19]. An equivalent control arm was imperative to respect and honor the time and participation of the research participants. We selected science, technology, engineering, and math (STEM)–related SMS text messages because we felt that they would not interfere with the help-seeking skills demonstrated in the BRAVE arm and would be of equal value to participants and because we had access to STEM role model videos that could closely mirror the content and frequency in the study arm.

All data collection methods were approved by the Portland Area Indian Health Service Institutional Review Board in Portland, OR (principal investigator: SCR, *protocol no:* 1384639). A waiver for parental consent was requested and approved by the Institutional Review Board. In addition, a consent form was included on the cover page of the pre- and postsurveys. All instruments and data collection methods were reviewed and approved by the Portland Area Indian Health Service Institutional Review Board before data collection.

Methods

Participant Eligibility and Recruitment

The efficacy study included self-identified AI/AN teenagers and young adults aged 15-24 years. All participants were required to have a cell phone with SMS text messaging capabilities. Eligibility was described via SMS text messages and confirmed using a presurvey.

From September to December 2019, the NPAIHB recruited AI/AN teenagers and young adults via *We R Native* social media channels (ie, Facebook, SMS text message, and Instagram) [20]. Additional recruitment took place through listservs associated with tribes, Indian health and Indian education organizations, and human service organizations that serve AI/AN young adults (Indian Health Service, Methamphetamine Suicide Prevention Initiative, Healthy Native Youth, etc). Interested teenagers and young adults were asked to text the keyword BRAVE to 97779, which triggered a series of eligibility and consent SMS text messages. Over 2330 AI/AN teenagers and young adults texted BRAVE to learn more about the study.

Enrollment and Randomization

To enroll in the study, participants were required to complete a presurvey. Those who met the eligibility criteria were randomized into the study (n=1044) using a 1:1 allocation ratio. mHealth used Excel (Microsoft) software to randomize participants into each study arm. There were a total of eight waves of enrollment from October to December 2019. Data were collected using web-based questionnaires in Qualtrics (SAP) at baseline and at 3, 5, and 8 months. In appreciation of their time, participants received a US $10 Amazon gift code for each survey they completed, up to US $40 per person.

Intervention and Control Messages

AI/AN teenagers and young adults randomized into the intervention arm were immediately exposed to the BRAVE campaign, containing 8 weeks of SMS text messages with three messages per week. Participants in the control arm received messages designed to elevate and reaffirm Native voices in STEM and medicine. The STEM messages were delivered three times per week for 8 weeks. Both arms were designed to include a similar number of messages per week, with a combination of information, role model videos, images, and opportunities for reflection and engagement with the campaign (ie, reply for more information, provide a Q&A response, and click links to access resources). A paper by Stephens et al [20] described the theory that informed the design of campaign messages, as well as the sequence and content of the messages in greater detail.

Data Collection

Data collection began on September 1, 2019. All four pre- and postsurveys were delivered using Qualtrics, an online data collection platform [21]. Questions collected information about standard demographic information, resilience measures, self-esteem, positive and negative coping skills, help-seeking self-efficacy, mental health, and cultural pride (see Table 1 and Multimedia Appendix 3 for the complete BRAVE survey). Data from the surveys were collected, stored, and maintained by mHealth Impact Lab.

The retention was high across the two study arms. For BRAVE enrollees, only 41 participants opted out during the intervention, and only 25 opted out at crossover. For STEM enrollees, only 45 participants opted out during the control phase, and only 18 opted out at crossover. The washout period between the study arms was 1 week. In total, 86 participants opted out of the study during the first arm, and 43 opted out after the crossover, resulting in an 87% retention rate, as shown in Figure 1.

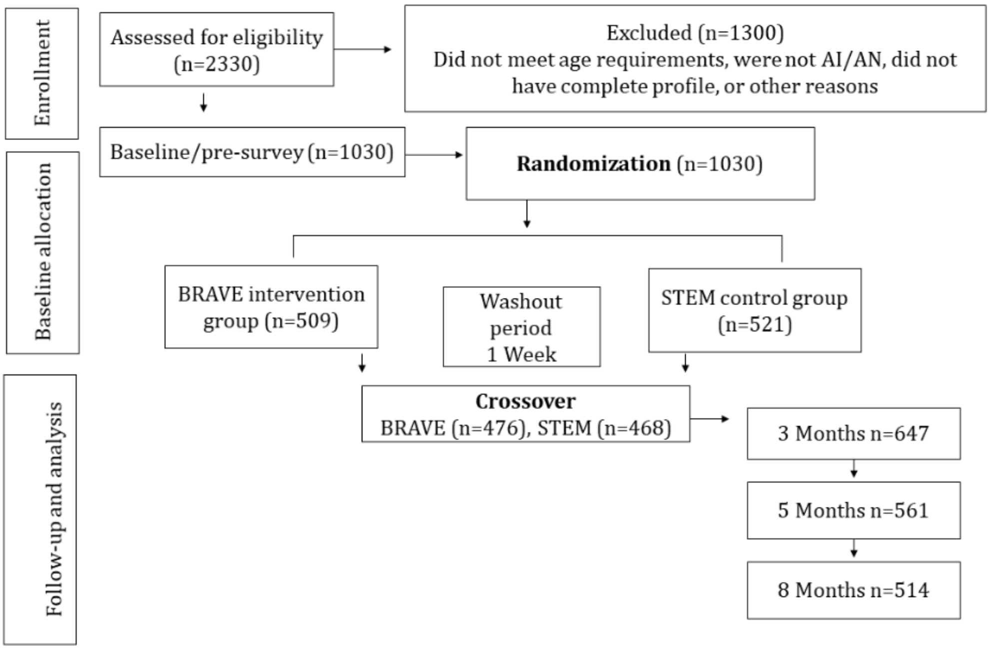
All participants were required to complete the baseline survey at the time of enrollment (presurvey). The presurvey was used to assess eligibility, randomize participants, and gauge baseline measures. Enrollees were asked to complete the same survey after the first set of messages (first postsurvey at 3 months). At the end of the intervention period, participants crossed over to receive the second set of messages and were asked to complete the survey a third time (second postsurvey at 5 months). The study team discontinued communication and asked participants to complete the final survey 90 days later (third postsurvey at 8 months), as shown in Textbox 1.

Table 1. Self-reported survey measures collected from BRAVE participants by survey dimension, sample question, analysis, and answer choices (N=35).

Survey dimension (number of items)	Sample question or statement and validated tool	Analysis	Answer choices
Health (3)	Rate your physical health, YRBS[a] [22]	Changes in perceived physical, mental, and spiritual health	Excellent, very good, good, fair
Coping negative (2)	I've been using alcohol to make myself feel better, Youth Coping Responses Inventory [23]	Changes in problem drinking or drug use	Strongly agree, agree, disagree, strongly disagree, don't know or not sure, don't want to answer
Coping positive (5)	I've been taking action to try to make the unpleasant situation in my life better, Youth Coping Responses Inventory [23]	Proportion of respondents who report high scores of coping skills	Strongly agree, agree, disagree, strongly disagree, don't know or not sure, don't want to answer
Resilience (9)	I try to finish what I start, Child Youth Resilience Measure [24]	Proportion of respondents who report high scores of resilience	Strongly agree, agree, disagree, strongly disagree, don't know or not sure, don't want to answer
Self-efficacy (3)	I am able to reach out for help when I need it, Self-Efficacy Scale [25]	Proportion of respondents who report high scores of their own ability to succeed in different situations and tasks	Very confident, confident, somewhat confident, not at all confident, don't know or not sure, don't want to answer
Help-seeking skills (3)	I offer help or give advice to my friends who are struggling, Counseling Helping Questionnaire [26]	Proportion of respondents who report high scores of help-seeking	Often, sometimes, rarely, never, don't know or not sure, don't want to answer
Self-esteem (4)	As a whole, I am satisfied with myself, Rosenberg Self-Esteem Scale [27]	Proportion of respondents who report high scores of self-satisfaction, having good qualities, pride, self-worth, and self-respect	Strongly agree, agree, disagree, strongly disagree, don't know or not sure, don't want to answer
Cultural resilience and identity (6)	I enjoy my community's traditions, Child Youth Resilience Measure [24]	Proportion of respondents who report high scores of connection, identity, and cultural pride	Strongly agree, agree, disagree, strongly disagree, don't know or not sure, don't want to answer

[a] YRBS: Youth Risk Behavior Survey.

Figure 1. Participant recruitment and retention flow chart. AI/AN: American Indian and Alaska Native; STEM: science, technology, engineering, and math.



Textbox 1. BRAVE data collection timeline and activities.

0-2 Weeks

- Administration of survey 1 (baseline or presurvey) to determine eligibility, enrollment, and assignment to study arms

2 Months

- Sending out first set of messages (BRAVE intervention or science, technology, engineering, and math [STEM] control)

1 Week

- Administration of survey 2 (1st postsurvey)

1 Week

- Washout period

2 Months

- Crossover, second set of messages (BRAVE or STEM)

1 Week

- Administration of survey 3 (2nd postsurvey) and discontinued communication for 90 days

3 Months

- Administration of survey 4 (3rd postsurvey)

Survey Measures

Survey measures were influenced by the Healing of the Canoe Survey (*Tribal Health: Reaching out InVolves Everyone project*) [28] and taken from validated survey tools, including the Youth Risk Behavior Surveillance Survey [22], the Youth Coping Responses Inventory [23], the Child and Youth Resilience [24], the Bandura’s Self-Efficacy Beliefs of Adolescents Scale [25], the Counseling and Help Seeking Questionnaire [26], and the Rosenberg Self-Esteem Scale [27]. The primary outcomes assessed were changes in AI/AN teenager and young adult intentions, behavior, and self-efficacy related to mental health, alcohol and drug misuse assessed by negative coping scales, and help-seeking skills. Outcomes were assessed using standardized scales and Likert-type ratings, wherein answers were converted to numeric scales, and averages and SDs were calculated for each outcome. For example, the health measure is an average score generated from three questions assessing physical, mental, and spiritual health. The secondary outcomes of the study included self-efficacy, self-esteem, resilience, coping strategies, substance use, and cultural identity. Table 1 outlines the survey constructs, the number of items for each construct, and examples for each question in the questionnaire (see Multimedia Appendix 3 for a complete list of questions).

Data Analysis

The study data used in this analysis were collected by mHealth team members and managed using Qualtrics survey software [21] hosted at the University of Colorado Anschutz Medical Campus. All statistical analyses were performed using SAS statistical software (version 9.4) [29] and R (version 3.6) [30].

The study team explored the carryover effects between the BRAVE and STEM arms throughout the study period. Significant differences between the BRAVE and STEM arms were compared at baseline, crossover, and follow-up. Two analyses were conducted to explore the differences among primary outcome measures. First, a two-tailed paired *t* test was used to assess the treatment effect, comparing BRAVE with STEM arms using the difference in outcome scores for each measure. Second, a linear mixed-effect model (using a random effect for the subject) was used to test for changes over time. Treatment effects and changes in outcomes were considered significant at $P<.05$. The secondary outcome measures were analyzed using a series of statistical tests. Multiple linear regressions were used to assess the differences in the baseline and follow-up survey scores. Two models were used to assess the associations at baseline and changes in scores from baseline to study completion. A linear mixed-effect model (with random effects for subjects at 3, 5, and 8 months) was used to assess changes over time.

Results

Demographics

Participants who completed the presurvey were aged 15-24 years and identified as AI/AN were included in this analysis (n=833; Table 2). Most participants were female (552/833, 66.3%). Three-fourth were straight or heterosexual (628/833, 75.4%). Most planned to go to college (440/833, 52.8%), although some were undecided (88/833, 10.6%). Participants most frequently identified as AI/AN only, followed by two and three races. Only 11.3% (94/833) of the participants identified as Hispanic. Study participants represented nearly every state in the United States. Most were from western states including Oregon (n=213), Arizona (n=188), California (n=169), and Washington (n=138) as shown in Figure 2.

Table 2. Summary of American Indian and Alaska Native teenagers and young adults who participated in the study at baseline, 3, 5, and 8 months (N=833).

Characteristic	Participant, n (%)
Gender	
Female	552 (66.2)
Gender fluid	9 (1.1)
Male	241 (28.9)
Transgender female to male	2 (0.2)
Transgender male to female	1 (0.1)
Two spirit	14 (2)
Other (please specify)	6 (0.7)
Prefer not to answer	8 (1)
Sexual orientation[a]	
Asexual	6 (0.7)
Bisexual	78 (9.4)
Indigiqueer	7 (0.8)
Lesbian, gay, or homosexual	42 (5.1)
Pansexual	24 (2.9)
Queer	7 (0.8)
Straight or heterosexual	628 (75.8)
Two spirit	12 (1.5)
Other[b] (please specify)	11 (1.3)
Prefer not to answer	14 (1.7)
Race	
Identify as AI/AN[c] only	657 (78.9)
Identify as 2 races	157 (18.9)
Identify as s3	19 (2.3)
Hispanic[d]	
Yes	94 (11.3)
No	714 (85.8)
Prefer not to answer	24 (2.9)

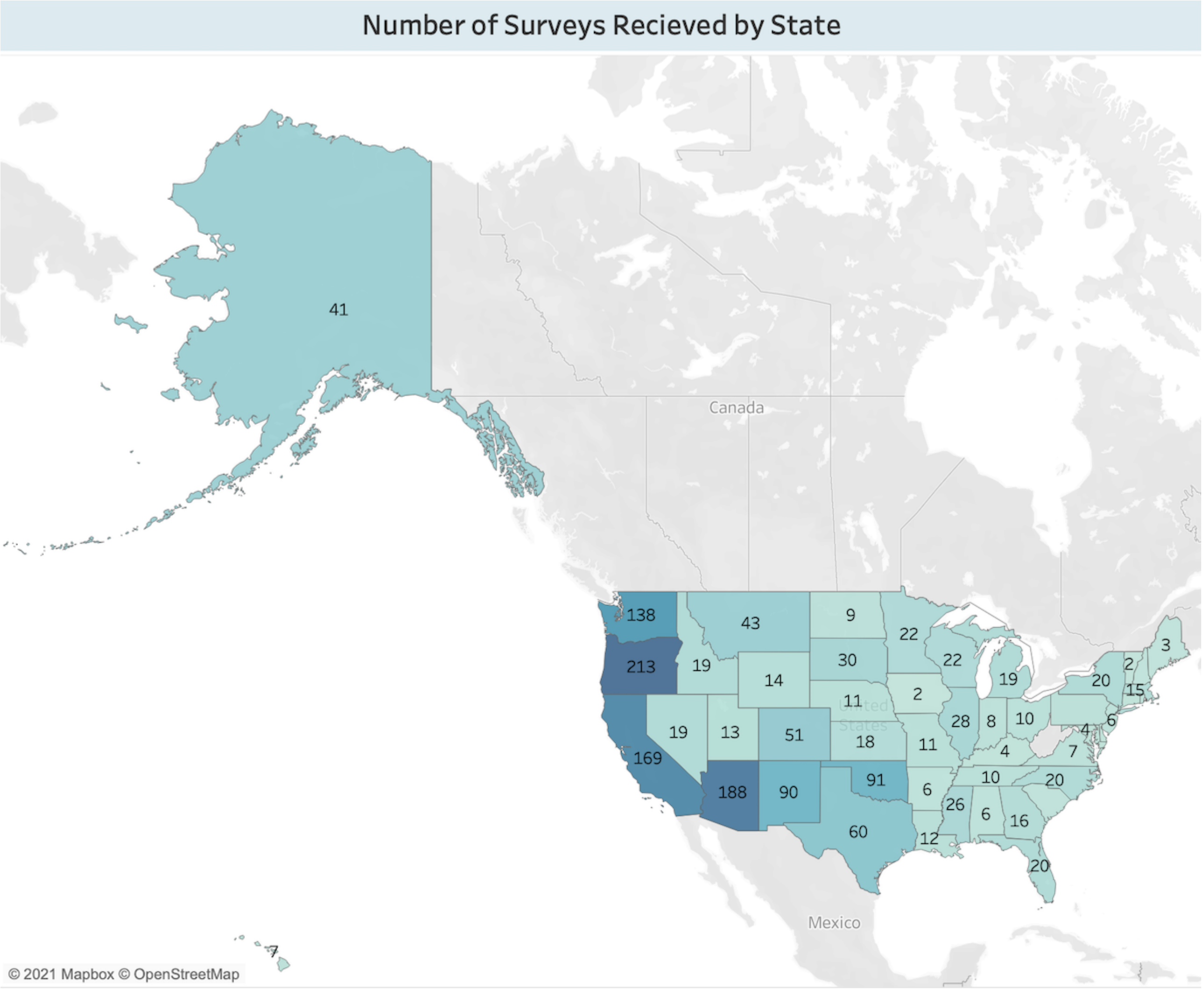
[a] Does not include four missing responses**.**

[b] Other responses were as follows: demisexual (n=2), questioning (n=2), straight (n=4), poly-panromantic asexual two spirit (n=1), no sexuality (n=1), and demisexual and biromantic (n=1).

[c] AI/AN: American Indian and Alaska Native.

[d] Does not include one missing response.

Figure 2. Map of the number of study participants by state in the United States.



Primary Outcomes

To test the study hypotheses and explore the primary and secondary outcomes of interest, the research team compared subjects with themselves and explored differences from pre- to postsurvey throughout the study period. Tests for differences between the two study arms did not show a significant difference within subjects, and statistical analyses revealed no carryover effects (Multimedia Appendix 4).

Participants in the BRAVE arm did not report better outcomes than those in the STEM arm. There were no significant differences in outcome measures at follow-up based on individual and aggregate survey measures. However, individuals in both study arms showed significant positive trends over the course of the study for all primary outcomes except cultural identity and help-seeking behavior.

Longitudinal Effects

A review of 3-, 5-, and 8-month mean scores when controlling for treatment order showed a positive and upward trend for nearly all constructs measured (Table 3). Mean scores were significantly different for health (*P*<.001), resilience (*P*<.001), negative coping (*P*=.03), positive coping (*P*<.001), self-efficacy (*P*=.02), and self-esteem (*P*<.001; Table 3).

Table 3. Comparison of baseline and 3-, 5-, and 8-month mean scores among study participants (N=833).

Measure	Score, mean (SD)				*P* value
	Baseline	3 months	5 months	8 months	
Health	3.87 (0.88)	3.95 (0.87)	4.08 (0.85)	4.12 (0.83)	*<.001* [a]
Resilience	5.13 (0.56)	5.18 (0.52)	5.25 (0.51)	5.23 (0.49)	*<.001*
Negative coping	2.88 (1.05)	2.89 (1.02)	2.92 (1.08)	2.92 (0.95)	*.03*
Positive coping	5.04 (0.68)	5.13 (0.61)	5.17 (0.59)	5.22 (0.53)	*<.001*
Self-efficacy	5.15 (0.61)	5.24 (0.59)	5.21 (0.6)	5.22 (0.55)	*.02*
Self-esteem	5.07 (0.66)	5.17 (0.62)	5.18 (0.6)	5.19 (0.6)	*<.001*
Cultural resilience and identity	5.4 (0.55)	5.38 (0.51)	5.4 (0.46)	5.4 (0.49)	.84
Help-seeking skills	4.02 (0.89)	4.03 (0.85)	4.02 (0.81)	3.98 (0.8)	.06

[a] Italicized values indicate statistical significance (*P*<.05).

Health and Identity, Cultural Pride, and Resilience

Participants who reported better health at baseline reported stronger cultural identity, cultural resilience, identity, and cultural pride. Results from the linear regression (with the health score as the outcome and the cultural identity score as the covariate) showed an association between health and cultural identity (*P*<.001) at baseline. At baseline, health measures were positively associated with cultural identity. On average, those who reported better health also reported greater cultural resilience, identity, and cultural pride (*P*<.001). The R^2 value was 0.488, indicating that 48% of the variation in health scores was explained by cultural identity. Those who reported a positive change in health from baseline to 8 months were also more likely to report a positive change in cultural identity (Table 4).

Table 4. Results of the linear model and answers to secondary outcome questions.

Secondary outcome measures and covariates[a]	β	*P* value	Effect size
Change in help-seeking self-efficacy			
Intercept	.452	<.001	0.021
Under 21	−.162	.18	—[b]
Gender male	−.154	.09	—
Risky baseline	−.280	.01	—
Health and cultural identity at baseline			
Intercept	1.23	—	0.092
Identity baseline	.488	<.001	—
Change in health and cultural identity			
Intercept	.144	<.001	0.027
Identity baseline difference	.241	<.001	—
Coping strategies, health, and substance use at baseline			
Intercept	0	<.001	0.153
Risky baseline	−.004	.94	—
Health baseline	.301	<.001	—
Change in coping strategies, health, and substance			
Intercept	.066	.02	0.028
Risky baseline	.114	.10	—
Health baseline	.123	.001	—

[a] Each outcome is presented as a separate linear model. Effect sizes are measured by R^2.

[b] The effect size is only reported for the intercept and compares the secondary outcome measures and covariates (eg, risky baseline and health baseline).

Positive Coping Strategies

Participants who reported positive coping scores also reported better health on average, with no difference in drug and alcohol misuse (P<.001). The R^2 value was 0.301, indicating that 30% of the variation in coping was explained by better health. Those who reported a positive change in coping strategies from baseline to 8 months were also more likely to report a positive change in health during the study (P=.001). The R^2 value was 0.123, indicating that 12% of the variation in health was explained by positive coping strategies (Table 4).

Help-Seeking Skills and Behavior

The changes observed in help-seeking self-efficacy were significant for those who reported risky behavior at baseline to 8 months (P=.01). The mean change from baseline in help-seeking behavior was −0.281 units lower for those exhibiting risky behavior at baseline. The R^2 value was 0.021, indicating that 2% of the variation in help-seeking self-efficacy was explained by the model containing only participants who reported risky behaviors at baseline. No differences were found among men or young adults aged ≥21 years (Table 4).

User Engagement and Interaction

Participants reported and demonstrated a high level of interaction and engagement with the SMS text messages of the intervention. They reported reading the majority of the messages sent; this activity rate remained high throughout the study, with more than 91.2% (458/502) reporting all or most SMS text messages read at 8 months. The number of participants who shared SMS text messages with family and friends increased from 3 months (206/574, 35.8%) to 8 months (277/502, 55.2%; P<.001; Table 5).

Table 5. Changes in the use of help-seeking skills among study participants (N=833) at different timepoints.

Questions and responses[a]	Participants, n (%)			Trend	P value
	3 months (n=647)	5 months (n=561)	8 months (n=514)		
How many of the study's SMS text messages did you read?				Decreasing	*.01* [b]
Don't want to answer	1 (0.1)	2 (0.3)	4 (0.8)		
None	2 (0.3)	1 (0.2)	3 (0.6)		
Some	35 (5.6)	43 (7.9)	33 (6.6)		
Don't know or not sure	6 (1)	4 (0.7)	4 (0.8)		
Most	148 (24)	133 (24.5)	106 (21.1)		
All	426 (68.9)	360 (66.3)	352 (70.1)		
How many of the study's videos did you watch?				Decreasing	.60
Don't want to answer	3 (0.5)	2 (0.4)	2 (0.4)		
None	57 (9.2)	38 (7)	30 (5.9)		
Some	139 (22.5)	110 (20.2)	94 (18.7)		
Don't know or not sure	21 (3.4)	19 (3.5)	10 (1.9)		
Most	143 (23.2)	163 (30)	224 (44.6)		
All	254 (41.2)	211 (38.9)	142 (28.3)		
How many of the messages did you share with your friends or family?				Increasing	*<.001*
Don't want to answer	4 (0.7)	5 (0.9)	4 (0.8)		
None	122 (19.8)	74 (13.6)	59 (12)		
Some	254 (41.2)	204 (37.6)	144 (28.7)		
Don't know or not sure	30 (4.9)	18 (3.3)	18 (3.6)		
Most	137 (22.2)	168 (31)	210 (41.8)		
All	69 (1.2)	74 (13.6)	67 (13.4)		

[a] Results of the linear mixed-effect model with a random effort to subject (one for each question) based on 3-, 5-, and 8-month timepoints.

[b] Italicized values indicate statistical significance (P<.05).

Changes in Help-Seeking Skills and Behavior

A comparison of 3-, 5-, and 8-month data showed significant improvements in help-seeking skills among BRAVE participants. Results from the linear mixed-effect model (with random effects for subjects) showed a significant increase. The number of participants who used the SMS text messages to help themselves increased from 69.1% (427/618) at 3 months to 76% (381/501) at 8 months (P<.001). Similarly, the number of participants who used the SMS text messages to help a friend or family member increased from 22.4% (138/616) at 3 months to 54.6% (272/498) at 8 months (P<.001; Table 6). At the end of the survey, participants were also asked to provide open-ended feedback on ways to improve the program for others. The team plans to conduct a qualitative analysis of user feedback to inform future improvements.

Table 6. User preferences and attitudes toward intervention observed among study participants at different timepoints.

Questions and responses[a]	Participants, n (%)			Trend	*P* value
	3 months (n=647)	5 months (n=561)	8 months (n=514)		
How likely are you to use any of the resources you learned about if you, a family member, or friend need them?				Decreasing	*.008* [b]
Don’t want to answer	3 (0.5)	2 (0.4)	3 (0.6)		
Very unlikely	2 (0.3)	1 (0.2)	0 (0)		
Unlikely	18 (3)	16 (3)	14 (3)		
Don’t know or not sure	33 (5)	23 (4.2)	17 (3)		
Likely	338 (54.8)	352 (64.8)	330 (65.7)		
Very likely	223 (36.1)	149 (27.4)	138 (27.5)		
Did you use any of the messages to help yourself?				Increasing	*<.001*
No	89 (14)	44 (8)	39 (8)		
Did not need them	102 (16.5)	65 (12)	81 (16)		
Yes	427 (69.1)	433 (79.9)	381 (76.1)		
Did you use any of the messages to help a friend or family member?				Increasing	*<.001*
No	363 (58.9)	196 (36.1)	119 (23.9)		
Did not need them	115 (18.7)	122 (22.5)	107 (21.5)		
Yes	138 (22.4)	225 (41.4)	272 (54.6)		
Did the messages encourage you to participate in any new wellness activities?				Increasing	.07
No	119 (19.3)	88 (16.3)	79 (15.8)		
Yes	498 (80.7)	453 (83.7)	421 (84.2)		
Is there anything else we can do to improve this program for others?				Decreasing	*<.001*
No	537 (87.6)	492 (90.7)	472 (94.8)		
Yes	76 (12.4)	50 (9.2)	26 (5.2)		

[a] Results of the linear mixed-effect model with a random effort to subject (one for each question) based on 3-, 5-, and 8-month timepoints.

[b] Italicized values indicate statistical significance (*P*<.05).

Discussion

Principal Findings

This is the first national RCT of an mHealth intervention among AI/AN teenagers and young adults to rigorously test the efficacy of a mental wellness intervention in relation to STEM career messages, conducted in a 100% virtual format—recruiting, consenting, and surveying participants—via SMS text messaging (Multimedia Appendix 5).

Although our results did not fully support the proposed hypotheses, there were no measurable treatment effects between the two study arms. The findings indicate that both culturally relevant mHealth interventions improved health outcomes, an important programmatic finding. For both groups, most survey measures improved over time, including notable improvements in mental health, resilience, coping skills, and better self-esteem, despite the study conducted in the midst of the global pandemic. There were also significant reductions in reported alcohol and drug misuse by participants over the course of the study. Both study arms showed positive improvements in composite scores and trends, arguably the most promising outcome of all, demonstrating that culturally tailored SMS text messages can improve health and wellness outcomes for Native teenagers and young adults.

The lack of significant treatment effects may be partially explained by the lack of representation of Native youth and young adult experience in popular media, making the control arm similarly novel and inspiring to study participants. These findings have direct implications for future research. When designing RCTs for AI/AN groups, it is essential to consider what constitutes a control versus intervention arm. The study team believed that STEM messages would not interfere with the modeling of BRAVE-related skills. This RCT suggests, however, that the STEM role model videos had a similar effect on the study participants.

The need for culturally relevant STEM interventions is also critical for Native youth and young adults [31]. Native students are chronically underrepresented in training programs for STEM professions. Expanding the diversity of the STEM and medicine workforce is needed to meet the unique needs and worldviews of AI/AN communities. Messaging campaigns, such as those offered in the control arm, may inspire Native youth and young adults to join the STEM workforce pathway.

Health and Identity, Cultural Pride, and Resilience

At baseline, physical, mental, and spiritual health measures were positively associated with cultural identity. This suggests that resilience, identity, and cultural pride may be associated with better health among AI/AN teenagers and young adults. These findings are consistent with a previous study that reported that AI/AN identity may be protective against a myriad of risk behaviors, including alcohol and drug misuse [32]. This research adds to a growing body of evidence that recognizes the foundational importance of building cultural pride and positive self-worth in adolescent health programs for AI/AN youth, further demonstrating that health and identity are inextricably intertwined.

Positive Coping Strategies

Notably, participants who reported better coping strategies at baseline (ie, having healthy outlets to use when stressed, taking active steps to improve mental health, or using positive self-talk to overcome unpleasant feelings) also reported better health on average but did not have any difference in risky behavior compared with their peers. In addition, participants who reported a positive change in coping strategies over the course of the study were more likely to report a positive change in physical, mental, and spiritual health during that period. These findings reinforce a previous study on AI/AN populations, which suggested that having healthy coping strategies may directly impact health [33]. Health advocates can build on these findings by encouraging students to find and practice healthy coping strategies that reflect their unique skills and preferences.

Alcohol and Drug Misuse May Compromise Help Seeking

Although we hypothesized that the BRAVE intervention might be more effective to the original audience of AI/AN males aged 21-24 years involved in formative research, it was not correct; we found that changes in help-seeking self-efficacy were not significantly different from younger AI/AN males aged 18-20 years. This was a welcome surprise, reinforcing our decision to expand the eligibility criteria for the study.

There was, however, one significant difference among males at baseline: males who reported greater alcohol and drug misuse also reported lower help-seeking behavior. Previous research in other populations suggests that help-seeking interventions are most effective when an individual is symptomatic and felt the need to ask for help [34]. Future research should determine the points or conditions in which help-seeking interventions, such as BRAVE, are the most beneficial for reducing alcohol and drug misuse.

Help-Seeking Skills and Behavior

Finally, self-reported help-seeking skills (ie, ability to recognize when a friend is struggling, and willingness to contact a helpline, seek counseling, or treatment if needed, for themselves or a friend) were moderate to high among study participants. Healthy participants with high help-seeking characteristics who entered an intervention showed less change in these attributes over time.

Similarly, self-reported data showed a high level of interaction and engagement throughout the study; however, this engagement did not translate to a significant intervention effect on the primary outcomes of interest. Future work could explore the efficacy of the BRAVE intervention among AI/AN teenagers and young adults who have been identified as high-risk due to their involvement with juvenile justice systems, foster care, treatment, or behavioral health programs.

Strengths and Limitations

The BRAVE study has several strengths and limitations. A major strength of the study was the RCT design, where random allocation allowed for a clean comparison between the intervention and control groups. The biggest strength of BRAVE was its development with input from AI/AN teenagers and young adults, tribal health educators, and topical experts. The focus of BRAVE on culturally relevant images, language, and the use of role model videos demonstrated respect for diversity and value. BRAVE created health communication messaging that AI/AN youth and young adults could identify with.

There are several limitations that should be noted. First, all data were self-reported. The sample was recruited largely through *We R Native*, which is a multimedia health and wellness resource. Participant familiarity with *We R Native* may have influenced their responses and participation. The initial goal was to enroll 125 participants from the 12 Indian Health Service geographic regions (n=1500) to explore the efficacy of BRAVE across regional differences. However, only 1030 participants, which is an insufficient sample size to explore regional differences, enrolled in BRAVE. Of these, only 833 were included in the analysis to improve data quality. The washout period of 1 week between the intervention and control arms may not have been sufficient to observe an effect in the treatment and control conditions. Finally, most participants reported high or favorable scores on the survey measures at baseline. This may have contributed to the lack of treatment effects between the two arms.

Conclusions

This study builds upon the extensive digital research activities already carried out by the NPAIHB and the mHealth Impact Lab and fills a critical need for evidence-based interventions that reflect the unique needs and worldview of AI/AN teenagers and young adults. This research provides new information on the development of mHealth interventions for AI/AN youth using evidence-based strategies and furthers our understanding of the connections between health and cultural resilience, identity, and cultural pride. This work demonstrates the feasibility of recruiting a national sample of AI/AN teenagers and young adults online, which is largely due to the trusted nature of the *We R Native* platform. It also underscores the acceptability of SMS text messaging as a vehicle to promote and support mental health and wellness, addressing a priority concern among AI/AN teenagers and young adults.

Researchers, practitioners, policy makers, and AI/AN-serving organizations may use this example to improve the relevance, efficacy, and use of other mHealth interventions to reach high-risk, underserved populations. BRAVE lessons can be easily integrated into the flow of services provided by clinics, schools, treatment centers, and other community-based programs and can be tailored to the needs and time constraints of any setting [35]. Future research may address the recommendations offered by study participants to improve campaigns for future users and assess the uptake of the service outside the study setting. Native youth and young adults can now text BRAVE to 97779 or STEM to 97779 to receive the SMS text message sequence on their own.

Taken together, these results demonstrate the importance of culturally relevant health resources to support AI/AN teenagers and young adults as they navigate common risky situations involving family and friends, including alcohol and drug misuse, dating violence, and suicidality. User-designed mHealth interventions are critical to reach and engage at-risk populations and nurture lifelong decision-making skills. In the words of one participant, demonstrating the power and promise of BRAVE, “It encouraged me to better my health not only for myself but for the future generations.”

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Editorial Notice

This randomized study was only retrospectively registered, explained by authors with "(1) It was not a process or requirement; (2) It was funded with private/foundation funds and not federal/NIH." The editor granted an exception from ICMJE rules mandating prospective registration of randomized trials, because the risk of bias appears low and the study was considered formative, guiding the development of the application. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

Conflicts of Interest

Authors SCR, DS, RP, CB, TGD, CM, DLB, MT, CC, MS, and PS are employees of Northwest Portland Area Indian Health Board, which developed the BRAVE intervention.

Multimedia Appendix 1
Healthy Native Youth BRAVE Website and Curriculum.
[PDF File (Adobe PDF File), 412 KB - mental_v8i9e26158_app1.pdf]

Multimedia Appendix 2
BRAVE study hypotheses.
[DOCX File , 14 KB - mental_v8i9e26158_app2.docx]

Multimedia Appendix 3
BRAVE survey questions.
[DOCX File , 17 KB - mental_v8i9e26158_app3.docx]

Multimedia Appendix 4
Treatment effect results and mean differences.
[DOCX File , 22 KB - mental_v8i9e26158_app4.docx]

Multimedia Appendix 5
Graphical abstract of the BRAVE study.
[PDF File (Adobe PDF File), 142 KB - mental_v8i9e26158_app5.pdf]

Multimedia Appendix 6
CONSORT-EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 716 KB - mental_v8i9e26158_app6.pdf]

References

1. American Indian and Alaska Native Alone or in Combination With One or More Races, 2013-2018 American Community Survey 5-year Estimates (B02010). United States Census Bureau. 2013. URL: https://www.census.gov/newsroom/press-releases/2019/acs-5-year.html [accessed 2020-11-20]
2. National Academies of Sciences, Engineering, and Medicine. Advancing Health Equity for Native American Youth. Washington, USA: The National Academies Press; 2016.
3. Gone JP, Trimble JE. American Indian and Alaska Native mental health: diverse perspectives on enduring disparities. Annu Rev Clin Psychol 2012;8:131-160. [doi: 10.1146/annurev-clinpsy-032511-143127] [Medline: 22149479]
4. Strickland CJ, Walsh E, Cooper M. Healing fractured families: parents' and elders' perspectives on the impact of colonization and youth suicide prevention in a pacific northwest American Indian tribe. J Transcult Nurs 2006 Jan;17(1):5-12. [doi: 10.1177/1043659605281982] [Medline: 16410431]
5. Kelley A, Small C. Documenting resiliency of American Indian youth: preliminary results from native PRIDE’s intergenerational connections project. J Indig Stud 2020;8:5. [doi: 10.26077/88kd-n107]
6. Rushing SC, Stephens D. Use of media technologies by Native American teens and young adults in the Pacific Northwest: exploring their utility for designing culturally appropriate technology-based health interventions. J Prim Prev 2011 Aug;32(3-4):135-145. [doi: 10.1007/s10935-011-0242-z] [Medline: 21805055]
7. Around Him D, Weilin L, Gross E, Warren J, DeMand A, Garcia-Baza I, et al. Twitter Analysis Can Help Practitioners, Policymakers, and Researchers Better Understand Topics Relevant to American Indian/Alaska Native Youth. Child Trends. URL: https://www.childtrends.org/publications/twitter-analysis-practitioners-policymakers-researchers-understand-topics-american-indian-alaska-native-youth [accessed 2020-11-20]
8. Around HD, Weilin L, Gross E, Warren J, DeMand A, Garcia-Baza I, et al. Twitter Analysis Can Help Practitioners, Policymakers, and Researchers Better Understand Topics Relevant to American Indian/Alaska Native Youth. Child Trends. 2020. URL: https://www.childtrends.org/publications/twitter-analysis-practitioners-policymakers-researchers-understand-topics-american-indian-alaska-native-youth [accessed 2020-11-20]
9. Reed N, Craig RS. Youth Health Tech Surveys. Healthy Native Youth. 2020. URL: https://www.healthynativeyouth.org/wp-content/uploads/2021/02/YHTS-No-Labels-FINAL.pdf [accessed 2021-02-25]
10. Gurol-Urganci I, de Jongh T, Vodopivec-Jamsek V, Atun R, Car J. Mobile phone messaging reminders for attendance at healthcare appointments. Cochrane Database Syst Rev 2013 Dec 5(12):CD007458 [FREE Full text] [doi: 10.1002/14651858.CD007458.pub3] [Medline: 24310741]
11. de Jongh T, Gurol-Urganci I, Vodopivec-Jamsek V, Car J, Atun R. Mobile phone messaging for facilitating self-management of long-term illnesses. Cochrane Database Syst Rev 2012 Dec 12;12:CD007459 [FREE Full text] [doi: 10.1002/14651858.CD007459.pub2] [Medline: 23235644]
12. Vodopivec-Jamsek V, de Jongh T, Gurol-Urganci I, Atun R, Car J. Mobile phone messaging for preventive health care. Cochrane Database Syst Rev 2012 Dec 12;12:CD007457 [FREE Full text] [doi: 10.1002/14651858.CD007457.pub2] [Medline: 23235643]
13. Head KJ, Noar SM, Iannarino NT, Harrington NG. Efficacy of text messaging-based interventions for health promotion: a meta-analysis. Soc Sci Med 2013 Nov;97:41-48. [doi: 10.1016/j.socscimed.2013.08.003] [Medline: 24161087]
14. Craig Rushing S, Gaston A, Kaufman CE, Markham C, Jessen C, Gorman G, et al. Using Technology to Promote Health and Wellbeing among American Indian and Alaska Native Teens and Young Adults. In: Dyson LE, Grant S, Hendriks M, editors. Indigenous People and Mobile Technologies. New York, NY: Routledge; 2015:163-178.
15. Schnall R, Rojas M, Bakken S, Brown W, Carballo-Dieguez A, Carry M, et al. A user-centered model for designing consumer mobile health (mHealth) applications (apps). J Biomed Inform 2016 Apr;60:243-251 [FREE Full text] [doi: 10.1016/j.jbi.2016.02.002] [Medline: 26903153]
16. Kaufman CE, Schwinn TM, Black K, Keane EM, Big Crow CK. The Promise of Technology to Advance Rigorous Evaluation of Adolescent Pregnancy Prevention Programs in American Indian and Alaska Native Tribal Communities. Am J Public Health 2016 Sep;106(S1):S18-S20. [doi: 10.2105/AJPH.2016.303335] [Medline: 27689483]
17. Craig Rushing S, Kelley A, Hafner S, Stephens D, Singer M, Bingham D, et al. The BRAVE Study: Formative Research to Design a Multimedia Intervention for American Indian and Alaska Native Young Adults. Am Indian Alsk Native Ment Health Res 2021;28(1):71-102. [doi: 10.5820/aian.2801.2021.71] [Medline: 33844480]
18. Fisher P, Ball T. Tribal participatory research: mechanisms of a collaborative model. Am J Community Psychol 2003 Dec;32(3-4):207-216. [doi: 10.1023/b:ajcp.0000004742.39858.c5] [Medline: 14703257]
19. Freedland KE, Mohr DC, Davidson KW, Schwartz JE. Usual and unusual care: existing practice control groups in randomized controlled trials of behavioral interventions. Psychosom Med 2011 May;73(4):323-335 [FREE Full text] [doi: 10.1097/PSY.0b013e318218e1fb] [Medline: 21536837]

20. Stephens D, Peterson R, Singer M, Johnson J, Rushing S, Kelley A. Recruiting and Engaging American Indian and Alaska Native Teens and Young Adults in a SMS Help-Seeking Intervention: Lessons Learned from the BRAVE Study. Int J Environ Res Public Health 2020 Dec 16;17(24):12 [FREE Full text] [doi: 10.3390/ijerph17249437] [Medline: 33339260]
21. Qualtrics. 2020. Qualtrics. URL: http://www.qualtrics.com/ [accessed 2020-11-20]
22. Grunbaum J, Kann L, Kinchen S, Williams B, Ross J, Lowry R, et al. Youth risk behavior surveillance--United States, 2001. J Sch Health 2002 Oct;72(8):313-328. [doi: 10.1111/j.1746-1561.2002.tb07917.x] [Medline: 12389372]
23. Hernandez B, Vigna J, Kelley ML. The Youth Coping Responses Inventory: development and initial validation. J Clin Psychol 2010 Sep;66(9):1008-1025. [doi: 10.1002/jclp.20697] [Medline: 20694963]
24. Ungar M, Liebenberg L. Assessing Resilience Across Cultures Using Mixed Methods: Construction of the Child and Youth Resilience Measure. Journal of Mixed Methods Research 2011 Apr;5(2):126-149. [doi: 10.1177/1558689811400607]
25. Bandura A. Guide for constructing self-efficacy scales. In: Self-efficacy beliefs of adolescents. Charlotte: Information Age Publishing; 2006:307-337.
26. Dauphinais P, LaFromboise T, Rowe W. Perceived problems and sources of help for American Indian Students. Counselor Education and Supervision 1980;20:37-44.
27. Rosenberg M. Society the adolescent self-image. In: Princeton University Press. Princeton: Princeton University Press; 1965:1-326.
28. Donovan D, Thomas L, Sigo R, Price L, Lonczak H, Lawrence N, et al. Healing of the canoe: preliminary results of a culturally tailored intervention to prevent substance abuse and promote tribal identity for Native youth in two Pacific Northwest tribes. In: Am Indian Alsk Native Ment Health Res. Healing of the Canoe: Preliminary results of a culturally grounded intervention to prevent substance abuse and promote tribal identity for Native youth in two Pacific Northwest tribe. Am Indian Alsk Native Ment Health Res (Online); 2015:42-76.
29. SAS. URL: https://www.sas.com/en_us/home.html [accessed 2020-12-25]
30. The R Project for Statistical Computing. URL: https://www.r-project.org/ [accessed 2020-12-23]
31. Stevens S, Andrade R, Page M. Motivating Young Native American Students to Pursue STEM Learning Through a Culturally Relevant Science Program. J Sci Educ Technol 2016 Jun 6;25(6):947-960. [doi: 10.1007/s10956-016-9629-1]
32. Brown RA, Dickerson DL, D'Amico EJ. Cultural Identity Among Urban American Indian/Alaska Native Youth: Implications for Alcohol and Drug Use. Prev Sci 2016 Oct;17(7):852-861 [FREE Full text] [doi: 10.1007/s11121-016-0680-1] [Medline: 27450682]
33. Elmquist DL, McLaughlin CL. Social Media Use Among Adolescents Coping with Mental Health. Contemp School Psychol 2017 Nov 16;22(4):503-511. [doi: 10.1007/s40688-017-0167-5]
34. Gulliver A, Griffiths KM, Christensen H, Brewer JL. A systematic review of help-seeking interventions for depression, anxiety and general psychological distress. BMC Psychiatry 2012 Jul 16;12:81 [FREE Full text] [doi: 10.1186/1471-244X-12-81] [Medline: 22799879]
35. BRAVE Users Guide. Healthy Native Youth. URL: https://www.healthynativeyouth.org/curricula/brave/ [accessed 2021-02-24]

Abbreviations

AI/AN: American Indian and Alaska Native
mHealth: mobile health
NPAIHB: Northwest Portland Area Indian Health Board
RCT: randomized controlled trial
STEM: science, technology, engineering, and math
TAM: Technology & Adolescent Mental Wellness

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Original Paper

Seeking Help From Trusted Adults in Response to Peers' Social Media Posts About Mental Health Struggles: Qualitative Interview Study Among Latinx Adolescents

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Abstract

Background: Rather than confiding in adults about their mental health struggles, adolescents may use social media to disclose them to peers. Disclosure recipients are tasked with deciding whether to alert an adult and, if so, whom to alert. Few studies have examined how adolescents decide on a trusted adult to help a friend who posts on social media about his/her mental health struggles. Moreover, Latinx adolescents are underrepresented in research on social media use, which creates gaps in understanding how social media may influence their well-being.

Objective: This qualitative study presents findings from semistructured interviews with Latinx adolescents to investigate how they seek out trusted adults when a friend posts on social media about their mental health struggles. Specifically, we sought to determine which adult ties they activated, the resources they believed the adult could provide, and the support they expected the adult to provide.

Methods: We recruited participants through a nonprofit organization serving the Latinx community (primarily of Mexican origin) located in Milwaukee, Wisconsin. We conducted 43 semistructured interviews, each lasting 60-90 minutes, with Latinx adolescents (25 females, 18 males) aged 13-17 years. All interviews were conducted in English, at the adolescents' request. Using a grounded theory approach, we identified the nature of the relationship between the trusted adult and either the disclosure recipient or distressed friend, and the resources and support the trusted adult is expected to provide.

Results: Participants nominated adults who were emotionally or physically proximate to either the disclosure recipient or distressed friend, particularly parents (of the recipient and friend) and school staff. However, some felt that not all parents and school staff were emotionally proximate. Adolescents sought trusted adults with access to two resources: experiential knowledge and authority. Some, particularly males, avoided adults with authority because of the risk of punishment and others thought their immigrant parents did not have relevant experiential knowledge to assist them. Interviewees felt that trusted adults with either resource could provide emotional and instrumental support either directly or indirectly, while those with experiential knowledge could provide informational support. Notably, interviews did not problematize the fact that the disclosure occurred on social media when deliberating about adults.

Conclusions: To assist a distressed friend posting on social media, Latinx adolescents look not only for trusted adults who are emotionally and physically proximate but also those who have key resources that facilitate support. Efforts should focus on connecting adolescents with trusted adults and training adults who hold positions of authority or experiential knowledge to offer both direct and indirect support. Additionally, efforts should consider how immigrant experiences shape parent-child relations and address the potential long-term consequences of oversurveillance of Latinx youth, particularly males, by school staff for their access to social support.

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KEYWORDS

adolescents; confidants; ethnicity; gender; network resources; privacy; race; social media; social support; tie activation; trust

Introduction

Adolescents who disclose their struggles with depression or anxiety to peers on social media may be experiencing clinically significant symptoms [1]. Disclosure on social media affords access to social relationships for receiving social support and managing mental well-being [2-4]. Because some posts with mental health disclosures from adolescents may warrant adult notification and intervention [5], it is critical to understand the perspectives of the peers who receive these disclosures on social media. Adolescent disclosure recipients are charged with shielding the original poster from negative peer judgment (eg, bullying, gossip, and rumors) and potential punishment from adult authority figures (eg, parents and teachers) [6,7]. Disclosures on social media magnify the urgency of successful shielding because the medium facilitates rapid transmission of content in a way that sacrifices its original context and intended meaning [8-10]. Nonetheless, because adolescents may not seek help for mental health on their own [11-13], disclosure recipients are also faced with the burden of deciding whether concerning posts should be shared with an adult and, if so, with whom. In short, disclosure recipients must decide whether concealing from or disclosing to an adult would be better for protecting a friend who publishes concerning posts on social media.

Adults within the network of the disclosure recipient then likely serve as critical resources for responding to concerning posts. For example, adults may operate as gatekeepers who mediate access to mental health services [12]. The mere presence of adults, however, does not guarantee the provision of support because they may be deemed inappropriate for the health concern in question [14]. Some adults may exacerbate distress by questioning the credibility of the mental health concern [15,16], while others may have positive intentions to assist but be ill-equipped to respond because of limited guidance and training [17,18]. In addition, the occurrence of the disclosure on social media would further complicate the issue. Adults could punish either the disclosure recipient or distressed adolescent, perhaps for using social media outside of agreed upon rules or for any illegal, unethical, or risky behavior described in the post. Accordingly, disclosure recipients likely selectively activate ties with adults in their own network to marshal resources on behalf of friends who make mental health disclosures on social media. Concurrent with previous reports, we refer to such adults as “trusted adults” [19,20].

While prior studies have conceptualized trusted adults as having traits such as empathy, confidentiality, and physical and emotional availability, they focused on adolescents seeking help for themselves rather than for a friend [19-21]. One study on American Indian and Alaskan native youth examined how they would respond to concerning posts from a friend and offered initial evidence about the traits and roles of trusted adults [18]. A deeper understanding of how adolescents navigate their own networks to seek help for a friend who publishes concerning posts on social media is key for supporting the mental well-being of adolescents and may also reveal gaps in the resources that adolescents can marshal.

This study focused on how Latinx adolescents view trusted adults, specifically how they determine which adult ties to activate and the support they expect the adult to provide when a friend makes a hypothetical disclosure on social media about mental health struggles. Despite being one of the fastest growing demographic groups in the United States and segments of social media users [22,23], adolescents are underrepresented in research on social media use [8,24]. This potentially overlooks how social media can be beneficial for the mental wellness of adolescents. Latinx adolescents experience high rates of depression; nonetheless, they face socioeconomic and cultural barriers to receiving care [25]. Moreover, concerns over stigmatization shape who they seek for mental health support [26], which likely influences their perspectives on trusted adults. We therefore conducted qualitative interviews with Latinx adolescents to address gaps in studies on trusted adults and social media.

Methods

The institutional review board at the University of Wisconsin-Milwaukee approved the study procedures. We collaborated with the United Community Center (UCC), a nonprofit organization serving the Latinx community in Milwaukee, Wisconsin, to recruit participants from a summer youth program. The Latinx population in Milwaukee is primarily of Mexican origin [27]. Like other Latinx youth in the United States, those in Milwaukee face disparities in mental health and access to trusted adults [27,28]. Prior to the start of the study, we conducted a focus group session with 15 Latinx youth at UCC to identify common mental health concerns (eg, feeling like a failure, suicidal thoughts, and unpleasant termination of relationships) to reference during the interviews. UCC screened eligible participants, who were Latinx adolescents aged 13-17 years who posted on social media at least once per week. We collected signed assent and consent forms from all adolescents and their guardians, respectively, before beginning with data collection. Assent and consent forms were available in both English and Spanish. Participants who enrolled in the study received an incentive of US $40.

We conducted 60-90–minute, semistructured, in-person interviews with 43 Latinx adolescents (25 females, 18 males) in a quiet room at UCC from June to July 2019. A Spanish-speaking interviewer was available, but all interviews were conducted in English at the request of the adolescents. The interview began with participants providing demographic information and selecting a pseudonym, which we use here to quote and summarize responses. After answering questions on social media and mental health disclosures, participants completed a card-sorting task presenting their mental health concerns. Informed by prior studies on how individuals make privacy decisions [29,30], participants were asked to separate the items that they would disclose to an adult, if they witnessed an adolescent friend express them on through social media posts, and to discuss general rules guiding their decisions. Participants were asked open-ended questions on their choice of the adult they would tell and why. This approach ensured that all participants were able to reflect on hypothetical situations that they personally felt warranted adult intervention. All interviews were digitally recorded and professionally transcribed verbatim. Interviewers wrote memos following each interview to reflect on findings, which the study team reviewed to identify emergent patterns and revise the interview guide accordingly.

A grounded theory approach was used to analyze transcripts [31]. During initial coding, 2 senior members of the research team read the first 12 interviews for instances in which interviewees reflected their choice of adults they would tell and why. This resulted in codes capturing the rationales for seeking adult intervention, the adults they would seek and why, and the traits of ideal and flawed trusted adults. Through discussion, initial codes were transformed into a codebook that described a smaller number of focused codes. We used MAXQDA 2018 (VERBI Software GmbH) to apply the codebook to all transcripts.

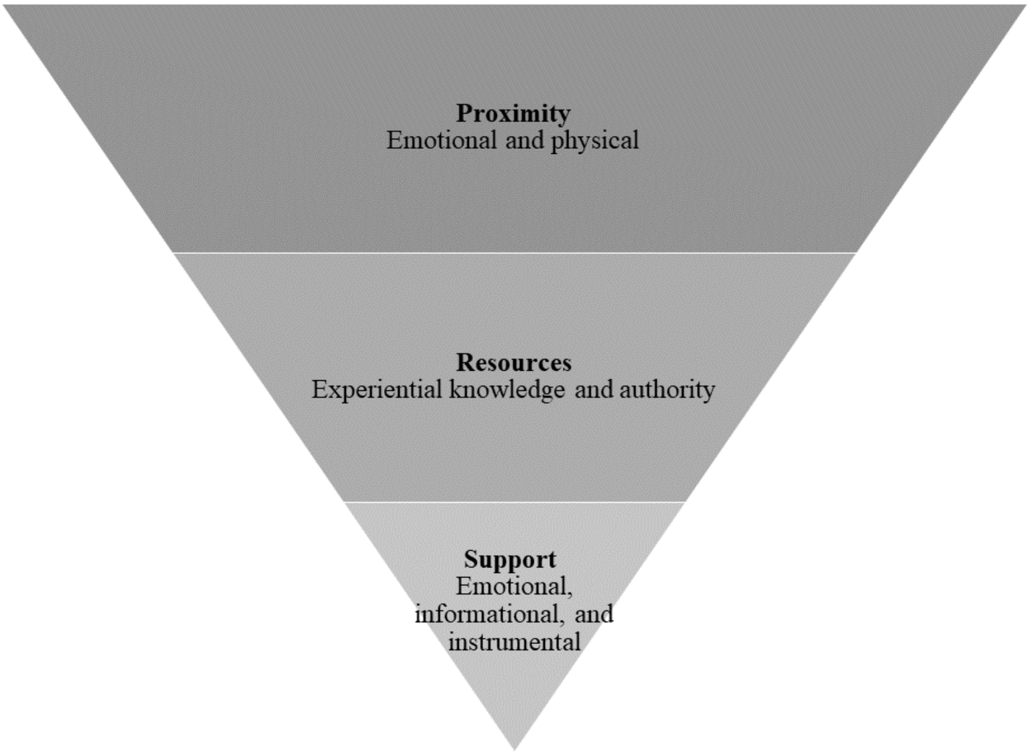
During the focused coding stage, 11 transcripts were coded by at least 2 team members, with each transcript discussed code-by-code. When code definitions shifted through discussion and the constant comparative method, we recoded previously reviewed transcripts as needed. We then examined focused codes in relation to each other and developed key categories, around which the results are organized.

Results

Results Overview

Figure 1 shows the categories that summarize how Latinx adolescents select a trusted adult to provide support to a friend who posted about his/her mental health struggles on social media. The figure emphasizes how adolescents filter through possible adults to arrive at an ideal choice. We first describe the nature of the relationship (emotional and physical proximity) to either the disclosure recipient or the distressed friend and then present a model describing broad categories of resources interviewees sought out in trusted adults and the types of support they could provide. The overarching category of “resources” represents the resources that the interviewees seek when selecting a trusted adult: authority and experiential knowledge. The second category “support” captures the types of support the adolescents sought from trusted adults: emotional, instrumental, and informational.

Figure 1. Categories that summarize how Latinx adolescents select a trusted adult to help with a friend who posted on social media about his/her mental health struggles.



Nature of the Relationship

The most common types of trusted adults mentioned are indicated in Table 1, stratified by gender, which was the primary axis of difference. Across interviews, parents—of either the interviewee or the friend publishing a concerning social media post—were nominated. The interviewee’s own parents, particularly the mother, were commonly named. Alternatives to parents comprised adults at schools, including teachers, counselors, and principals. Overall, no individual type of adult was uniformly endorsed as optimal for assisting a friend posting on social media about being distressed. Instead, the nature of the relationship to either the disclosure recipient or distressed friend was key and varied across adult types.

Table 1. Frequencies and percentages of the type of adult nominated, stratified by the self-reported gender of the interviewee (N=43).

Type of adult	Females (n=25), n (%)	Males (n=18), n (%)	Total (n=43), n (%)
Own parent	22 (88)	12 (67)	34 (79)
Friend’s parent	14 (56)	10 (56)	24 (56)
Adult sibling	3 (12)	2 (11)	5 (12)
Other family member	3 (12)	4 (22)	7 (16)
Teacher	13 (52)	6 (33)	19 (44)
Counselor	10 (40)	5 (28)	15 (35)
Principal	5 (20)	2 (11)	7 (16)

Proximity to the Distressed Friend

Adolescents sought trusted adults with emotional and physical proximity to the distressed friend. This generally favored the parent of the friend over other adults, particularly because of an assumption that the parent was unaware of the affected adolescent’s mental health struggle. One participant noted, “I feel like I would really trust their parents because I feel like they themselves should know how their child is feeling” [Participant #41, female]. Some expressed practical concerns, which the physical proximity of the friend’s parent addressed. For example, while adolescents can proffer their own help, adolescents recognized limitations:

> *We’re not going to be there in person to watch them. So, if it’s a parent, they’re with them in the house, they make sure that that child is okay.* [Participant #21, female]

Some also felt that teachers inherently had a strong emotional proximity to students. One participant, for example, named teachers as a suitable choice of adult “since some of the teachers, well not some, all of the teachers care about you” [Participant #7, female].

However, emotional proximity of parents to their children was not always assumed. For example, a participant echoed others in believing that parents should know about a post, but then qualified his statement by stating that parents cannot be globally entrusted:

> *I feel like a parent…should know… I feel like it really depends. Because there might be some kids with a rough home life.* [Participant #3, male]

Others described proximity as having disadvantages. One participant reflected on the family dynamics within Latinx families and stated, “Especially a Latino, something about our parents just terrifies us” [Participant #20, male]. Further, the proximity of teachers and school staff to peers raised concerns among adolescents that reaching out to them would spur gossip and rumors.

Proximity to Disclosure Recipient

Participants also considered the physical and emotional proximity of the adult to themselves. Some participants, including one particular participant, felt that the parents of their friends were approachable:

> *I will most likely talk to their parents, especially since I know many of the parents of my friends. It would be really easy to reach out to them.* [Participant #32, male]

More commonly, however, participants identified their own parents as trusted adults because of proximity, with physical proximity breeding emotional proximity over time. One participant stated that she would tell her parents about a friend in need because of the following reason:

> *I really trust them. They’ve been taking care of me since I was little and they’ve always been there for me.* [Participant #36, female]

However, as with the parents of friends, several participants expressed concerns about their own parents, indicating physical proximity was insufficient for entrusting them.

Resources

The interviews cited “authority,” which is the expectation that others would comply with the adult’s directives, as a resource of trusted adults. They saw authority as helpful in stopping a distressed friend from having harmful thoughts and behaviors, as determined from a participant’s interview: “[adults] can’t always stop suicidal thoughts; [they] can always stop suicide” [Participant #42, male]. Another participant wanted to activate ties with trusted adults with authority to immobilize those who were harming the distressed friend: “If they’re bullying you and you tell the teachers or your parents, the bullying is going to stop” [Participant #27, male].

Activating ties with a trusted adult with authority also had disadvantages. One participant, for example, was cautious about trusted adults using their authority to punish the disclosure recipient or distressed friend: “Because you never know like if they could just kick you out of their school for doing something like that” [Participant #4, female]. Others felt that adolescents such as themselves were overburdened by their required contact with school officials and were alienated because of the frequent exercise of authority over them, as one participant noted: “Because the school has done enough with us. Sometimes we just want a break from school in general” [Participant #20, male].

Adults in formal positions of authority offered an additional resource that adolescents were poised to activate: formal training. Several cited a distressed friend as falling under the authority of those who were formally trained in this domain by making comments such as it is "their job to help people." One participant had a similar opinion and further stated that their formal training can determine the severity of the situation:

> *I would tell somebody at my school, like a teacher or a guidance counselor, about like, oh, this person is feeling this way. Like I don't know if it's something super serious, but I feel like I see it that way. So I don't know how you guys are going to handle this, but this is how somebody's feeling.* [Participant #18, female]

Unlike expertise derived from training needed to assume a formal position of authority, experiential knowledge is gleaned from direct life experiences. Because the disclosure recipient is younger than an adult, interviews suggested that trusted adults "might know more than you do about how to react to these types of situations" [Participant #5, male]. Even those who occasionally seemed reticent to involve adults, owing to the assumption that they may not understand, conceded; for example, one participant stated that "they were teenagers at some point, so they know" [Participant #39, female]. In particular, disclosure recipients sought those with experiential knowledge germane to the problem that their friend was facing.

A signal influencing the perceived relevance of the experience was the similarity between the trusted adult and either the disclosure recipient or the distressed friend. This included having "been through something similar" or having a similar background, such as being proximate in age to the adolescents. One participant, for example, described why she would contact her adult sister rather than her parents:

> *[My parents] are not old but we also lived in different times. You know, like they would always mention to me like, 'Oh, like in Mexico like they did this in school'…But…my older sister…we're close so we--I talk to her about a lot of things. She's gone through similar things as I did, more similar than, you know, with what my parents have gone through.* [Participant #19, female]

The interview depicts another concern among Latinx adolescents with immigrant parents, which is that their parents' experiences were irrelevant because of contextual differences in upbringing.

Support

The interviews detailed different types of specific support the interviewees thought trusted adults could provide, which appeared related to the resources possessed. The first, emotional support, included listening and providing comfort and sympathy to the distressed friend. While not assumed to be present in every potential trusted adult, participants that felt both resources could yield emotional support. For example, one participant viewed an emotionally proximate adult, his adult sister, as possessing relevant experiential knowledge because they have "just grown up with each other" [Participant #23, male]. Consequently, he felt she could offer emotional support because they "literally tell each other everything" and that she provided "a safe environment" for communication. Adults with authority were also mentioned as providing emotional support. Another participant believed that by telling teachers, they could also be "on the lookout" within their classroom. Because they are physically proximate, teachers could observe a friend's state. A teacher's authority over a classroom grants them the ability to do more than observe and "lookout," which would be helpful because one participant stated "they could sympathize" with his distressed friend [Participant #22, male].

Instances where interviews described tangible assistance were considered "instrumental support." This was often related to formal positions of authority, where the trusted adult could curb harmful thoughts and behaviors. For trusted adults without a formal position, this included operating as a gatekeeper to contact others who did (eg, alerting teachers about cyberbullying perpetrated by a classmate) or to access formal avenues of support, including mental health services. Several participants stated that their most proximal contact, their parents, could reach out to the friend's parents on their behalf. One participant, for example, stated, "I would tell my parents, and then they would probably talk to their parents about it or seek out help" [Participant #11, male].

The last type of support indicated here was "informational support," which included guidance or advice and appeared to be related to trusted adults with experiential knowledge. In particular, trusted adults who endured circumstances similar to those that the friend encountered could offer input on how they overcame the ordeal. A participant interview explained that a distressed friend "could hear stories from somebody else who went through drugs who could have possibly died or were close to dying but survived and became someone greater than they were" [Participant #39, female]. One participant echoed the importance of hearing from someone who overcame one's own struggle: "So they probably had mistakes that they have been through, so that they can tell them what to do next" [Participant #27, male].

Discussion

Principal Findings

We conducted interviews with Latinx adolescents to understand how they decide whom among their trusted adults they would engage with when concerned about a friend disclosing his/her mental health struggles on social media. Among the adults within their network, they considered the nature of the relationship between the adult and either themselves or their distressed friend and the resources and support the adult could provide. The findings clarify the resources and expected support sought by adolescents, while revealing circumstances potentially unique to Latinx adolescents. In turn, this study identifies prospective ways to foster adolescent-adult relationships and support access to resources mediated by adults.

The types of adults commonly nominated were parents, particularly the mothers of the disclosure recipient. Parents generally fit the stated criteria for trusted adults, which were being emotionally and physically proximate to either the disclosure recipient or distressed friend. This emphasis on proximity broadly echoes previous reports on the traits of trusted adults [21]. The focus on mothers complements other reports on the importance of mothers as confidants and for shaping mental health outcomes [32-34] by suggesting that they also serve as an important resource for their children's friends. While not nominated as frequently, fathers are also important, especially in Latinx families where they tend to play a strong role in shaping screen time [35]. In instances where a parent was not nominated, this was due in part to parents immigrating to the United States and growing up in a context different from that of the adolescents. These findings suggest that culturally sensitive interventions aimed at addressing resource deficits should be tailored to the gender and immigration status of parents.

For adolescents concerned about contacting parents on behalf of a friend, adults at schools present an alternative. Teachers are charged with monitoring and assisting with the well-being of their students, such as confronting bullying between classmates, but students do not always depend on them [36]. Despite teachers' physical proximity to both participants and distressed friends and the belief that their authority could halt harmful thoughts and behaviors, we found that some adolescents were reticent to alert teachers owing to a lack of emotional proximity. The reasoning they offered indicated feeling overburdened by the frequency of teachers exercising authority over them. For Latinx adolescents, particularly males, this may be a consequence of the harsh punishment and oversurveillance they endure compared to their White counterparts [37-40]. This presents both a gap in resources and a need to recognize and disrupt the potential long-term consequences of systemic racism within schools with respect to the social resources that adolescents can marshal when they or their peers are in need.

Our findings indicate that adolescents further vet trusted adults by the resources and support they can offer. Authority and experiential knowledge both represent areas where adolescents are traditionally lacking owing to both age and social dynamics. These 2 resources allow adolescents to mobilize adults to provide desired forms of support. However, one resource that was noticeably absent was digital literacy. Further, the interviews did not problematize the fact that the friend's disclosure occurred on social media as they described their preferred adults. In this case it appears that, despite the social media context of the friend in distress, the key preconditions for activating an adult tie are whether the adult can offer emotional, instrumental, or informational support.

Studies such as ours on adolescents' understandings of trusted adults can help inform interventions aimed at creating adolescent-adult connections and fostering resources and support skills among adults [19]. Adolescents deemed each type of adult nominated as capable of providing emotional support, suggesting that any trusted adult can be trained to provide it. While adolescents did not perceive every type of adult as providing instrumental support to assist a distressed friend, they did see the potential for someone to provide such support indirectly by mediating access to another adult who could. This suggests opportunities to provide guidance to adults about key contacts for mental health support. We subsequently intend to survey parents or guardians (ie, the most commonly nominated trusted adult) on their views of adolescents expressing mental health struggles on social media, perceived efficacy for supplying support, and awareness of resources to assist them, while focusing on identifying gaps that future interventions could address.

Limitations

The limitations of this study include sampling of English-speaking Latinx adolescents from a summer program in a mid-sized US city whose residents are largely of Mexican origin. Such sampling potentially misses important differences by country of origin and language barriers faced in contacting adults outside of home. Focus on a setting in which Latinx adolescents report fewer adult confidants than other ethnoracial groups helped identify local gaps in resources. Another limitation is that the interviews largely described who would be contacted in hypothetical scenarios, thus limiting the ability to determine what events occur in an actual emergency. Our findings should be interpreted as describing normative ideals and in which case it is still illuminating to observe instances when certain types of adults were avoided.

Conclusions

Adults within the network of adolescents may not always be well-informed about their well-being [32,34,36]. Instead, adolescents may use social media to confide in their peers, making it critical to understand how disclosure recipients may marshal adult support. Semistructured interviews with Latinx adolescents revealed how resources and support provided by trusted adults are linked. Not every adult physically proximate to an adolescent is considered trustworthy, and Latinx adolescents may experience gaps in access to trusted adults, thus reflecting their families' immigrant experiences and long-term consequences of systemic racism. Future efforts should support forging connections between adolescents and adults and guide adults on ways in which they can provide different types of support.

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Conflicts of Interest

None declared.

References

1. Moreno MA, Christakis DA, Egan KG, Jelenchick LA, Cox E, Young H, et al. A pilot evaluation of associations between displayed depression references on Facebook and self-reported depression using a clinical scale. J Behav Health Serv Res 2012 Jul;39(3):295-304 [FREE Full text] [doi: 10.1007/s11414-011-9258-7] [Medline: 21863354]
2. Best P, Manktelow R, Taylor B. Online communication, social media and adolescent wellbeing: A systematic narrative review. Children and Youth Services Review 2014 Jun;41:27-36 [FREE Full text] [doi: 10.1016/j.childyouth.2014.03.001]
3. Ziebland S, Wyke S. Health and illness in a connected world: how might sharing experiences on the internet affect people's health? Milbank Q 2012 Jun;90(2):219-249 [FREE Full text] [doi: 10.1111/j.1468-0009.2012.00662.x] [Medline: 22709387]
4. Gritton JC, Rushing SC, Stephens D, Kerr B, Moreno M. “People Care”: Recommendations from Native Youth to Address Concerning Mental Health Displays on Social Media. J Adolesc Health 2016 Feb;58(2):S58. [doi: 10.1016/j.jadohealth.2015.10.128]
5. Moreno MA, Ton A, Selkie E, Evans Y. Secret Society 123: Understanding the Language of Self-Harm on Instagram. J Adolesc Health 2016 Jan;58(1):78-84 [FREE Full text] [doi: 10.1016/j.jadohealth.2015.09.015] [Medline: 26707231]
6. Eder D, Enke JL. The Structure of Gossip: Opportunities and Constraints on Collective Expression among Adolescents. Am Sociol Rev 1991 Aug;56(4):494. [doi: 10.2307/2096270]
7. Faris R, Felmlee D. Casualties of Social Combat. Am Sociol Rev 2014 Mar 31;79(2):228-257. [doi: 10.1177/0003122414524573]
8. Marwick AE, Boyd D. Networked privacy: How teenagers negotiate context in social media. New Media & Society 2014 Jul 21;16(7):1051-1067. [doi: 10.1177/1461444814543995]
9. Solove DJ. The Future of Reputation: Gossip, rumor, and privacy on the Internet. London: Yale University Press; 2007.
10. Marwick AE, Boyd D. I tweet honestly, I tweet passionately: Twitter users, context collapse, and the imagined audience. New Media Soc 2010 Jul 07;13(1):114-133. [doi: 10.1177/1461444810365313]
11. Michelmore L, Hindley P. Help-seeking for suicidal thoughts and self-harm in young people: a systematic review. Suicide Life Threat Behav 2012 Oct;42(5):507-524. [doi: 10.1111/j.1943-278X.2012.00108.x] [Medline: 22889130]
12. Stiffman AR, Pescosolido B, Cabassa LJ. Building a model to understand youth service access: the gateway provider model. Ment Health Serv Res 2004 Dec;6(4):189-198 [FREE Full text] [doi: 10.1023/b:mhsr.0000044745.09952.33] [Medline: 15588030]
13. Planey AM, Smith SM, Moore S, Walker TD. Barriers and facilitators to mental health help-seeking among African American youth and their families: A systematic review study. Child Youth Serv Rev 2019 Jun 23;101:190-200 [FREE Full text] [doi: 10.1016/j.childyouth.2019.04.001] [Medline: 23881944]
14. Perry BL, Pescosolido BA. Functional specificity in discussion networks: The influence of general and problem-specific networks on health outcomes. Social Networks 2010 Oct;32(4):345-357 [FREE Full text] [doi: 10.1016/j.socnet.2010.06.005]
15. Pilgrim D. The survival of psychiatric diagnosis. Soc Sci Med 2007 Aug;65(3):536-547. [doi: 10.1016/j.socscimed.2007.03.054] [Medline: 17470381]
16. Barker K, Galardi TR. Diagnostic Domain Defense: Autism Spectrum Disorder and the DSM-5. Social Problems 2015 Feb 08;62(1):120-140. [doi: 10.1093/socpro/spu001]
17. Kerr B, Stephens D, Pham D, Ghost Dog T, McCray C, Caughlan C, et al. Assessing the Usability, Appeal, and Impact of a Web-Based Training for Adults Responding to Concerning Posts on Social Media: Pilot Suicide Prevention Study. JMIR Ment Health 2020 Jan 20;7(1):e14949 [FREE Full text] [doi: 10.2196/14949] [Medline: 31958066]
18. Gritton J, Rushing SC, Stephens D, Ghost Dog T, Kerr B, Moreno MA. Responding to concerning posts on social media: Insights and solutions from American Indian and Alaska Native youth. Am Indian Alsk Native Ment Health Res 2017;24(3):63-87. [doi: 10.5820/aian.2403.2017.63] [Medline: 29161455]
19. Pringle J, McAteer J, Whitehead R, Scott E, Milne D, Jepson R. Developing a taxonomy to characterise trusted adult support in the lives of adolescents. J Adolesc 2019 Oct;76:30-36 [FREE Full text] [doi: 10.1016/j.adolescence.2019.08.004] [Medline: 31442812]
20. Pringle J, Whitehead R, Milne D, Scott E, McAteer J. The relationship between a trusted adult and adolescent outcomes: a protocol of a scoping review. Syst Rev 2018 Nov 24;7(1):207 [FREE Full text] [doi: 10.1186/s13643-018-0873-8] [Medline: 30474574]
21. Hassett A, Green C, Zundel T. Parental Involvement: A Grounded Theory of the Role of Parents in Adolescent Help Seeking for Mental Health Problems. SAGE Open 2018 Oct 17;8(4):215824401880778. [doi: 10.1177/2158244018807786]
22. Anderson M, Jiang J. Teens, Social Media and Technology 2018. Pew Research Center. 2018 May 31. URL: https://www.pewresearch.org/internet/2018/05/31/teens-social-media-technology-2018/ [accessed 2021-06-14]
23. Lopez M, Krogstad J, Flores A. Key facts about young Latinos, one of the nation's fastest-growing populations. Pew Research Center. 2018 Sep 13. URL: https://www.pewresearch.org/fact-tank/2018/09/13/key-facts-about-young-latinos/ [accessed 2021-06-14]
24. Barroso CS, Springer AE, Ledingham CM, Kelder SH. A qualitative analysis of the social and cultural contexts that shape screen time use in Latino families living on the U.S.-Mexico border. Int J Qual Stud Health Well-being 2020 Dec;15(1):1735766 [FREE Full text] [doi: 10.1080/17482631.2020.1735766] [Medline: 32118520]
25. Alegria M, Vallas M, Pumariega AJ. Racial and ethnic disparities in pediatric mental health. Child Adolesc Psychiatr Clin N Am 2010 Oct;19(4):759-774 [FREE Full text] [doi: 10.1016/j.chc.2010.07.001] [Medline: 21056345]

26. Chang J, Chen C, Alegría M. Contextualizing Social Support: Pathways to Help Seeking in Latinos, Asian Americans, and Whites. J Soc Clin Psychol 2014 Jan;33(1):1-24. [doi: 10.1521/jscp.2014.33.1.1]
27. West Allis-West Milwaukee Community Health Assessment 2015. West Allis City Hall. 2015. URL: https://www.westalliswi.gov/DocumentCenter/View/7269/2015-WAWM-Community-Health-Assessment- [accessed 2021-06-14]
28. Conducting a YRBS. Wisconsin Department of Public Instruction. URL: https://dpi.wi.gov/sspw/yrbs/online [accessed 2020-11-30]
29. Caine K, Hanania R. Patients want granular privacy control over health information in electronic medical records. J Am Med Inform Assoc 2013 Jan 01;20(1):7-15 [FREE Full text] [doi: 10.1136/amiajnl-2012-001023] [Medline: 23184192]
30. Nippert-Eng C. Islands of Privacy. Chicago, IL: The University of Chicago Press; 2010.
31. Charmaz K. Constructing Grounded Theory. Thousand Oaks, CA: Sage Publications; 2014.
32. Keijsers L, Voelkle MC, Maciejewski D, Branje S, Koot H, Hiemstra M, et al. What drives developmental change in adolescent disclosure and maternal knowledge? Heterogeneity in within-family processes. Dev Psychol 2016 Dec;52(12):2057-2070. [doi: 10.1037/dev0000220] [Medline: 27893247]
33. Van der Giessen D, Branje S, Keijsers L, Van Lier PAC, Koot HM, Meeus W. Emotional variability during mother-adolescent conflict interactions: longitudinal links to adolescent disclosure and maternal control. J Adolesc 2014 Jan;37(1):23-31. [doi: 10.1016/j.adolescence.2013.10.007] [Medline: 24331301]
34. Shin Y. How do mothers manage their privacy with adolescents? Exploring mother–adolescent communication in Mexican immigrant families. J Soc Pers Relat 2019 Mar 18;36(11-12):3733-3751. [doi: 10.1177/0265407519836282]
35. Zhang Y, Hurtado GA, Flores R, Alba-Meraz A, Reicks M. Latino Fathers' Perspectives and Parenting Practices Regarding Eating, Physical Activity, and Screen Time Behaviors of Early Adolescent Children: Focus Group Findings. J Acad Nutr Diet 2018 Nov;118(11):2070-2080. [doi: 10.1016/j.jand.2018.03.025] [Medline: 29945853]
36. Fekkes M, Pijpers FIM, Verloove-Vanhorick SP. Bullying: who does what, when and where? Involvement of children, teachers and parents in bullying behavior. Health Educ Res 2005 Feb;20(1):81-91. [doi: 10.1093/her/cyg100] [Medline: 15253993]
37. Lopez N. Hopeful Girls, Troubled Boys: Race and Gender Disparity in Urban Education. New York, NY: Routledge; 2003.
38. Kiki E. Victor M. Rios: Human Target: Schools, Police, and the Criminalization of Latino Youth. J Youth Adolescence 2017 Oct 31;46(12):2484-2487. [doi: 10.1007/s10964-017-0779-0]
39. Musto M. Brilliant or Bad: The Gendered Social Construction of Exceptionalism in Early Adolescence. Am Sociol Rev 2019 Apr 25;84(3):369-393. [doi: 10.1177/0003122419837567]
40. Peguero AA, Shekarkhar Z. Latino/a Student Misbehavior and School Punishment. Hisp J Behav Sci 2011 Jan 19;33(1):54-70. [doi: 10.1177/0739986310388021]

Abbreviations

UCC: United Community Center

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Original Paper

A Social Media Group Cognitive Behavioral Therapy Intervention to Prevent Depression in Perinatal Youth: Stakeholder Interviews and Intervention Design

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Abstract

Background: Adolescents and young adults aged <25 years (youth) are at a higher risk of perinatal depression than older adults, and they experience elevated barriers to in-person care. Digital platforms such as social media offer an accessible avenue to deliver group cognitive behavioral therapy (CBT) to perinatal youth.

Objective: We aim to develop the Interactive Maternal Group for Information and Emotional Support (IMAGINE) intervention, a facilitated social media group CBT intervention to prevent perinatal depression in youth in the United States, by adapting the Mothers and Babies (MB) course, an evidence-based in-person group CBT intervention. In this study, we report perspectives of youth and health care providers on perinatal youths' mental health needs and document how they informed IMAGINE design.

Methods: We conducted 21 semistructured in-depth individual interviews with 10 pregnant or postpartum youths aged 14-24 years and 6 health care workers. All interviews were recorded, transcribed, and analyzed using deductive and inductive approaches to characterize perceptions of challenges and facilitators of youth perinatal mental health. Using a human-centered design approach, stakeholder perspectives were incorporated into the IMAGINE design. We classified MB adaptations to develop IMAGINE according to the Framework for Modification and Adaptation, reporting the nature, timing, reason, and goal of the adaptations.

Results: Youth and health care workers described stigma associated with young pregnancy and parenting, social isolation, and lack of material resources as significant challenges to youth mental wellness. They identified nonjudgmental support, peer companionship, and access to step-by-step guidance as facilitators of youth mental wellness. They endorsed the use of a social media group to prevent perinatal depression and recommended that IMAGINE facilitate peer support, deliver content asynchronously to accommodate varied schedules, use a confidential platform, and facilitate the discussion of topics beyond the MB curriculum, such as navigating support resources or asking medical questions. IMAGINE was adapted from MB to accommodate stakeholder recommendations and facilitate the transition to web-based delivery. Content was tailored to be multimodal (text, images, and video), and the language was shortened and simplified. All content was designed for asynchronous engagement, and redundancy was added to accommodate intermittent access. The structure was loosened to allow the intervention facilitator to respond in real time to topics of interest for youth. A social media platform was selected that allows multiple conversation *channels* and conceals group member identity. All adaptations sought to preserve the fidelity of the MB core components.

Conclusions: Our findings highlight the effect of stigmatization of young pregnancy and social determinants of health on youth perinatal mental health. Stakeholders supported the use of a social media group to create a supportive community and improve access to evidence-based depression prevention. This study demonstrates how a validated intervention can be tailored to this unique group.

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KEYWORDS

depression; mental health; perinatal; pregnancy; postpartum; adolescent; youth; social media; group; mobile phone

Introduction

Background

Perinatal depression is defined as clinically significant depressive symptoms during pregnancy or up to 1 year postpartum. An estimated 13% of pregnant and postpartum women are affected by perinatal depression [1], with potentially significant effects on their psychological health, relationships with close family and friends, and the health of their children. Perinatal depression is associated with an elevated risk of preterm birth, insecure mother-infant attachment, and childhood emotional and behavioral problems [1-3]. Adolescents and young adults aged <25 years (youth) are at a higher risk of perinatal depression than older women (estimated prevalence 16-44% vs 10-20%) [4-7]. In 2017, an estimated 24.9% of births in the United States were to youth [8]. Although the frequency of adolescent pregnancy has declined over the last 25 years, marked racial and economic disparities persist, with significantly higher rates of pregnancy in youth of color than White youth [8]. These disparities are the result of intersecting inequities in access to financial resources, employment, education, medical care, and instrumental support, driven by structural racism and classism [9]. These forces mean that pregnant and postpartum youth experience multiple elevated stressors, compounded by their ongoing neurocognitive development.

Several interventions have been developed to prevent perinatal depression in adults. A recent US Preventive Services Task Force systematic review of intervention trials to prevent perinatal depression reported that counseling-based interventions were efficacious [10,11]. One of the counseling interventions identified by the report as supported by published studies is the Mothers and Babies (MB) course. Originally developed for low-income racial minority women in the United States, MB is based on cognitive behavioral therapy (CBT), a structured form of psychotherapy that focuses on identifying and modifying thought patterns and behaviors to interrupt their impact on feelings [12]. MB has been associated with a decline in depression incidence and depressive symptom severity in three randomized controlled trials and has been implemented at scale [13-17]. The course can be delivered in a group format, which cultivates mutual peer support, reduces stigma associated with mental health care, and is resource-efficient [13,18]. This feature also makes it ideally suited for use with youth, whose developmental stage is characterized by the growing influence of peer relationships and who may have especially limited social support [19-21]. Trials of MB have included youth participants, but no study has focused on evaluating its use exclusively in this age group.

Although in-person group counseling is a standard of care, it may be difficult for clients to access due to lack of transportation and child care, difficulty committing to a prespecified time to attend sessions, and experienced or internalized stigma of seeking mental health care [21,22]. Clinic-based care is often designed for the needs and expectations of privileged adult populations, so these barriers may be most acute among youth, whose neurocognitive development and societal position limit their engagement in clinic-based care [23]. In addition, the COVID-19 pandemic and consequent physical distancing protocols have created enormous disruptions in in-person mental health care, while disproportionately disrupting the economic stability, social connection, and mental health of women, children, and adolescents, particularly in low-income communities and communities of color [24].

Technological applications such as social media (interactive forms of web-based content and communication) provide an opportunity to overcome access barriers to in-person services [25,26]. Several internet-based CBT interventions have been developed and applied to perinatal depression, including electronic adaptation of the MB course, but most have not leveraged the benefits of group delivery, and none have targeted youth [26-34]. Social media offers an underexplored and accessible avenue through which to deliver group CBT to perinatal youth; as of 2018, 94% of those aged 13-17 years in the United States used social media and 95% had a smartphone [35].

We adapted the evidence-based MB course from a 6-session in-person group intervention to a 12-week social media group intervention tailored for youth aged <25 years. The resulting intervention, named the Interactive Maternal Group for Information and Emotional Support (IMAGINE), is being evaluated in an ongoing pilot study. Our adaptation process used a human-centered design approach [36], focusing on modifications to MB that were needed to (1) meet the unique mental health needs of perinatal youth and (2) deliver content through a digital delivery modality. The adaptation of evidence-based interventions, defined as thoughtful and deliberate alteration of their design or delivery to improve fit or effectiveness [37], is an important process that frequently accompanies *real-world* implementations. Some adaptations may enhance intervention effectiveness, whereas others may undermine it. Detailed documentation of adaptations is therefore crucial for interpreting data on intervention efficacy and effectiveness and understanding the core functions of evidence-based interventions. The Framework for Modification and Adaptation (FRAME) was developed as a structure for systematic reporting of modifications in terms of what was modified (context, content, or training), the nature of the modification, who made the modification, when in the process of implementation was the modification done, the reason and goal of the modification, and whether the modification was fidelity-consistent [37,38].

Objectives

In this paper, we aim to present findings from formative stakeholder interviews regarding perinatal youths' mental health challenges, facilitators, and design recommendations for a social media intervention to prevent perinatal depression. On the basis of these formative findings, we aim to describe the adaptations made to MB to develop IMAGINE, systematically reporting our modifications according to the FRAME.

Methods

Study Design

This paper documents the development of the IMAGINE intervention, a social media group CBT intervention tailored for perinatal youth. Two sources of formative data were analyzed: (1) in-depth interviews (IDIs) with perinatal youth and health care providers exploring youths' perinatal mental health experiences and their design recommendations for a social media intervention and (2) study memos documenting adaptations and refinements made to the MB course to target youth and be delivered by social media. Study memos were reflexively composed by the study team after both rounds of IDIs and intervention development was completed to document the team's own decisions.

Study Population and Participant Recruitment

Two rounds of IDIs were conducted between November 2019 and July 2020. The first included six IDIs with perinatal youth and six IDIs with health care providers who care for perinatal youth. The second round included IDIs with nine perinatal youths, five of whom were also participants in the first round. Youth participants were purposively recruited through in-person outreach at health care facilities and community events and through targeted advertisements on Instagram and Facebook in Washington State. In round 2, Instagram and Facebook advertisements were expanded throughout the United States. Health care providers throughout the United States were purposively recruited via email and phone through the professional networks of the study team.

Eligible youth were pregnant or ≤2 years postpartum, aged 14-24 years during pregnancy, had access to a smartphone, and spoke English. These criteria were selected to reflect the target population for the IMAGINE pilot study. Although perinatal depression is defined as occurring up to 1 year postpartum, youth who were up to 2 years postpartum were included to allow participants to reflect on the entire period of risk for perinatal depression. Eligible providers were aged ≥18 years and worked as nurses, physicians, social workers, or mental health care workers (HCWs) with perinatal youth.

Data Collection

The first round of IDIs was conducted either in-person in Seattle, Washington, or via phone, per participant preference. The second round occurred after the COVID-19 restrictions were instated, and all interviews were conducted by phone or videoconference. IDIs were conducted in English and included a demographic questionnaire, administered electronically using REDCap (Research Electronic Data Capture; Vanderbilt University), followed by a semistructured discussion guide exploring literature-based determinants of perinatal depression and elements of the MB intervention. All IDIs were audio recorded and transcribed.

Round 1 IDIs discussed expectations, challenges, and support during and after pregnancy, as well as the need for additional support. After outlining a hypothetical virtual group intervention, interviews explored different content areas of interest and social media platform functionality, content delivery, and considerations about coparticipants and facilitators. A rapid content analysis was performed to identify key themes after the first round of IDIs, and the results were used to inform design and social media platform selection for an IMAGINE prototype. The second round of IDIs explored the impact of COVID-19 on mental well-being and included a live, interactive demonstration of the IMAGINE prototype presented by screensharing over videoconference to elicit detailed participant feedback. Rapid analysis of round 2 IDIs was used to refine the IMAGINE content.

The study team prepared memos documenting the team's design discussions and decisions during the adaptation of the MB course to develop IMAGINE. Publicly available MB materials were used as the starting point, with some material drawn from an online version, e-MB [29,39]. Adaptation occurred through a series of collaborative meetings, including the study principal investigator (KR), research assistant (AG), intervention facilitator (KD), and community member advisor (MJB). Additional input was sought from other coauthors, including a researcher who led previous MB trials (DT).

Data Analysis

We conducted a descriptive content analysis of all 21 IDIs, focusing on characterizing perinatal youth's mental health challenges, facilitators, and the potential role of a social media intervention. Authors AL, AG, and KR generated an initial codebook for IDIs that included deductive codes based on the literature and inductive codes based on a review of a subset of transcripts. Study team memos were also coded using a second codebook based on the domains of the FRAME to categorize the decisions made and reasoning given by the research team [37]. Following the initial development of both codebooks, a consensus coding process was carried out by AL, AG, and KR and modifications were made to each codebook and code definition until all parties agreed. Following consensus coding, all transcripts and study team memos were coded independently by AL or AG and reviewed by another team member. Disagreements were resolved through group discussions with KR. All coding was conducted using Dedoose (version 7.0.23, SocioCultural Research Consultants, LLC). Coded excerpts were organized and synthesized into thematic memos and discussed by AG, AL, and KR.

Ethical Considerations

The study was reviewed and approved by the institutional review board of the University of Washington. All participants provided informed consent. Waivers were obtained for written documentation of informed consent and parental consent for adolescents aged <18 years.

Results

Characteristics of Study Participants

The sociodemographic characteristics of the youth and HCW participants in the formative interviews are summarized in Table 1. A total of 15 interviews were conducted with 10 youths and 6 interviews were conducted with HCWs. Youths interviewed in round 1 resided in Washington State and had a median age of 22 years (IQR 21-23). All round 1 participants identified as people of color. In total, of the 6 participants, 2 (33%) were currently pregnant, and the rest had children of a median age of 5 months. Most (5/6, 83%) had some experience with mental health counseling. Youths interviewed in round 2 resided in Washington, Michigan, and Texas and had a median age of 21 years (IQR 20-23). All round 2 participants identified as people of color. In total, of the 9 participants, 2 (22%) were currently pregnant, and the rest had children of a median age of 7 months. Most (7/9, 78%) had some experience with mental health counseling. HCWs were mostly (4/6, 66%) physicians, 1 nurse, and 1 physician’s assistant, working in Washington, Colorado, and Rhode Island. They had been working for a median of 6 years in their profession (IQR 2-27) and saw a range of <10 to >100 perinatal youth participants annually.

Table 1. Participant characteristics.

Characteristic	Values
Youth round 1	
Age (years; n=6), median (IQR)	22 (21-23)
Race[a] (n=6), n (%)	
African American	2 (33.3)
American Indian or Alaska Native	1 (16.7)
Asian	1 (16.7)
Latinx	3 (50)
Native Hawaiian or Pacific Islander	0 (0)
White	1 (16.7)
Other	2 (33.3)
Primiparous (n=6), n (%)	1 (16.7)
Currently pregnant (n=6), n (%)	2 (33.3)
Age of youngest child (months; n=5), median (IQR)	5 (0-5)
History of depression diagnosis (n=5), n (%)	1 (20)
History of mental health counseling (n=6), n (%)	5 (83.3)
State (n=6), n (%)	
Washington	6 (100)
Youth round 2[b]	
Age (years; n=9), median (IQR)	21 (20-23)
Race[a] (n=9), n (%)	
African American	2 (22.2)
American Indian or Alaska Native	0 (0)
Asian	2 (22.2)
Latinx	5 (55.6)
Native Hawaiian or Pacific Islander	0 (0)
White	1 (11.1)
Other	1 (11.1)
Primiparous (n=9), n (%)	1 (11.1)
Currently pregnant (n=9), n (%)	2 (22.2)
Age of youngest child (months; n=8), median (IQR)	7 (3-17)
History of depression diagnosis (n=8), n (%)	6 (75)
History of mental health counseling (n=9), n (%)	7 (77.8)
State (n=9), n (%)	
Washington	7 (77.8)
Michigan	1 (11.1)
Texas	1 (11.1)
Health care worker	
Age (years; n=6), median (IQR)	42 (37-58)
Profession (n=6), n (%)	
Nurse	1 (16.7)
Physician	4 (66.7)

Characteristic	Values
Physician’s assistant	1 (16.7)
Years in profession (n=6), median (IQR)	6 (2-27)
Pregnant patients aged <25 years seen in last year (n=6), n (%)	
<10	1 (11.1)
10-50	2 (33.3)
51-100	0 (0)
>100	3 (50)
State (n=6), n (%)	
Washington	2 (33.3)
Colorado	3 (50)
Rhode Island	1 (11.1)

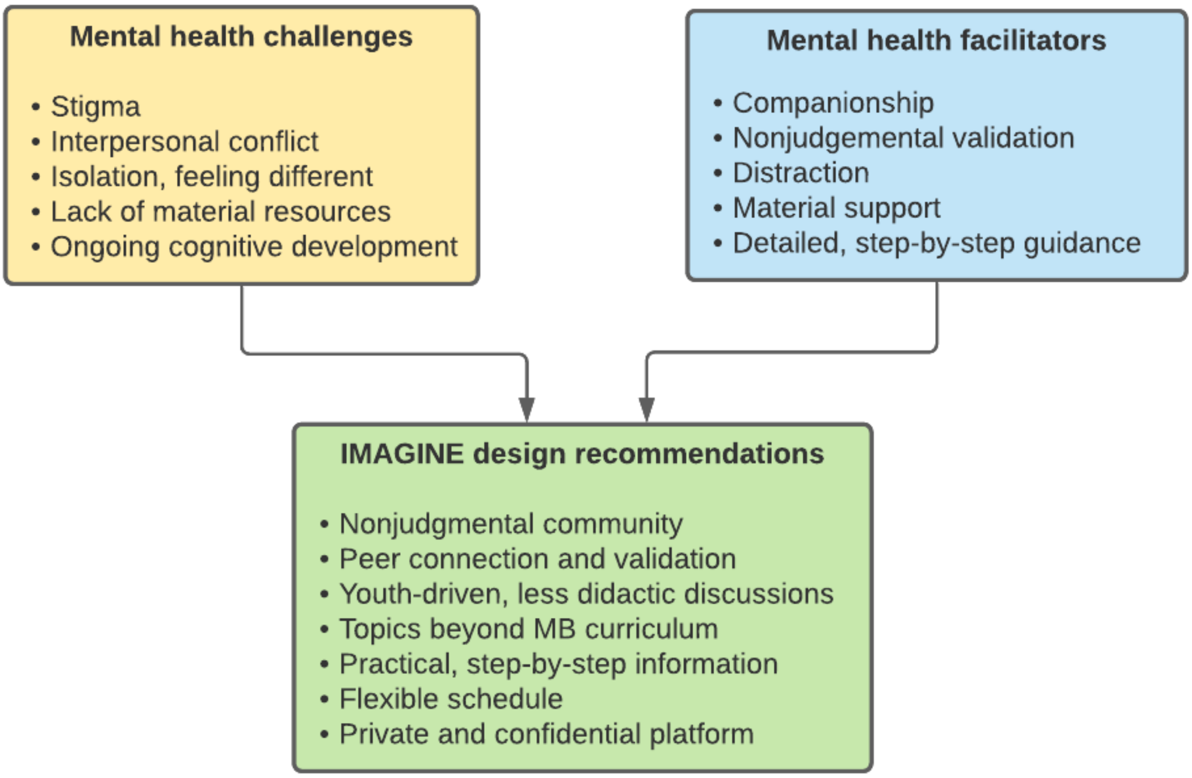
[a] Race categories are not mutually exclusive.

[b] Five round 1 participants were also interviewed in round 2.

Challenges Contributing to Youth Perinatal Depression: Stigma, Isolation, and Lack of Material Resources

Figure 1 summarizes the factors identified by the youth and HCWs as challenges to youths’ mental wellness, as well as the factors participants described as enabling youth mental wellness and the resulting IMAGINE design suggestions they offered (described in detail in the sections below on facilitators and intervention adaptation). Overall, the youth and HCWs highlighted similar themes.

Figure 1. Summary of youth and health care worker interview themes regarding challenges to and facilitators of youth perinatal mental health and Interactive Maternal Group for Information and Emotional Support design recommendations. MB: Mothers and Babies, IMAGINE: Interactive Maternal Group for Information and Emotional Support.



Participants frequently identified stigma associated with young pregnancy and parenthood as a significant challenge to their mental health. They described family, friends, and religious communities as sources of judgment and harsh criticism in pregnancy and the postpartum period. The youth described losing material and emotional support and, in some cases, losing relationships entirely as a result of their pregnancy, leading to feelings of loneliness, humiliation, and self-doubt:

> *I had to actually change schools because when people started finding out about my pregnancy, they began to say some, let's just say, very disparaging things. Like "you shouldn't have kids. You'll be a terrible mother. I feel bad for that baby. She deserves better." And just a whole bunch of very mean and negative things that made me very depressed...Listening to one of your closest friends say that you shouldn't have kids or that you're gonna make a terrible mother is a very hard thing to hear because you need support at that time.* [Youth participant 1008]

In relationships that continued through pregnancy and childbirth, the youth and HCWs highlighted considerable stress associated with negotiating new relationship roles and dynamics. Interpersonal conflicts were frequently mentioned, with the youth's family of origin, partners, coparents, friends at school, and friends on social media. In particular, participants reported their parenting decisions being judged and questioned, which led to feelings of guilt and internal conflict. For example, one participant felt immense relief after finally securing a job and starting to pay bills after her delivery but struggled to balance this with the cultural stigma she felt from her family, who believed she should be caring for her baby rather than working:

> *My parents are from Mexico and there's a lot of...stigma, like, being there with your...child the whole time and not taking them in daycare. [My family said that] I started work too soon...I'm not taking care of her.* [Youth participant 1004]

Similarly, negative interactions with HCWs in which the youth felt disregarded were reported to contribute to feelings of shame and postpartum depression. One participant described a traumatic interaction with a physician during delivery, impacting her mental health for months afterward:

> *I was 19? 20? when I gave birth and so I wasn't really sure how to advocate for myself and what I wanted from people, especially in the delivery room. I had a pretty uncomfortable experience with the male provider in charge of my labor...and then I ended up having an emergency C-section. And then...the first four months I was really unable to connect with my kiddo just because of how traumatic the birth was, and getting over C-section, and being young and confused...I felt something was wrong with me because I couldn't connect with my child and feel that automatic love and connection.* [Youth participant 1006]

Many participants felt that they would have been more respected if they were older and commented on intersectionality with their race and ethnicity. One participant reported that her assessment of her due date and last menstrual period was ignored:

> *I don't know why, maybe [because of] my ethnicity. Maybe, I don't know, my age.* [Youth participant 1004]

HCW participants themselves also identified providers as sources of stigma and emotional distress:

> *There is a lot of stigma associated with being a pregnant youth or young parent. Stigma from peers, stigma from family, stigma from community, and stigma from health care providers. This has major implication for mental health.* [HCW participant 4001]

Youth participants commonly reported feeling *different*, both from age-mates, who typically did not have children, and from older mothers, who did not experience the same level of stigma and appeared to have more resources. This difficulty in connecting with others contributed to the isolation and lack of emotional support:

> *[B]eing a young mom there is a lot of, not necessarily shame, but a little bit of stigma and difficulty in my ability to interact with people my age because...at 19, people aren't usually pregnant or raising children or worried about bills and household and all. But for me...I always felt like, OK, I spend this much time out of the house and away from my kid, and then I have to work on top of that. And then I go home and I do homework, so [my daughter] is not really getting the attention that she needs from me, so I can't justify going out with friends. So I haven't done that in years.* [Youth participant 1006]

Participants argued that these relational and emotional challenges were heightened by the youths' lack of material resources. Several youths reported that the need to earn money and lack of childcare support meant they had very little time to attend to their emotional or physical needs, such as eating or sleeping, and that these needs were secondary to caring for their child. HCWs and youth also highlighted that these challenges were exacerbated by their *growing up early* and navigating a transition to parenthood while still developing their own cognition and sense of self:

> *I was so young when I had my first daughter, I was 14...I'm just now starting to talk like I'm a teen again...just now starting to figure out what I want...how I actually want to dress...instead of just doing what I can because I have to focus on my kids first.* [Youth participant 1005]

> *Being responsible for another human being on an ongoing basis all the time: that's a big change. Negotiating the place in their family...whereas before they're a teenager in the family and now suddenly they're the mother of a child and teenager in the family, that's a big problem. And then there's financial issues. Actually taking care of the child and getting finances together. And then there's social challenges, learning how to interact with their peers and find their own place just as an individual.* [HCW participant 4002]

In the youth IDIs conducted during the COVID-19 pandemic, participants discussed COVID-19 and related restrictions as additional challenges, for example, by hampering previous methods of stress relief, undermining therapeutic relationships with HCWs, and increasing anxiety.

Facilitators of Perinatal Mental Wellness in Youth: Nonjudgement, Material Support, and Distraction

Figure 1 summarizes the themes that the youth and HCWs identified as supportive of youth perinatal mental wellness. The youth consistently spoke of nonjudgmental support and companionship from others with shared experience as a crucial facilitator of their mental wellness. Three youth respondents had attended in-person support groups for young mothers and highlighted the friendships formed through these groups as especially important. In these interactions, they felt affirmed and could bond over shared experiences with other group members, free of stigma:

> *I would say [the only non-judgmental adults] that are in my life [are] my mommy groups, just because, you know, they're going through what I'm going through, they went through something worse of what I went through.* [Youth participant 1002]

Furthermore, the youth identified that their peers' shared experiences rendered their advice more credible and relevant than advice from health care providers:

> *Some doctors, they don't go through...the things they see people go through...Doctors could be like 30 and have a kid, and [the people in my support group] were like 19 or 20 that had to deal with negativity...[They] would just basically tell me how they dealt with depression and how they dealt with insecurity and stuff like that. So I just went off of what they did.* [Youth participant 1010]

Similarly, some HCWs commented that although many in-person groups centered around perinatal care, peer-to-peer connections were more difficult to find and a crucial source of positive reinforcement that mothers could call upon throughout pregnancy and afterward. When prompted, many youths shared that they found supportive *online friends* through informal social media groups or perinatal support mobile apps, who provided honest advice, validation, and companionship. One postpartum participant reported that the act of helping others by posting in an online group lifted her spirits and supported her own mental wellness.

Youth participants argued that access to material support and childcare were important facilitators of mental wellness. Several reported that they accessed assistance programs for new parents, and some had a health care provider with whom they felt very close and who provided support and information. However, some participants reported that although they knew that support was available, they did not always feel confident in navigating the details. This highlighted detailed, concrete guidance as an often-unmet need:

> *[I wish] someone would inform me about events, activities...WIC tells me about birthing classes, like "you should look into that". But I'm like, "Okay, where do I start? Who do I ask?" That information is given, but not someone that can help you with specifics.* [Youth participant 1003]

Several youths, especially those who were pregnant at the interview, named a variety of distractions and stress reduction methods they used to support their mental wellness, including listening to music, exercise, digital entertainment, or going to a salon. Several postpartum participants identified their children as a source of motivation and support: one participant stated that caring for her baby kept her present and focused and another highlighted that her children gave her a renewed sense of purpose and drive to accomplish goals.

IMAGINE Design Recommendations to Support Youth Mental Wellness

To emulate the facilitators identified earlier, the youth recommended that a virtual program such as IMAGINE provides a space to connect with peers and discuss members' specific concerns and circumstances. They suggested that IMAGINE addresses youth-driven topics beyond the MB depression prevention curriculum:

> *The one thing that most pregnant people who are by themselves need is just somebody to listen to them. Because it's very easy to feel overwhelmed and unheard of when people around you are speaking such negative comments. So if [I] can just...have this group that I go to and I can talk about what I feel. I can ask as many questions as I want, and they will give me positive feedback and they will let me know whatever information I need so I can make myself a better person. That would have been very helpful.* [Youth participant 1005]

Some youths described positive experiences with online forums where multiple conversations about different topics could take place in parallel *channels*:

> *Let's say that I had a bad day, for instance. And I just kinda wanted to get some positive vibes from people who I was engaging with over the last few weeks...It would be really cool to have, like, a vent/get positive signs type chat room.* [Youth participant 1012]

HCWs similarly suggested that the amount of structured content could be reduced to create more flexibility and space for youth-driven discussions:

> *What resonates with [youth] are human interactions where they can tell their story, where they feel like other people care for them and where they learn in a more subtle fashion than somebody sort of didactically telling them what to do.* [HCW participant 4002]

Consistent with the material challenges listed earlier, HCWs and youths described difficulties in attending appointments at fixed times due to busy and unpredictable schedules. Participants were therefore enthusiastic about asynchronous content or discussions that could be accessed and caught up on whenever they had a break, such as when their child was asleep.

The privacy of a social media group was discussed by many participants. HCWs reported more concern than youth participants and suggested that clear norms regarding confidentiality be established and continually reinforced by the group facilitator. When prompted, youth participants agreed that social media groups could breed hostility and confidentiality breaches but said they would feel comfortable engaging if options were provided to conceal one's identity, for example, making photos or video-based contributions optional:

> *Confidentiality would depend on the rules of the game and everyone participating, understanding those rules and standing by them...Confidentiality issues are a little bit trickier on the online platform and what your securities are.* [HCW participant 4005]

> *You know how on iPhones you can, like, screen record? Not saying that this is going to happen at all. But someone who is a part of [the group] can screen record and put someone's personal business out.* [Youth participant 1001]

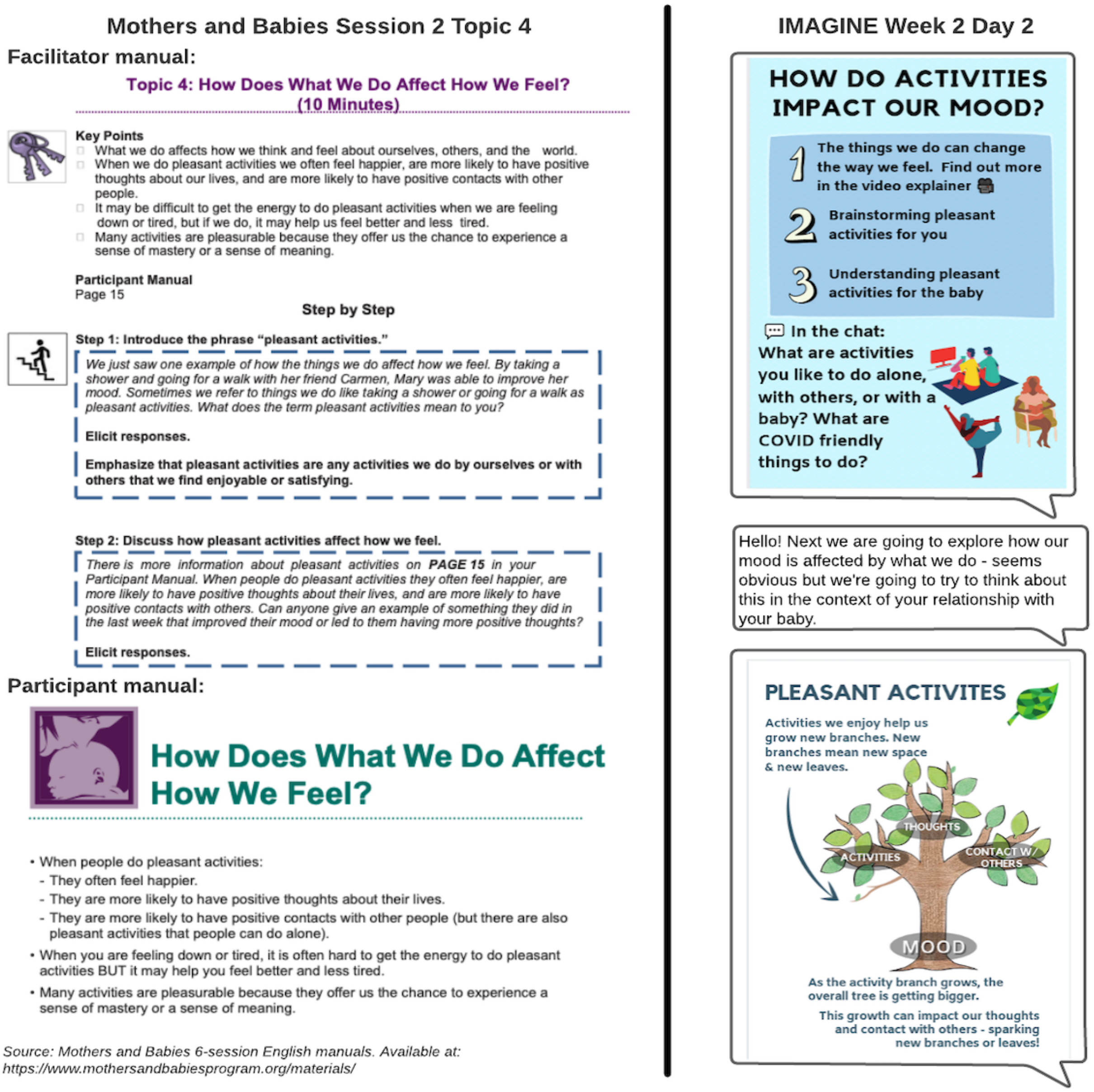
Adaptation of the MB Course to Create the IMAGINE Intervention

The abovementioned stakeholder input was used to inform the adaptation of MB course materials by the study team and documented in the study team memos. In the following section, we describe the final IMAGINE intervention and outline the adaptations made in developing it.

Overview of the IMAGINE Intervention

Figure 2 illustrates the example content in the MB manual compared with the corresponding messages in IMAGINE. The IMAGINE intervention consists of groups of 6-10 perinatal youths on the messaging platform, Slack, facilitated by a study social worker. The group facilitator delivers adapted MB course content through daily communication, including text messages, informational graphics, and short prerecorded *selfie* videos of the facilitator. Facilitator communication is intended to promote group discussions and personal reflections. Once per week, the facilitator holds a group video call, in which participants are encouraged but not required to attend. All content can be engaged asynchronously, and the material discussed in the video call is also summarized in a message. The Slack group contains five *channels* for different communications. The *#daily-content* channel contains the facilitator's daily MB content and resulting participant discussions, as well as summaries of weekly video calls. The *#reference-materials* channel contains visual summaries shared in the *#daily-content* channel as the intervention proceeds, to act as reference materials for future review. The *#community-conversations* channel allows participants to discuss topics of their choosing that are unrelated to MB content. The *#ask-an-expert* channel is intended for participants to submit questions when they want detailed information or guidance from someone with specialized training, such a midwife, therapist, or social worker. The facilitator is responsible for working with a multidisciplinary team to address these questions. Finally, the *#personal-project* channel is a private channel to which only individual participants and the facilitator have access, in which the participant answers reflection questions three times per week regarding their mood and CBT activities. In addition, participants are able to send a private direct message to other participants and to the facilitator. Participants can also choose how they are identified in the group: Slack accounts are identified by email address, and there is no requirement to create a username that reflects the participant's name.

Figure 2. An example of Mothers and Babies and adapted Interactive Maternal Group for Information and Emotional Support content.



Mothers and Babies Session 2 Topic 4

Facilitator manual:

Topic 4: How Does What We Do Affect How We Feel? (10 Minutes)

Key Points

- ☐ What we do affects how we think and feel about ourselves, others, and the world.
- ☐ When we do pleasant activities we often feel happier, are more likely to have positive thoughts about our lives, and are more likely to have positive contacts with other people.
- ☐ It may be difficult to get the energy to do pleasant activities when we are feeling down or tired, but if we do, it may help us feel better and less tired.
- ☐ Many activities are pleasurable because they offer us the chance to experience a sense of mastery or a sense of meaning.

Participant Manual
Page 15

Step by Step

Step 1: Introduce the phrase "pleasant activities."

We just saw one example of how the things we do affect how we feel. By taking a shower and going for a walk with her friend Carmen, Mary was able to improve her mood. Sometimes we refer to things we do like taking a shower or going for a walk as pleasant activities. What does the term pleasant activities mean to you?

Elicit responses.

Emphasize that pleasant activities are any activities we do by ourselves or with others that we find enjoyable or satisfying.

Step 2: Discuss how pleasant activities affect how we feel.

There is more information about pleasant activities on ***PAGE 15*** *in your Participant Manual. When people do pleasant activities they often feel happier, are more likely to have positive thoughts about their lives, and are more likely to have positive contacts with others. Can anyone give an example of something they did in the last week that improved their mood or led to them having more positive thoughts?*

Elicit responses.

Participant manual:

How Does What We Do Affect How We Feel?

- When people do pleasant activities:
  - They often feel happier.
  - They are more likely to have positive thoughts about their lives.
  - They are more likely to have positive contacts with other people (but there are also pleasant activities that people can do alone).
- When you are feeling down or tired, it is often hard to get the energy to do pleasant activities BUT it may help you feel better and less tired.
- Many activities are pleasurable because they offer us the chance to experience a sense of mastery or a sense of meaning.

Source: Mothers and Babies 6-session English manuals. Available at: https://www.mothersandbabiesprogram.org/materials/

IMAGINE Week 2 Day 2

HOW DO ACTIVITIES IMPACT OUR MOOD?

1 The things we do can change the way we feel. Find out more in the video explainer

2 Brainstorming pleasant activities for you

3 Understanding pleasant activities for the baby

In the chat:
What are activities you like to do alone, with others, or with a baby? What are COVID friendly things to do?

Hello! Next we are going to explore how our mood is affected by what we do - seems obvious but we're going to try to think about this in the context of your relationship with your baby.

PLEASANT ACTIVITES

Activities we enjoy help us grow new branches. New branches mean new space & new leaves.

As the activity branch grows, the overall tree is getting bigger.

This growth can impact our thoughts and contact with others - sparking new branches or leaves!

Summary of Adaptations

Table 2 summarizes the major adaptations made to MB in producing IMAGINE, categorized according to the elements outlined in the FRAME. The goal of all adaptations was not to revise core intervention domains hypothesized to lead to mental health outcomes but rather to modify components of the intervention's *adaptable periphery* [40]. All adaptations were therefore intended to be fidelity-consistent.

Table 2. Summary of adaptations made to the Mothers and Babies course in developing Interactive Maternal Group for Information and Emotional Support, classified according to the Framework for Modification and Adaptation.

Adaptation	Classification	Reasons	Goal	Timing	Participant recommendation addressed
Asynchronous, virtual delivery through the Slack messaging platform	• *Context*[a]: format	• *Recipient*: increased barriers to in-person and synchronous care among young people • *Recipient*: limited access to resources necessitates free, phone-compatible platform • *Recipient*: Slack compatible with functionality preferences identified in formative interviews	• Improve fit with recipients • Increase reach	• A priori conceptualization • After formative interviews	• Flexible schedule • Confidential platform • Topics beyond MB[b] curriculum
Multimodal communication (graphics, text messages, recap videos, and optional video calls); redundant content	• *Context*: format • *Content*: tailoring • *Content*: repeating	• *Recipient*: multimedia content appeals to youth • *Recipient*: limited time and access to technology mean intermittent engagement and necessitate redundancy • *Setting*: virtual platform necessitates varied content to avoid participant overwhelm • *Provider*: metaphors and exercises used in facilitator's prior work with youth provided alternative materials	• Improve fit with recipients • Improve effectiveness	• After formative interviews	• Flexible schedule • Youth-driven, less didactic discussions
Shorter, simplified language	• *Content*: shortening	• *Recipient*: short, simple text better understood by youth • *Setting*: visual delivery necessitates many short messages rather than fewer longer messages	• Improve effectiveness	• A priori conceptualization	—[c]
Conversion of six 2-hour sessions to 10-12 weeks	• *Content*: lengthening, spreading	• *Setting*: visual delivery necessitates many short messages rather than fewer longer messages	• Improve fit with recipients • Improve feasibility	• A priori conceptualization	—

Adaptation	Classification	Reasons	Goal	Timing	Participant recommendation addressed
Increased emphasis on encouraging peer participation; addition of *channel* for unstructured peer discussions and practical advice	• *Content*: tailoring • *Content*: adding	• *Setting*: virtual platform increases challenge of creating connection • *Recipient*: developmental stage and stigma make peer support especially powerful and didactic *school-like* content especially unappealing	• Improve effectiveness	• After formative interviews	• Peer connection and validation • Topics beyond MB curriculum • Practical, step-by-step information
Breaks and pauses in content for discussion; adaptable timing based on participant feedback	• *Context*: format • *Content*: loosening structure	• *Setting*: asynchronous platform increases risk of losing participant engagement and limits enforcement of regular participation • *Recipient*: youths' experiences of dismissal and stigma drive desire for youth-driven content	• Improve fit with recipients • Improve effectiveness	• After formative interviews	• Flexible schedule • Youth-driven, less didactic discussions
Emphasis on normalizing challenges; ensuring exercises not viewed as judgmental	• *Content*: tailoring	• *Recipient*: youths' experiences of dismissal and stigma drive need for validation and normalization	• Improve fit with recipients • Improve effectiveness	• After formative interviews	• Peer connection and validation
Incorporation of COVID-19 as a stressor and modifier of activities	• *Content*: adding	• *Sociopolitical*: COVID-19 is a new stressor and modifier of resilience strategies	• Improve fit with recipients	• After formative interviews	• Practical, step-by-step information
Removing assigned educational video and role-playing	• *Content*: skipping	• *Setting*: asynchronous platform made role-playing impractical • *Recipient*: 15-minute educational video viewed as unappealing to youth	• Improve fit with recipients • Improve feasibility	• After formative interviews	• Youth-driven, less didactic discussions
Mood assessment three times per week rather than daily	• *Content*: skipping	• *Setting*: need for reduced message volume on virtual platform	• Improve fit with recipients • Improve feasibility	• After formative interviews	• Flexible schedule
Participants are located all over the United States	• *Context*: setting	• *Setting*: virtual delivery facilitates remote recruitment • *Setting*: study timeline requires parallel recruitment in multiple sites	• Improve feasibility	• After formative interviews	—

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[a] Italics indicate Framework for Modification and Adaptation elements.

[b] MB: Mothers and Babies.

[c] The adaptation did not address a participant recommendation.

The most significant adaptation, which motivated many other adaptations, was modifying the context from in-person to virtual delivery. This change was a central premise of the IMAGINE study, driven by the goal of increasing reach and improving fit with youth recipients who are not well served by in-person or synchronous care. Formative interviews confirmed that attending meetings at fixed times was challenging for many youths, so all content was designed to be accessed asynchronously. The Slack platform was selected for intervention delivery based on its ability to fulfill desired functionalities discussed in formative interviews, specifically having multiple parallel conversation *channels*, individual messaging with the facilitator, and nonidentifiability. In the second round of formative interviews, youth participants universally reported that the platform was acceptable.

The use of virtual, asynchronous delivery necessitated additional adaptations to the context and content of the intervention. On the basis of youth and HCW recommendations that the intervention be youth-driven and less didactic, the study team determined that delivering all MB content through text messages would create a large message volume that would quickly lead to recipient disengagement. In order to improve fit with recipients and therefore improve effectiveness, MB content was summarized into short text messages using simplified language and spread from six 2-hour sessions into multiple daily messages over 10-12 weeks. To accommodate different engagement styles, multimodal visual content was developed, including graphical summaries of complex concepts, 1- to 3-minute informal videos of the facilitator summarizing materials, and optional weekly synchronous video calls. Materials deliberately included some redundancy so that recipients who did not access the intervention daily or were unable to attend synchronous video calls could still remain up to date. An additional reason for developing visual and simplified content was that youth recipients' neurocognitive and educational stages made short multimedia content especially appropriate.

In response to recommendations for a flexible intervention and youth-driven discussion (Figure 1), a looser, more adaptable structure was used, with intentional breaks in content for discussion, as well as active solicitation of participant feedback during the intervention. In view of youths' experiences of stigma and requests for nonjudgmental and affirming support, examples were examined carefully and tailored to normalize mental health challenges and avoid content that could be perceived as judgmental. Several additions were made to content to improve fit with the youth's stated preferences, including having multiple parallel *channels* where participants could have an unstructured conversation about topics not included in the MB curriculum and receive practical step-by-step guidance on their own questions. Structured, planned facilitator content was minimal in these channels; the goal was to provide a forum in which participants could ask questions of each other or the facilitator and share advice with each other. COVID-19 was additionally incorporated throughout the content to acknowledge its impact as a stressor and barrier to certain pleasant activities or contact with others. To improve feasibility online and reduce didactic content, some activities, including an educational video and role-plays, were removed, and daily mood checks were reduced in frequency to three times per week. Finally, for reasons of feasibility, the pilot study recruits participants throughout the United States, and youth from multiple locations will be in the same virtual group.

Discussion

Principal Findings

In this manuscript, we presented the perspectives of youths and health care providers in the United States on perinatal youths' mental health challenges, resources, and design recommendations for a social media intervention. We also reported how we incorporated these perspectives and recommendations into the development of IMAGINE by adapting the MB course for virtual delivery, tailored for youth aged <25 years.

We found that the youth and HCWs identified stigma, isolation, and lack of material resources as significant challenges to their mental wellness. Stigma associated with young pregnancy and parenting was described as leading to interpersonal conflict and a lack of community support, fueling feelings of guilt and shame. Poverty and lack of time for self-care compounded these challenges, and COVID-19 presented a new stressor and barrier to resilience activities.

The youth and HCWs also identified a number of facilitators of perinatal mental wellness and highlighted ways to augment these through IMAGINE. Relational factors were identified as supportive of perinatal mental wellness, with validation, companionship, and peer support highlighted as critical means by which a virtual group could counteract the stigmatization and isolation many reported as challenges. Practical support, such as access to information and step-by-step guidance, was also identified as a desired function that could be delivered through a virtual communication platform.

The recommendations made in our formative interviews led to several adaptations to the content and context of MB to develop IMAGINE. The goals of the adaptations were to improve fit with recipients, improve effectiveness, increase reach, and improve feasibility. All adaptations were fidelity-consistent, based on consultation with a developer of the MB course. Content adaptations were mostly tailoring content and loosening structure, with a few additions and reductions in frequency. The reasons for the adaptations were motivated mostly by recipient characteristics and recommendations shared in formative work, such as elevated barriers to synchronous care, limited access to resources, stigmatization, and developmental appropriateness of written versus visual material. Many adaptations have been made to accommodate virtual delivery.

Comparison With Prior Work

Qualitative accounts of perinatal youths' own perspectives on contributors to their mental wellness are critical to inform responsive and effective care. Findings from our formative interviews add to the literature describing perinatal youth experiences [41,42]. Consistent with our findings of challenges and facilitators of perinatal mental wellness and the interplay between them, a recent systematic review and meta-ethnography reported themes at the individual, relational, societal, and economic levels shaped youths' mental well-being [41]. Collectively, these findings highlight the impact of the stigmatization of young pregnancy and the importance of addressing interpersonal relationships and social determinants of health to improve youth perinatal mental health [43,44].

In addition to providing insights into perinatal youths' experiences, our study reports recommendations to inform the development of a social media CBT intervention. Several studies have tested internet or mobile app delivery of individual-level CBT for perinatal depression and found promising results [26,27,29-34]. However, only one virtual intervention was designed for delivery in a group format [30,31], and to our knowledge, none have focused specifically on perinatal youth. Our study therefore provides novel data to inform the design of social media interventions for perinatal youth mental health. Two previous interventions have adapted the MB course for virtual delivery. Barrera et al [29] adapted the program as a self-guided individual internet program that included videos, written materials, and visual summaries. Consistent with our findings, the intervention of Barrera et al [45] recommended simplification of content, detailed instructions, and graphical representations. Sawyer et al [30,31] also used the MB content as part of a mobile app. However, the approach used to adapt the MB curriculum for virtual delivery in this intervention has not been reported. Our use of formative interviews to drive a human-centered design process provided unexpected design recommendations, such as the use of a platform that allowed multiple parallel conversations, flexibility in timing and medium of communication, and provision of practical step-by-step information.

The process of adaptation is increasingly recognized as an important determinant of the effectiveness of evidence-based interventions, with implementers often weighing the importance of maintaining intervention fidelity against the need to adapt delivery for a specific context. Our structured reporting of adaptations according to the FRAME contributes to a growing body of literature that systematically reports adaptation processes [46,47]. To our knowledge, this study is the first to apply this approach to the virtual adaptation of an in-person intervention and to the adaptation of an intervention by a research team *before* its implementation. This approach can be used by others planning the adaptation of an evidence-based intervention to ensure that modifications are well-justified and provide documentation to inform the interpretation of effectiveness data.

Limitations

Our findings should be interpreted in light of the limitations of the study. First, our study population was recruited through convenience sampling, and although participants from across the United States were included, our sample size was small and Washington State was overrepresented. In addition, we recruited several youth participants through health care facilities and community programs, which may have preferentially captured the perspectives of youth who had relatively high engagement in existing services, which may explain the high proportion (approximately 80%) of youth participants who had experience with mental health counseling. Our evaluation of the intervention adaptation process was reflexive. We assessed our own changes, so it is possible that we omitted some changes that would have been noted by an external reviewer or misclassified our motivation for making them. Finally, when making adaptations, we sought guidance from one of the developers of the MB course in an effort to preserve fidelity. However, data on which elements of the course are core for efficacy are limited, and we have not conducted a formal assessment of fidelity [48]. The impact of our adaptations on intervention efficacy will need to be empirically tested as part of IMAGINE's evaluation.

Conclusions

In conclusion, our study provides an in-depth assessment of the mental health needs and assets of perinatal youth and systematic documentation of adaptation of the MB course for digital delivery in response to youth's context and recommendations. Our study highlights the potential of social media group interventions to support perinatal youth mental wellness and provides an example of how existing intervention materials can be tailored to this unique group.

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Authors' Contributions

KR designed the study, conceptualized the manuscript, guided the analysis, supported manuscript writing, and obtained funding. AG, AL, and KR conducted the data analyses. AG, KD, MJB, and HH contributed to the data collection. All authors contributed to the development of the intervention and reviewed and approved the manuscript for submission.

Conflicts of Interest

None declared.

References

1. Gavin NI, Gaynes BN, Lohr KN, Meltzer-Brody S, Gartlehner G, Swinson T. Perinatal depression: a systematic review of prevalence and incidence. Obstet Gynecol 2005 Nov;106(5 Pt 1):1071-1083. [doi: 10.1097/01.AOG.0000183597.31630.db] [Medline: 16260528]
2. Stein A, Pearson RM, Goodman SH, Rapa E, Rahman A, McCallum M, et al. Effects of perinatal mental disorders on the fetus and child. Lancet 2014 Nov 15;384(9956):1800-1819. [doi: 10.1016/S0140-6736(14)61277-0] [Medline: 25455250]
3. Slomian J, Honvo G, Emonts P, Reginster J, Bruyère O. Consequences of maternal postpartum depression: a systematic review of maternal and infant outcomes. Womens Health 2019;15:1745506519844044 [FREE Full text] [doi: 10.1177/1745506519844044] [Medline: 31035856]
4. Recto P, Champion JD. Psychosocial risk factors for perinatal depression among female adolescents: a systematic review. Issues Ment Health Nurs 2017 Aug;38(8):633-642. [doi: 10.1080/01612840.2017.1330908] [Medline: 28650677]
5. Dinwiddie KJ, Schillerstrom TL, Schillerstrom JE. Postpartum depression in adolescent mothers. J Psychosom Obstet Gynaecol 2018 Sep;39(3):168-175. [doi: 10.1080/0167482X.2017.1334051] [Medline: 28574297]
6. Reid V, Meadows-Oliver M. Postpartum depression in adolescent mothers: an integrative review of the literature. J Pediatr Health Care 2007;21(5):289-298. [doi: 10.1016/j.pedhc.2006.05.010] [Medline: 17825726]
7. Siegel RS, Brandon AR. Adolescents, pregnancy, and mental health. J Pediatr Adolesc Gynecol 2014 Jun;27(3):138-150. [doi: 10.1016/j.jpag.2013.09.008] [Medline: 24559618]
8. Martin JA, Hamilton BE, Osterman MJ, Driscoll AK, Drake P. Vital Statistics Online Data Portal. Centers for Disease Control and Prevention. 2017. URL: https://www.cdc.gov/nchs/data_access/Vitalstatsonline.htm [accessed 2019-06-20]
9. Brindis CD, Decker MJ, Gutmann-Gonzalez A, Berglas NF. Perspectives on adolescent pregnancy prevention strategies in the united states: looking back, looking forward. Adolesc Health Med Ther 2020;11:135-145 [FREE Full text] [doi: 10.2147/AHMT.S219949] [Medline: 33117030]
10. US Preventive Services Task Force, Curry SJ, Krist AH, Owens DK, Barry MJ, Caughey AB, et al. Interventions to prevent perinatal depression: US preventive services task force recommendation statement. J Am Med Assoc 2019 Feb 12;321(6):580-587. [doi: 10.1001/jama.2019.0007] [Medline: 30747971]
11. O'Connor E, Senger C, Henninger M, Coppola E, Gaynes BN. Interventions to prevent perinatal depression: evidence report and systematic review for the US preventive services task force. J Am Med Assoc 2019 Feb 12;321(6):588-601. [doi: 10.1001/jama.2018.20865] [Medline: 30747970]
12. Butler AC, Chapman JE, Forman EM, Beck AT. The empirical status of cognitive-behavioral therapy: a review of meta-analyses. Clin Psychol Rev 2006 Jan;26(1):17-31. [doi: 10.1016/j.cpr.2005.07.003] [Medline: 16199119]
13. Muñoz RF, Huynh-Nhu L, Ippen CG, Diaz MA, Urizar GG, Soto J, et al. Prevention of postpartum depression in low-income women: development of the mamás y bebés/mothers and babies course. Cogn Behav Pract 2007 Feb;14(1):70-83. [doi: 10.1016/j.cbpra.2006.04.021]
14. Le H, Perry DF, Stuart EA. Randomized controlled trial of a preventive intervention for perinatal depression in high-risk Latinas. J Consult Clin Psychol 2011 Apr;79(2):135-141. [doi: 10.1037/a0022492] [Medline: 21319897]
15. Tandon SD, Perry DF, Mendelson T, Kemp K, Leis JA. Preventing perinatal depression in low-income home visiting clients: a randomized controlled trial. J Consult Clin Psychol 2011 Oct;79(5):707-712. [doi: 10.1037/a0024895] [Medline: 21806298]
16. Tandon SD, Leis JA, Mendelson T, Perry DF, Kemp K. Six-month outcomes from a randomized controlled trial to prevent perinatal depression in low-income home visiting clients. Matern Child Health J 2014 May;18(4):873-881 [FREE Full text] [doi: 10.1007/s10995-013-1313-y] [Medline: 23793487]
17. Huynh-Nhu L, Perry DF, Mendelson T, Tandon SD, Muñoz RF. Preventing perinatal depression in high risk women: moving the mothers and babies course from clinical trials to community implementation. Matern Child Health J 2015 Oct;19(10):2102-2110. [doi: 10.1007/s10995-015-1729-7] [Medline: 25673369]
18. Goodman JH, Santangelo G. Group treatment for postpartum depression: a systematic review. Arch Womens Ment Health 2011 Aug;14(4):277-293. [doi: 10.1007/s00737-011-0225-3] [Medline: 21720793]
19. Patton GC, Sawyer SM, Santelli JS, Ross DA, Afifi R, Allen NB, et al. Our future: a Lancet commission on adolescent health and wellbeing. Lancet 2016 Jun 11;387(10036):2423-2478. [doi: 10.1016/S0140-6736(16)00579-1] [Medline: 27174304]

20. Scope A, Leaviss J, Kaltenthaler E, Parry G, Sutcliffe P, Bradburn M, et al. Is group cognitive behaviour therapy for postnatal depression evidence-based practice? A systematic review. BMC Psychiatry 2013 Nov 28;13:321 [FREE Full text] [doi: 10.1186/1471-244X-13-321] [Medline: 24283266]
21. Johansen SL, Robakis TK, Williams KE, Rasgon NL. Management of perinatal depression with non-drug interventions. Br Med J 2019 Feb 25;364:l322. [doi: 10.1136/bmj.l322] [Medline: 30803997]
22. Tandon SD, Leis JA, Ward EA, Snyder H, Mendelson T, Perry DF, et al. Adaptation of an evidence-based postpartum depression intervention: feasibility and acceptability of mothers and babies 1-on-1. BMC Pregnancy Childbirth 2018 Apr 11;18(1):93 [FREE Full text] [doi: 10.1186/s12884-018-1726-0] [Medline: 29642868]
23. Denno DM, Hoopes AJ, Chandra-Mouli V. Effective strategies to provide adolescent sexual and reproductive health services and to increase demand and community support. J Adolesc Health 2015 Jan;56(1 Suppl):S22-S41 [FREE Full text] [doi: 10.1016/j.jadohealth.2014.09.012] [Medline: 25528977]
24. Golberstein E, Gonzales G, Meara E. How do economic downturns affect the mental health of children? Evidence from the national health interview survey. Health Econ 2019 Aug;28(8):955-970 [FREE Full text] [doi: 10.1002/hec.3885] [Medline: 31165566]
25. Keesara S, Jonas A, Schulman K. Covid-19 and health care's digital revolution. N Engl J Med 2020 Jun 4;382(23):e82. [doi: 10.1056/NEJMp2005835] [Medline: 32240581]
26. van den Heuvel JF, Groenhof TK, Veerbeek JH, van Solinge WW, Lely AT, Franx A, et al. eHealth as the next-generation perinatal care: an overview of the literature. J Med Internet Res 2018 Jun 5;20(6):e202 [FREE Full text] [doi: 10.2196/jmir.9262] [Medline: 29871855]
27. Lau Y, Htun TP, Wong SN, Tam WS, Klainin-Yobas P. Therapist-supported internet-based cognitive behavior therapy for stress, anxiety, and depressive symptoms among postpartum women: a systematic review and meta-analysis. J Med Internet Res 2017 Apr 28;19(4):e138 [FREE Full text] [doi: 10.2196/jmir.6712] [Medline: 28455276]
28. Loughnan SA, Sie A, Hobbs MJ, Joubert AE, Smith J, Haskelberg H, et al. A randomized controlled trial of 'MUMentum pregnancy': internet-delivered cognitive behavioral therapy program for antenatal anxiety and depression. J Affect Disord 2019 Jan 15;243:381-390. [doi: 10.1016/j.jad.2018.09.057] [Medline: 30266030]
29. Barrera AZ, Wickham RE, Muñoz RF. Online prevention of postpartum depression for Spanish- and English-speaking pregnant women: a pilot randomized controlled trial. Internet Interv 2015 Sep 1;2(3):257-265 [FREE Full text] [doi: 10.1016/j.invent.2015.06.002] [Medline: 26273567]
30. Sawyer A, Kaim A, Huynh-Nhu L, McDonald D, Mittinty M, Lynch J, et al. The effectiveness of an app-based nurse-moderated program for new mothers with depression and parenting problems (eMums plus): pragmatic randomized controlled trial. J Med Internet Res 2019 Jun 4;21(6):e13689 [FREE Full text] [doi: 10.2196/13689] [Medline: 31165715]
31. Sawyer AC, Kaim AL, Reece CE, McDonald D, Huynh-Nhu L, Clark J, et al. Evaluating the effectiveness of an app-based nurse-moderated program for new mothers with depression and parenting problems (eMums plus): protocol for a pragmatic randomized controlled trial. JMIR Res Protoc 2019 Jan 16;8(1):e11549 [FREE Full text] [doi: 10.2196/11549] [Medline: 30664487]
32. Forsell E, Bendix M, Holländare F, von Schultz BS, Nasiell J, Blomdahl-Wetterholm M, et al. Internet delivered cognitive behavior therapy for antenatal depression: a randomised controlled trial. J Affect Disord 2017 Oct 15;221:56-64 [FREE Full text] [doi: 10.1016/j.jad.2017.06.013] [Medline: 28628768]
33. Solness CL, Kroska EB, Holdefer PJ, O'Hara MW. Treating postpartum depression in rural veterans using internet delivered CBT: program evaluation of MomMoodBooster. J Behav Med 2020 Oct 14:- epub ahead of print [FREE Full text] [doi: 10.1007/s10865-020-00188-5] [Medline: 33052526]
34. Loughnan SA, Joubert AE, Grierson A, Andrews G, Newby JM. Internet-delivered psychological interventions for clinical anxiety and depression in perinatal women: a systematic review and meta-analysis. Arch Womens Ment Health 2019 Dec;22(6):737-750. [doi: 10.1007/s00737-019-00961-9] [Medline: 31101993]
35. Teens, Social Media and Technology 2018. Pew Research Center. 2018. URL: https://www.pewresearch.org/internet/wp-content/uploads/sites/9/2018/05/PI_2018.05.31_TeensTech_FINAL.pdf [accessed 2020-12-12]
36. Holeman I, Kane D. Human-centered design for global health equity. Inf Technol Dev 2019 Sep 29;26(3):477-505 [FREE Full text] [doi: 10.1080/02681102.2019.1667289] [Medline: 32982007]
37. Stirman SW, Baumann AA, Miller CJ. The FRAME: an expanded framework for reporting adaptations and modifications to evidence-based interventions. Implement Sci 2019 Jun 6;14(1):58 [FREE Full text] [doi: 10.1186/s13012-019-0898-y] [Medline: 31171014]
38. Stirman SW, Miller CJ, Toder K, Calloway A. Development of a framework and coding system for modifications and adaptations of evidence-based interventions. Implement Sci 2013 Jun 10;8:65 [FREE Full text] [doi: 10.1186/1748-5908-8-65] [Medline: 23758995]
39. Mothers and Babies Program. Mothers and Babies. URL: http://www.mothersandbabiesprogram.org/ [accessed 2019-03-23]
40. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci 2009 Aug 7;4:50 [FREE Full text] [doi: 10.1186/1748-5908-4-50] [Medline: 19664226]

41. Lucas G, Olander EK, Ayers S, Salmon D. No straight lines - young women's perceptions of their mental health and wellbeing during and after pregnancy: a systematic review and meta-ethnography. BMC Womens Health 2019 Dec 5;19(1):152 [FREE Full text] [doi: 10.1186/s12905-019-0848-5] [Medline: 31806005]
42. Erfina E, Widyawati W, McKenna L, Reisenhofer S, Ismail D. Adolescent mothers' experiences of the transition to motherhood: an integrative review. Int J Nurs Sci 2019 Apr 10;6(2):221-228 [FREE Full text] [doi: 10.1016/j.ijnss.2019.03.013] [Medline: 31406896]
43. Harrison ME, Clarkin C, Worth K, Norris ML, Rohde K. But we're not like the people on TV: a qualitative examination of how media messages are perceived by pregnant and parenting youth. Matern Child Health J 2016 Mar;20(3):684-692. [doi: 10.1007/s10995-015-1868-x] [Medline: 26518008]
44. Egan J, Bhuiya N, Gil-Sanchez L, Campbell S, Clark J. Engaging expectant and parenting adolescents: lessons from the Massachusetts pregnant and parenting teen initiative. Matern Child Health J 2020 Sep;24(Suppl 2):191-199 [FREE Full text] [doi: 10.1007/s10995-020-02880-z] [Medline: 31981063]
45. Ramphos ES, Kelman AR, Stanley ML, Barrera AZ. Responding to women's needs and preferences in an online program to prevent postpartum depression. Internet Interv 2019 Dec;18:100275 [FREE Full text] [doi: 10.1016/j.invent.2019.100275] [Medline: 31890624]
46. Chlebowski C, Hurwich-Reiss E, Wright B, Brookman-Frazee L. Using stakeholder perspectives to guide systematic adaptation of an autism mental health intervention for Latinx families: A qualitative study. J Community Psychol 2020 May;48(4):1194-1214 [FREE Full text] [doi: 10.1002/jcop.22296] [Medline: 31816103]
47. Simione M, Frost HM, Cournoyer R, Mini FN, Cassidy J, Craddock C, et al. Engaging stakeholders in the adaptation of the connect for health pediatric weight management program for national implementation. Implement Sci Commun 2020;1:55 [FREE Full text] [doi: 10.1186/s43058-020-00047-z] [Medline: 32885211]
48. Diebold A, Ciolino JD, Johnson JK, Yeh C, Gollan JK, Tandon SD. Comparing fidelity outcomes of paraprofessional and professional delivery of a perinatal depression preventive intervention. Adm Policy Ment Health 2020 Jul;47(4):597-605 [FREE Full text] [doi: 10.1007/s10488-020-01022-5] [Medline: 32086657]

Abbreviations

CBT: cognitive behavioral therapy
FRAME: Framework for Modification and Adaptation
HCW: health care worker
IDI: in-depth interview
IMAGINE: Interactive Maternal Group for Information and Emotional Support
MB: Mothers and Babies
REDCap: Research Electronic Data Capture

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Original Paper

Evaluating a Middle-School Digital Citizenship Curriculum (Screenshots): Quasi-Experimental Study

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Abstract

Background: *Screenshots* is an in-school curriculum that seeks to develop positive digital social skills in middle school students with the long-term goal of improving their health and well-being. The program imparts knowledge and teaches skills upon which young adolescents can build a set of beliefs and behaviors that foster respectful interactions, prosocial conflict resolutions, and safe and secure use of communication technology. Intervening in this way can improve young people’s mental health by limiting their exposure to cyberbullying and other forms of negative online interactions. This study reports on an evaluation of the *Screenshots* program conducted with seventh graders in a public school system in a midsized New England city.

Objective: This study aims to determine the effectiveness of the *Screenshots* program in increasing participants’ knowledge about key concepts of digital citizenship and in shifting beliefs and intended behaviors to align with prosocial and safe online interactions. In addition, the study examines whether the program has varying effects on males’ and females’ conflict and bullying resolution strategies.

Methods: This quasi-experimental evaluation was conducted in four middle schools in which one group of seventh graders received the *Screenshots* curriculum and another did not. Before and after the curriculum, all students completed a questionnaire that measured their knowledge of and beliefs about digital citizenship and related online behavioral concepts, their attitudes regarding strategies for stopping online bullying, and their intended online conflict resolution behaviors.

Results: The sample included 92 students who received the curriculum and 71 students who were included in the comparison group. Pre- to postinstruction retention rates ranged from 52% (33/63) to 84% (21/25), varying by school and condition. The results showed an increase in knowledge about key curricular concepts for some students ($F_{1,32}$=9.97; P=.003). In response to some individual items, students decreased their belief supportive of a negative online behavior ($F_{1,76}$=9.00; P=.004) and increased their belief consistent with an online safety behavior ($F_{1,42}$=4.39; P=.04) compared with the comparison group. Gender moderated the results related to conflict resolution, with males from one school reducing their endorsement of an aggressive option ($F_{2,40}$=5.77; P=.006) and males from another school increasing their reported tendency to pursue a nonaggressive option ($F_{2,28}$=3.65; P=.04). On average, participants reported learning something new from the classes.

Conclusions: This study represents a rare evaluation of an in-school digital citizenship program and demonstrates the effectiveness of *Screenshots*. Students’ increased knowledge of key curricular concepts represents a foundation for developing future beliefs and healthy behaviors. Differences in how adolescent males and females experience and perpetrate online aggression likely explain the conflict resolution findings and emphasize the need to examine gender differences in response to these programs. Students’ high ratings of the relevance of *Screenshots*’ content reinforce the need for this type of intervention.

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KEYWORDS

digital citizenship; cyberbullying; evaluation; media literacy; middle school; conflict resolution; internet safety; mobile phone

Introduction

Background

For decades, educators and other related stakeholders have developed curricula to teach media literacy; critical thinking; and associated skills necessary to analyze, decode, evaluate, and produce media messages [1]. There is considerable evidence that such programs have been successful in intervening on the impact of media on multiple social and health behaviors, including aggression [2], poor nutritional choices [3], and smoking [4]. As screen media transformed from a primarily receptive format with a few powerful creators to an interactive platform with countless, everyday authors, aspects of media literacy were applied to programs created to enhance *digital citizenship* and positive online social behaviors, including tolerance, respect, and empathy [5], that contribute to prosocial participation in online communities [6]. Although in-school cyberbullying interventions are regularly evaluated [7], assessments of other broader digital citizenship initiatives are very rare [8], with a single dissertation [9] identified in a recent review of this topic [10] and only a few published since then [11]. The purpose of this study is to examine the impact of *Screenshots*, a program designed by Media Power Youth that applies a health lens to digital citizenship. *Screenshots* strives to achieve digital wellness and improve young people’s mental health by encouraging respectful online behaviors, fostering prosocial conflict resolution, reducing cyberbullying, and interrupting negative peer pressure.

Social and Digital Media and Adolescents’ Mental Health

There has been an increase in adolescent mental health issues (eg, depression and anxiety) and a decrease in psychological well-being (eg, self-esteem and life satisfaction) over the last two decades, which has occurred contemporaneously with a massive increase in smartphone adoption and social networking site use [12]. Meta-analyses and reviews of work linking digital media use in general and social media use in particular to adolescents’ mental health have found small, although significant, associations [13,14]. Many explanations for this potential link have been presented, ranging from social comparison to sedentary behaviors [14]. However, the consequences of social media use are not homogenous; the specific experiences young people have online will dictate the magnitude and direction of their impact. Youth can find positive peer support in social media [15] or they can experience increased depression [16] and risk for suicidal behaviors as a result of cyberbullying [17]. It would follow that being engaged with an online social network where interactions are guided by empathy and positive forms of conflict resolution would improve a young person’s mental health in ways similar to the positive effects of offline peer relationships [18]. Developing adolescents’ positive social behaviors and attitudes evident in digital citizenship would, therefore, encourage beneficial rather than detrimental interactions. Existing evidence is consistent with this approach, showing that digital citizenship is associated with lower levels of cyberbullying victimization and perpetration as well as a higher likelihood of being a helpful bystander [5].

Designing In-School Initiatives

Media literacy education programs that are administered in schools as part of the standard school day take advantage of existing educational structures and norms, potentially increasing their impact over other delivery alternatives. Integrating this content into existing programming is a considerable challenge in most US schools, as their curricula are fairly inflexible. Working with health and art teachers has been successful when implementing educational initiatives in elementary school but might not work for middle school students who have a more rigid curriculum [19]. Incorporating digital citizenship messages across multiple middle school classes that already teach relevant information is potentially the strongest approach [8,20]; however, it is considerably difficult, as it requires coordination, training, and curricular development across faculty and disciplines. An alternate approach is to create digital citizenship curricula that are flexible enough to be taught by a number of different classroom teachers or other specialists while simultaneously meeting numerous core curricular goals.

Theoretical and Conceptual Framework

Digital citizenship and related programs have at their core the goal of changing or shaping youth behavior, encouraging positive and respectful online behaviors [5] while preventing negative behaviors, such as cyberbullying [8]. The behavior change goals are well informed by existing models of human behavior. The Theory of Planned Behavior (TPB) illustrates how behavior can be altered by changing attitudes about a behavior, increasing a young person’s sense of self-efficacy to perform an action, and altering their perceived norms about the behavior [21]. TPB has been shown to be a useful framework for understanding and intervening on cyberbullying [22,23].

The Habits of Thought Model [24] provides an additional conceptualization of how changing beliefs and building a foundation of fact-based knowledge can encourage positive behaviors and constructive conflict resolution. On the basis of the work demonstrating the cognitive mediators of aggression [25], the Habits of Thought Model posits that the content of beliefs (what one thinks) and cognitive skills (how one thinks) shape an individual’s interpretation of an experience and their subsequent behavioral response. This model stems from Social Learning Theory and suggests that aggressive behaviors are learned and occur because an individual has underdeveloped abilities or existing biases in how they process social information [26]. Therefore, through education and practice that develop cognitive skills and alter related biases, aggressive behaviors can be reduced and positive behaviors can be increased. Interventions that follow this model train youth in effective conflict resolution strategies and alternate thought processes that encourage positive and empathetic choices for perpetrators of violence as well as victims and bystanders [27]. Students’ social processing skills are enhanced through exercises that help them avoid immediate negative responses, take time to assess social situations, and choose a prosocial solution. Therefore, the model is especially informative for programs seeking to foster prosocial online behaviors and digital citizenship. The anonymity available on the internet as well as the lack of immediate social consequences of negative behaviors contribute to antisocial behaviors online, even among young people who otherwise might not exhibit malicious behavior [28]. Furthermore, there are limited opportunities in online communication channels to express emotion and tone, making understanding the intent of online behaviors especially difficult. Considering how the online environment seems to foster a unique set of cognitive habits about aggression, digital citizenship programs that take a Habits of Thought approach can teach cognitive skills relevant to processing social information online and choosing positive behaviors and conflict resolution strategies in the digital space.

Gender Differences in Aggression

Adolescent males and females perpetrate and experience aggression differently, both online and offline. In face-to-face settings, males tend to experience overt, externalized aggression, and females are more likely to be victims of relational, internalized aggression [29]. There is some evidence that these differences manifest in online aggression as well. Cyberbullying among males tends to be outwardly aggressive, with more threats of violence and direct insults, whereas females are more likely to post gossip with the intent to harm their peers [30,31]. Considering these differences, violence prevention interventions may be more effective if they target males and females separately using strategies aligned with the observed differences in aggression. In mixed-gender classrooms, such an approach is difficult to implement. The genders are, therefore, likely to react differently to lessons designed for and delivered in this setting. Understanding how males and females differ in their response to the cyberbullying and conflict resolution components of a digital citizenship education program can help inform the design of future curricula.

Study Aim

The purpose of this study is to evaluate the effectiveness of *Screenshots* in improving students' knowledge and changing beliefs and behaviors in the targeted areas of digital citizenship and to determine the extent to which students found the material engaging and relevant. The study also seeks to determine whether the program has varying effects on males' and females' conflict and bullying resolution strategies.

Methods

Curriculum Design

Media Power Youth is an educational nonprofit organization that provides media literacy and health curricula, youth programs, family education, and professional development for educators and staff of youth-serving organizations. Staff members and volunteers have experience in education, youth development, advertising, film making, and health advocacy. Media Power Youth directly facilitates programming and collaborates extensively with professionals across disciplines, including public health, technology, media, and research. Their programs have been developed as interventions to address youth risk factors, including substance use, violence, and mental health concerns, in diverse and underresourced populations.

Media Power Youth developed the *Screenshots* curriculum following the research, development, and implementation of elementary school media literacy curricula [19] and multiple out-of-school programs for youth and their families. The program was developed by a team of experienced educators who gathered and used feedback from teachers, social workers, and other professionals working with youth. The curriculum development and related activities were funded by the New Hampshire Department of Justice Office of the Attorney General, the Granite United Way, and the Norwin S. and Elizabeth N. Bean Foundation.

Screenshots is a nine-lesson, in-class, middle school curriculum that uses educational and behavior change strategies based on media literacy, TPB, and Habits of Thought to teach students how to think critically about the social media messages they create, receive, and disseminate. It delivers lessons that help youth manage online conflict, recognize how online behavior contributes to mental health problems, practice empathy, and explore the role of digital media in peer pressure that can lead to bullying and substance use. *Screenshots* helps students to gain knowledge about how online communication impacts behaviors, to develop beliefs about how best to promote online prosocial and healthy behaviors, and to cultivate the cognitive skills to actualize these new knowledge-based beliefs. It consists of three units with three lessons, each with each lesson designed to be implemented within a standard 45-minute class.

Screenshots aligns with the Common Core State Standards [32], International Society for Technology in Education Standards [33], and the New Hampshire Health Curriculum Standards [34], thereby increasing its usefulness in middle schools and ease of integration into existing curricula. Lessons feature suggested scripts for educators, hands-on student activities, role-play scenarios, and interactive notebooks for student reflections. The purpose of this multifaceted approach was to create an environment that supports multiple learning styles and student engagement. Podcasts are used as a springboard to introduce each unit. The curriculum concludes with a final project that enables students to share what they have learned by producing a form of media, an approach proven to enhance media literacy program effectiveness. Table 1 provides details about the lessons.

Table 1. Sample lesson plan objectives, activities, and messages from the Media Power Youth Screenshot curriculum.

Objectives	Activities	Messages
Unit 1—Lesson 3: Healthy and Respectful Behavior Online		
• Recognize that their online actions can have consequences that affect both their lives and the lives of others. • Use the internet as an educational tool and a way to positively connect with others.	• Online scenarios—students review online scenarios to stimulate discussion about their own behaviors. • Online behavior quiz—students reflect on how their positive and negative behaviors impact other people. • Stay safe—students review and add ways to stay safe online.	• Online actions are part of who you are and can affect both your present and future. • Students can show respect for themselves and others by acting appropriately online.
Unit 2—Lesson 2: Cyberbullying		
• Recognize cyberbullying and empathize with the targets of cyberbullying. • Recognize the key similarities and differences between in-person bullying and cyberbullying. • Identify the strategies for dealing responsibly with cyberbullying.	• Me or My Avatar—students create their own avatar. • Online scenarios—students answer questions about how to react in certain online scenarios. • Stop and STAND[a]—students learn a system to remember strategies for stopping and preventing cyberbullying.	• The use of avatars might allow online users to say things or behave in ways they normally would not. • Interacting with others in the digital world can sometimes lead to miscommunication. • Online behaviors can be exaggerated, which can cause conflicts and result in situations escalating quickly.
Unit 3—Lesson 1: Digital Peer Pressure		
• Identify what digital peer pressure is and the impact it can have on their choices and behaviors. • Recognize images that are considered unhealthy and can lead to digital peer pressure. • Take action to create more positive media messages.	• Media images—students view images of drugs and alcohol and answer questions pertaining to them. • Edit that Screenshot!—students learn techniques to help them handle peer pressure and apply the strategies to a novel scenario. • Did you know?—Students view statistics about peer pressure.	• Digital peer pressure can impact choices with regard to drug and alcohol use. • Students can mitigate digital peer pressure by embracing instincts, deciding why they feel the way they do, identifying an appropriate action, and taking action by removing or editing unhealthy images.

[a]STAND: Screenshot, Talk, Activate, Note, Defend.

Curriculum Implementation

Overview

The curriculum was taught to seventh graders in four public middle schools in a midsized New England city. These schools were identified by district-level administrators as having a diverse student body as well as the resources and capacity necessary to implement the curriculum and follow the evaluation methods. Media Power Youth provided educator training before implementation for lead teachers in each school. At each school, teachers had multiple sessions of their class and chose one to be the curriculum group and another to be the no curriculum group. Although it was preferred that the first session of the day be designated as the curriculum group and the second session as the no curriculum group, the final decision of group assignment was left to the teachers' discretion. The no curriculum group received standard instruction during the time in which the study was being conducted, and teachers were asked to implement the curriculum for the no curriculum group in the semester following the study. There was no schoolwide component of the curriculum, and no curriculum-related materials were posted in classrooms, thereby reducing the potential for cross-group contamination. Both groups completed pencil and paper questionnaires administered by their classroom teachers before and after the curriculum group received the lessons.

Although the curriculum was designed to be implemented as part of a designated course, each school had discretion in how they delivered the curriculum; as such, it was implemented in a variety of formats providing appropriate time blocks for delivering the materials, including during health classes, library sessions, and advisory periods. One of the four schools was dropped from the study as their implementation of the curriculum and evaluation deviated significantly from the others, resulting in a low retention rate (18/66, 27%) and introducing additional variables that prohibit comparison with the other schools. Teachers were asked to complete a fidelity reporting form following each lesson to track the administration of the lessons and to identify any problems with instruction. No major issues beyond what would be expected in a typical class were reported.

Procedures

Between October 2019 and January 2020, students at all four schools were given pre- and postinstruction questionnaires that obtained their demographic information and assessed their knowledge of key digital citizenship concepts as well as their beliefs about online behaviors, conflict resolution, and online bullying. The assessment was designed to be completed in approximately 20 minutes, so that, along with instructions and any potential questions, it could be completed during a single class. A complete list of the survey questions can be found in

Multimedia Appendix 1. Participants' two questionnaires were connected according to their responses to three questions: the last three letters of their last name, the day they were born, and the number of their home address (with instructions to cover various housing situations). The evaluation protocol was implemented by Media Power Youth staff and approved by the school board and school administrators, including an opt-out parental permission process standard for the participating district. The Boston Children's Hospital Institutional Review Board designated the management and analysis of the anonymous data as exempt.

Sample Characteristics

Of the students who participated in the *Screenshots* program across all four schools, 218 completed both pre- and post -instruction assessments. Of the three schools included in the analyses (schools 1-3), 92 received the curriculum, and 71 served as a comparison. Table 2 provides demographic data by school. The students' average age was approximately 12 years. Although the majority of students identified as a White person, there was considerable representation from other races and ethnic groups as well. Retention rates in the included schools differed by school and condition and varied from 52% (33/63) to 84% (21/25).

Table 2. Sample demographics (N=218).

Characteristic	School 1	School 2	School 3	School 4[a]
Students per group, n (%)				
Curriculum	21 (48)	52 (61)	19 (56)	37 (67)
No curriculum	23 (52)	33 (39)	15 (44)	18 (33)
Questionnaire completion				
Curriculum				
Postinstruction completion, n	21	52	19	37
Preinstruction completion, N	25	71	24	48
Questionnaire completion rate (%)	84	73	79	77
No curriculum				
Postinstruction completion, n	23	33	15	18
Preinstruction completion, N	28	63	23	66
Questionnaire completion rate (%)	82	52	65	27
Age (years), mean (SD)	12.1 (0.4)	12.2 (0.4)	12.2 (0.4)	12.2 (0.4)
Gender (female), n (%)	17 (38.6)	42 (49.4)	21 (61.8)	27 (50.0)
Race, n (%)				
White (non-Hispanic)	24 (54.5)	47 (55.3)	20 (58.8)	32 (58.2)
Black (non-Hispanic)	2 (4.5)	7 (8.2)	3 (8.8)	4 (7.3)
Hispanic	4 (9.1)	17 (20.0)	5 (14.7)	13 (24.1)
Other and/or mixed race	14 (31.8)	14 (16.5)	6 (17.6)	5 (9.1)

[a] Owing to implementation differences, school 4 was not included in any further analyses.

Measures of Knowledge, Beliefs, and Behaviors

Core Curriculum Knowledge

To assess the acquisition of the concepts taught in the *Screenshots* curriculum, we created nine multiple-choice, general knowledge questions based on the three focus areas covered in the program: digital citizenship, online conflict resolution, and media and peer pressure. For example, participants were asked, "Which of the following should you NOT share online?" with the following answer options: "a video of an activity you do," "your first name," "your phone number" (correct answer), "sports/activities you play." All questions had four answer choices and one answer that best aligned with the curriculum. The total number of questions answered correctly were summed and used for the data analysis.

Digital Citizenship Beliefs

Key beliefs targeted by the curriculum and reflective of an alignment with digital citizenship concepts were assessed through seven questions created for the evaluation. Questions asked participants to rate on a 5-point Likert scale how strongly they agreed or disagreed with specific beliefs related to the acceptability, impact, and risk of different online behaviors and actions, including, for example, "My online posts are my own thoughts and do not impact other people." Separate analyses were conducted for each question.

Digital Citizenship Behaviors

Students were asked to report on their own prosocial online behaviors that would be indicative of well-developed citizenship. Four questions were adapted from a Department of Justice funded internet safety education outcome survey [35]. Participants reported how much each statement sounded like them using a five-point scale that ranged from *not at all* to *very much*. Items included their tendency to end arguments and drama online as well as other indicators of respectful behaviors and were analyzed individually.

Measures of Aggression

Conflict Resolution

Participants were given two scenarios of potential conflict and six different strategies for responding to the situations. The first scenario dealt with rumors being spread around school through negative posts on social media about a participant's friend. The second detailed a scenario in which a photo of *you* that *you* did not like was taken and shared on social media. Participants rated on a five-point Likert scale how likely (from *would definitely* to *would definitely not*) they were to use each of the six different strategies categorized as verbal problem solving, avoidance, seeking help from a trusted adult, information seeking or understanding the situation, verbal aggression, and overt aggression. This approach is based on an offline conflict resolution scale [25], with scenarios adapted from previous media literacy program evaluations and the internet safety education outcome survey [5,20,35].

Strategies for Stopping Online Bullying

Participants were asked to imagine that they were being bullied in an online group and to rate, on a five-point Likert scale, the effectiveness of each strategy to stop the bullying (eg, telling the bully to stop bothering you and talking to a trusted adult or family member about the bullying).

Responsiveness and Relevance

Four responsiveness and three relevance questions derived from previous media literacy evaluations [19,36] were given to participants who received the curriculum on the postinstruction questionnaire. The questions asked participants to rate how strongly they agreed or disagreed (five-point Likert scale) with statements about their engagement and enjoyment of the curriculum as well as the importance of the program content.

Analysis Plan

Mixed method (within- and between-subjects) analyses of variance were performed to compare the two conditions in their pre- and postinstruction responses with a time-by-condition interaction, indicating a difference in pre-post change between the two groups. Given that schools differed substantially in their implementation of the curriculum, we conducted analyses separated by school. To examine gender differences in responses to the conflict and bullying resolution components of the curriculum, we added a three-way time-by-condition-by-gender interaction to analyze questions related to these concepts. Along with our significant findings of $P<.05$, we presented results with significance values of $P<.10$ and considered the effect sizes (partial η^2) of the findings as we interpreted the results. We interpreted these findings when they were supportive of or similar to the significant findings. The aim of this approach was to avoid discarding results that may not reach statistical significance but may still be meaningful for those implementing and designing digital citizenship programs.

Results

Core Curriculum Knowledge

Table 3 shows the results of the mixed analyses of variance for the core curriculum knowledge questions. For school 3, there was a significant increase in questions answered correctly after receiving the *Screenshots* curriculum. For school 2, there was some evidence, although only at the level of $P=.08$, that the curriculum and comparison groups differed in the same way as in school 3.

Table 3. Results of the mixed analyses of variance for the core curriculum knowledge questions.

School and group	Group pretest, mean[a] (95% CI)	Group posttest, mean[a] (95% CI)	*F* test (*df*)	*P* value	Partial η^2
School 1			0.001 (1,42)	.97	0.00
Curriculum	5.76 (5.14-6.39)	6.05 (5.29-6.81)			
Comparison	5.04 (4.45-5.64)	5.35 (4.62-6.08)			
School 2			3.17 (1,83)	.08	0.04
Curriculum	5.02 (4.60-5.44)	5.37 (4.93-5.80)			
Comparison	5.15 (4.63-5.68)	4.85 (4.30-5.40)			
School 3			9.97 (1,32)	.003	0.24
Curriculum	4.84 (4.11-5.58)	6.00 (5.43-6.57)			
Comparison	5.27 (4.44-6.10)	4.93 (4.30-5.57)			

[a] The mean number of correct responses to the nine multiple-choice questions assessing participants' understanding of core digital citizenship concepts.

Digital Citizenship Beliefs

In school 2, students increased their mean beliefs regarding the three questions to be better aligned with digital citizenship concepts. They disagreed more strongly with the statement, "If my friends and I need a laugh, it's ok for us to post a funny and embarrassing picture of someone else online" (pretest=4.41; posttest=4.54; $F_{1,76}=9.00$; $P=.004$; $\eta_p^2=0.106$). Although not reaching the level of significance, other results showed differences in the same direction: "My online posts are my own thoughts and do not impact other people” (pretest=3.40; posttest=3.65; $F_{1,77}$=3.25; P=.08; η_p^2=0.04) and “It’s ok to share my online passwords with a friend that I trust” (pretest=3.96; posttest=4.02; $F_{1,76}$=2.79; P=.10; η_p^2=0.035). The comparison group increased their agreement with each of these statements. At school 1, students significantly increased their agreement with the statement, “If there’s a video or picture that I don’t want lots of people to see, setting my profile to ‘private’ will keep it secret” (pretest=3.52; posttest=3.33; $F_{1,42}$=4.39; P=.04; η_p^2=0.095), whereas the comparison group decreased their agreement.

Conflict Resolution

With regard to the conflict resolution scenarios, a condition-by-time-by-gender interaction was tested to determine whether the effects of the curriculum differed between males and females. For the scenario describing someone posting a photo of *you* that *you* do not like, males in the *Screenshots* group of school 1 decreased their endorsement of an aggressive response, “Tell them they better take the photo down or you’ll get back at them” (pretest=3.36; posttest=2.36; $F_{2,40}$=5.77; P=.006; η_p^2=0.224), whereas their peers in the comparison group increased their endorsement (pretest=2.69 and posttest=2.81). Females in the program slightly increased their endorsement of this aggressive behavior (pretest=2.50 and posttest=3.00), and females in the comparison group decreased their endorsement (pretest=3.00 and posttest=2.00). At school 3, males increased (pretest=2.67 and posttest=3.50) and females decreased (pretest=3.83 and posttest=3.58) their reported likelihood of seeking additional information about the behavior (“asking the person why they posted the photo online”; $F_{2,28}$=3.65; P=.04; η_p^2=0.207).

Strategies for Stopping Bullying

In school 3, a significant three-way interaction indicated differences between how males and females endorsed the effectiveness of the strategy of “standing up to the bully by fighting back.” Males who received the curriculum showed an increased endorsement (pretest=3.00 and posttest=3.17), whereas males in the comparison group (pretest=3.20 and posttest=2.40) showed a decreased endorsement ($F_{3,29}$=4.399; P=.02; η_p^2=0.233). Females in both the *Screenshots* (pretest=2.54 and posttest=2.62) and comparison groups (pretest=1.88 and posttest=2.50) increased their endorsement of this strategy. The results for other questions and at other schools did not reach significance but may indicate at least weak evidence for differences. Among students who received *Screenshots* in school 2, males increased their mean endorsement of talking to a trusted adult as a method to stop bullying (pretest=3.75 and posttest=4.07), whereas those in the comparison group showed a mean decrease (pretest=3.93; posttest=3.79; $F_{2,77}$=2.56; P=.08; η_p^2=0.062). For females, the curriculum group decreased their assessment of the strategy (pretest=4.32 and posttest=4.27), whereas the comparison group increased their assessment of the strategy (pretest=3.35 and posttest=3.88).

Responsiveness and Relevance

Table 4 shows the mean responses of students to each of the four responsiveness and three relevance questions. Students responded fairly neutrally to the program, with scores near 3 on a five-point scale for items about their interest in and enjoyment of the classes. Relevance items received higher ratings, indicating that the students regularly agreed that they learned something new from the class and that other students should take the course.

Table 4. Results of the responsiveness and relevance questions.

Question[a]	School 1, mean (SD)	School 2, mean (SD)	School 3, mean (SD)
The classes were interesting	2.92 (1.09)	3.21 (0.86)	2.55 (1.14)
I got easily distracted during the classes	3.46 (1.14)	2.95 (0.99)	3.35 (0.98)
I enjoyed the classes	2.96 (1.24)	3.27 (1.04)	2.83 (1.03)
The classes were boring	3.23 (1.24)	2.85 (0.99)	3.48 (1.16)
I learned something new from these classes	3.62 (0.94)	3.89 (1.01)	3.35 (1.52)
Other kids my age should take these classes	3.38 (1.20)	3.88 (0.99)	3.22 (0.95)
I learned something from these classes that I will use in my own life	3.44 (1.08)	3.82 (1.04)	2.91 (1.31)

[a] Results represent the mean (SD) of seven postassessment questions given to participants who received the *Screenshots* curriculum, with response choices of 1=strongly disagree and 5=strongly agree.

Discussion

Principal Findings

The aim of this study is to evaluate the effectiveness of the *Screenshots* curriculum in improving students’ knowledge and changing their beliefs and intended behaviors around positive online social interactions, conflict resolution, and other aspects of digital citizenship. In one of the three schools included in the analyses, the students in the program increased their knowledge relevant to the lessons from the pretest to the posttest. Although the evidence was weaker, a similar change was observed at a second school. There was also some evidence showing that students’ beliefs changed to be less supportive of unkind online behavior and supportive of privacy and safety, including understanding that privacy settings will protect a profile.

The results for conflict resolution and bullying differed by gender and were somewhat inconsistent in direction. At one school, males in the program decreased the likelihood that they would use verbal aggression and increased their endorsement of the more prosocial conflict resolution approach of seeking additional information about another person’s behaviors. Females at the same school showed the opposite results; they increased their likelihood of using verbal aggression and decreased their likelihood of seeking additional information. Males in the *Screenshots* group increased their endorsement of strategies to disrupt bullying that were both overly assertive (standing up to the bully and fighting back) and, to a lesser extent, prosocial (seeking adult help and peer involvement).

Digital Citizenship Knowledge, Beliefs, and Behaviors

Screenshots was most successful at improving participants’ knowledge of online behaviors and healthy communication practices consistent with digital citizenship. In addition, students self-reported that they had learned something new in the curriculum. Such a change is at the core of the program and can serve as a foundation for a belief and behavior system that is based on information rather than erroneous ideas. College students have been found to have limited knowledge regarding good digital citizenship, and experience using the internet does not seem to compensate for this shortcoming [37]. Programs such as *Screenshots* that target young adolescents are necessary to fill this educational gap.

There was some, although limited, evidence that participants changed their beliefs in response to the program, but they did not change their immediate behaviors. However, this is not surprising. Experienced educators in this field have observed that students often demonstrate an understanding of appropriate online behaviors, but they do not actually follow through in practice [10]. Furthermore, altering strongly held beliefs in young adolescents through direct education, especially in a topic in which they have a sense of proficiency, is particularly difficult as they are moving from adults to peers as their primary source of social information [38]. Even given this challenge, *Screenshots* encouraged students in one school to hold beliefs more consistent with the idea that it is not okay to post embarrassing pictures of other people or to share online passwords. These results demonstrate potential changes relevant to the two roles of cyberbullying: sharing embarrassing pictures is a common tool for perpetrators of cyberbullying and sharing online passwords may increase the risk of victimhood [39,40]. Although these findings represent a modest success of *Screenshots*, long-term interventions or programs with additional booster lessons over multiple school years would likely be necessary to help students more fully assimilate new knowledge from the curriculum and ensure it is translated into behaviors. Other educational approaches should also be explored, such as project-based learning that encourages students to guide their own investigation into the topic and develop solutions, thereby becoming more connected to the content [41].

Gender Differences

Although not universal, violence prevention programs have been shown to operate differently for males and females. In one such intervention, males were found to reduce their externalizing behavior problems and bullying [42], whereas females showed better outcomes related to relational aggression [43]. Our results reflect these findings to some extent, with some males decreasing their endorsement of a verbally aggressive behavior choice. Other males, however, increased their likelihood of using prosocial problem solving to address a potential conflict, but females did not. Males likely perceive the role of aggression in online conflict very differently from females and experience it in a different context, including it being modeled as a solution in violent video games [44]. Considering that the Habits of Thought Model was originally developed as an approach to reduce aggression in males, the approaches used by *Screenshots* may be somewhat more effective for males. It is worth noting that we also observed that males increased their endorsement of *Standing up to the bully by fighting back online*. The program may have encouraged males to support their friends, and it was the helping, rather than the subtle aggression, that they were responding to in these responses. Similarly, females slightly increased their likelihood to *Tell them they better take the photo down or you’ll get back at them.* Again, the females in the program may be focusing on the verbal assertion rather than the retaliation component of this behavior. Regardless, future research should determine whether this observed boomerang effect is replicated or unique to this evaluation. Furthermore, additional work is necessary to fully understand the moderating role of gender on the effects of online conflict resolution interventions, especially the potential for varying impacts among sexual minority youth.

Study Limitations

This study represents one of the very few empirical evaluations of an in-school digital citizenship program. However, the findings of this study should be interpreted within the context of some important limitations. School district requirements led to the study’s focus on seventh graders rather than the full middle school age range, resulting in a much smaller sample than would be ideal. The use of a single grade level as well as the constrained geographic location of schools limit the generalizability of the findings. Furthermore, differences across the schools in programming and daily class structures limited our ability to maintain identical implementation techniques at each site and contributed to various administration challenges. As a result, we were unable to use data from all schools and could not pool data across schools. Such challenges are an inherent aspect of research conducted in school settings where teachers must first meet and adjust to structural, administrative, and student needs before attending to the needs of a research study. Together, these limitations reduced our intended sample size and our ability to detect small effects of the curriculum, meaning that some important differences may not have risen to the level of significance. Presenting and discussing some findings that only reached the significance level of $P<.10$ is an additional limitation to our approach, as it increases the likelihood that we are making claims based on chance findings. Nevertheless, the in-school, quasi-experimental design strengthens the approach of this study, making it a rare example of a real-world evaluation of this type of program.

Conclusions

It is the goal of our schools to prepare children for their future. The COVID-19 pandemic has dramatically altered that future in that vestiges of full-time online instruction, technology-mediated communication, and internet-based social systems that have dominated this time will inevitably persist well beyond the COVID era. Skills related to online conflict resolution and positive behaviors that were once considered niche abilities are now essential for overall mental health. *Screenshots* and other similar programs that teach these skills fill a critical educational need in today's world. This study demonstrated that *Screenshots* improved seventh graders' knowledge and holds some promise in changing beliefs related to digital citizenship and the prosocial behaviors that support mental health. Students recognized the need for this program, indicating that they learned something new that would be relevant to other children. Hopefully, this work will inspire additional school-based research in this area, so that educators can be armed with curricula known to be effective in encouraging positive online behaviors and subsequently improving mental health and well-being.

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Conflicts of Interest

HKI and RZ are employed by Media Power Youth, the organization that developed the curriculum evaluated in the research study. The other authors have no conflicts to declare.

Multimedia Appendix 1
Survey measures of the <italic>Screenshots</italic> evaluation.
[PDF File (Adobe PDF File), 174 KB - mental_v8i9e26197_app1.pdf]

References

1. Media literacy fundamentals. Media Smarts. URL: https://mediasmarts.ca/digital-media-literacy/general-information/digital-media-literacy-fundamentals/media-literacy-fundamentals [accessed 2020-11-30]
2. Scharrer E. "I Noticed More Violence:" The effects of a media literacy program on critical attitudes toward media violence. J Mass Media Ethics 2006;21(1):69-86. [doi: 10.1207/s15327728jmme2101_5]
3. Austin EW, Austin BW, Kaiser CK. Effects of family-centered media literacy training on family nutrition outcomes. Prev Sci 2020;21(3):308-318. [doi: 10.1007/s11121-020-01101-x] [Medline: 32060881]
4. Primack BA, Douglas EL, Land SR, Miller E, Fine MJ. Comparison of media literacy and usual education to prevent tobacco use: a cluster-randomized trial. J Sch Health 2014;84(2):106-115 [FREE Full text] [doi: 10.1111/josh.12130] [Medline: 25099425]
5. Jones LM, Mitchell KJ. Defining and measuring youth digital citizenship. New Media Soc 2016;18(9):2063-2079. [doi: 10.1177/1461444815577797]
6. Ghosn-Chelala M. Exploring sustainable learning and practice of digital citizenship: education and place-based challenges. Edu Citizen Soc 2018;14(1):40-56. [doi: 10.1177/1746197918759155]
7. Gaffney H, Ttofi MM, Farrington DP. Evaluating the effectiveness of school-bullying prevention programs: an updated meta-analytical review. Aggress Violent Behav 2019;45:111-133. [doi: 10.1016/j.avb.2018.07.001]
8. Finkelhor D, Walsh K, Jones L, Mitchell K, Collier A. Youth Internet Safety Education: Aligning Programs With the Evidence Base. Trauma, Violence, & Abuse 2020 Apr 03:1524838020916257. [doi: 10.1177/1524838020916257] [Medline: 32242503]
9. Boyle III CJ. The effectiveness of a digital citizenship curriculum in an urban school. In: [PhD Dissertation]. Providence, Rhode Island: Johnson & Wales University; 2010:1-105.
10. Hui B, Campbell R. Discrepancy between learning and practicing digital citizenship. J Acad Ethics 2018;16(2):117-131. [doi: 10.1007/s10805-018-9302-9]
11. Tapingkae P, Panjaburee P, Hwang G, Srisawasdi N. Effects of a formative assessment-based contextual gaming approach on students' digital citizenship behaviours, learning motivations, and perceptions. Comput Educ 2020;159:1-16. [doi: 10.1016/j.compedu.2020.103998]
12. Twenge JM, Martin GN, Campbell WK. Decreases in psychological well-being among American adolescents after 2012 and links to screen time during the rise of smartphone technology. Emotion 2018;18(6):765-780. [doi: 10.1037/emo0000403] [Medline: 29355336]

13. Odgers CL, Jensen MR. Annual Research Review: Adolescent mental health in the digital age: facts, fears, and future directions. J Child Psychol Psychiatry 2020;61(3):336-348 [FREE Full text] [doi: 10.1111/jcpp.13190] [Medline: 31951670]
14. Keles B, McCrae N, Grealish A. A systematic review: the influence of social media on depression, anxiety and psychological distress in adolescents. Int J Adolesc Youth 2019;25(1):79-93. [doi: 10.1080/02673843.2019.1590851]
15. Lenhard A. Teens, technology and friendships. Pew Research Center. 2015. URL: https://www.pewresearch.org/internet/2015/08/06/teens-technology-and-friendships/ [accessed 2020-11-30]
16. Reed KP, Cooper RL, Nugent WR, Russell K. Cyberbullying: A literature review of its relationship to adolescent depression and current intervention strategies. J Hum Behav Soc Environ 2015;26(1):37-45. [doi: 10.1080/10911359.2015.1059165]
17. van Geel M, Vedder P, Tanilon J. Relationship between peer victimization, cyberbullying, and suicide in children and adolescents: a meta-analysis. JAMA Pediatr 2014;168(5):435-442. [doi: 10.1001/jamapediatrics.2013.4143] [Medline: 24615300]
18. Valkenburg PM, Peter J. Online communication and adolescent well-being: testing the stimulation versus the displacement hypothesis. J Comput-Mediat Commun 2007;12(4):1169-1182. [doi: 10.1111/j.1083-6101.2007.00368.x]
19. Bickham DS, Slaby RG. Effects of a media literacy program in the US on children's critical evaluation of unhealthy media messages about violence, smoking, and food. J Child Media 2012;6(2):255-271. [doi: 10.1080/17482798.2012.662031]
20. Bickham DS, Hswen Y, Slaby RG, Rich M. A preliminary evaluation of a school-based media education and reduction intervention. J Prim Prev 2018;39(3):229-245. [doi: 10.1007/s10935-018-0510-2] [Medline: 29721652]
21. Ajzen I. The theory of planned behavior. Organ Behav Hum Decis Process 1991;50(2):179-211. [doi: 10.1016/0749-5978(91)90020-T]
22. Heirman W, Walrave M. Predicting adolescent perpetration in cyberbullying: an application of the theory of planned behavior. Psicothema 2012;24(4):614-620. [Medline: 23079360]
23. Vlaanderen A, Bevelander KE, Kleemans M. Empowering digital citizenship: an anti-cyberbullying intervention to increase children's intentions to intervene on behalf of the victim. Comput Hum Behav 2020;112:1-11. [doi: 10.1016/j.chb.2020.106459]
24. Slaby RG. Psychological mediators of violence in urban youth. In: McCord J, editor. Violence and Childhood in the Inner City. New York, NY: Cambridge University Press; 1997:171-206.
25. Slaby RG, Guerra NG. Cognitive mediators of aggression in adolescent offenders: I. Assessment. Dev Psychol 1988;24(4):580-588. [doi: 10.1037/0012-1649.24.4.580]
26. Dodge KA, Frame CL. Social cognitive biases and deficits in aggressive boys. Child Dev 1982;53(3):620-635. [Medline: 7094675]
27. Barnett RV, Brennan MA. Aggressors, victims and bystanders: preventing bullying in the middle school environment. J Youth Dev 2009;4(2):28-45. [doi: 10.5195/jyd.2009.262]
28. Paciello M, Tramontano C, Nocentini A, Fida R, Menesini E. The role of traditional and online moral disengagement on cyberbullying: do externalising problems make any difference? Comput Hum Behav 2020;103:190-198. [doi: 10.1016/j.chb.2019.09.024]
29. Carbone-Lopez K, Esbensen F, Brick BT. Correlates and consequences of peer victimization: gender differences in direct and indirect forms of bullying. Youth Violence Juv Justice 2010;8(4):332-350. [doi: 10.1177/1541204010362954]
30. Marcum C, Higgins G, Freiburger T, Ricketts M. Battle of the sexes: an examination of male and female cyber bullying. Int J Cyber Criminol 2012;6(1):904-911 [FREE Full text]
31. Dilmac B. Psychological needs as a predictor of cyber bullying: a preliminary report on college students. Educ Sci Theory Pract 2009;9:1307-1325 [FREE Full text]
32. Common core state standards initiative. Council of Chief State School Officers, National Governors Association Center for Best Practices. URL: http://www.corestandards.org/ [accessed 2020-11-30]
33. ISTE standards for students. International Society for Technology in Education. URL: https://www.iste.org/standards/for-students [accessed 2020-11-30]
34. Health Education Curriculum Guidelines. New Hampshire State Department of Education and the CCSSO~SCASS Health Education Assessment Project. URL: https://www.education.nh.gov/sites/g/files/ehbemt326/files/inline-documents/2020/standards-health.pdf [accessed 2020-11-30]
35. Jones LM, Mitchell KJ, Walsh WA. Evaluation of internet child safety materials used by ICAC Task Forces in school and community settings. Final Technical Report Executive Summary to U.S. Department of Justice. 2013. URL: https://www.ncjrs.gov/pdffiles1/nij/grants/242017.pdf [accessed 2020-11-30]
36. Greene K, Yanovitzky I, Carpenter A, Banerjee SC, Magsamen-Conrad K, Hecht ML, et al. A theory-grounded measure of adolescents' response to a media literacy intervention. J Media Lit Educ 2015;7(2):35-49 [FREE Full text] [Medline: 28042522]
37. Al-Abdullatif AM, Gameil AA. Exploring students’ knowledge and practice of digital citizenship in higher education. Int J Emerg Technol Learn 2020;15(19):122-142. [doi: 10.3991/ijet.v15i19.15611]
38. Fuligni AJ, Eccles JS. Perceived parent-child relationships and early adolescents' orientation toward peers. Develop Psychol 1993;29(4):622-632. [doi: 10.1037/0012-1649.29.4.622]

39. Cyberbullying tactics. U.S. Department of Health and Human Services. 2018. URL: https://www.stopbullying.gov/cyberbullying/cyberbullying-tactics [accessed 2020-11-30]
40. Mishna F, Khoury-Kassabri M, Gadalla T, Daciuk J. Risk factors for involvement in cyber bullying: victims, bullies and bully–victims. Child Youth Serv Rev 2012;34(1):63-70. [doi: 10.1016/j.childyouth.2011.08.032]
41. Blumenfeld PC, Soloway E, Marx RW, Krajcik JS, Guzdial M, Palincsar A. Motivating project-based learning: sustaining the doing, supporting the learning. Edu Psychol 1991;26(3-4):369-398. [doi: 10.1080/00461520.1991.9653139]
42. Sullivan TN, Sutherland KS, Farrell AD, Taylor KA, Doyle ST. Evaluation of violence prevention approaches among early adolescents: moderating effects of disability status and gender. J Child Fam Stud 2016;26(4):1151-1163. [doi: 10.1007/s10826-016-0629-9]
43. Van Schoiack-Edstrom L, Frey KS, Beland K. Changing adolescents' attitudes about relational and physical aggression: an early evaluation of a school-based intervention. School Psychol Rev 2019;31(2):201-216. [doi: 10.1080/02796015.2002.12086151]
44. Shao R, Wang Y. The relation of violent video games to adolescent aggression: an examination of moderated mediation effect. Front Psychol 2019;10:1-9 [FREE Full text] [doi: 10.3389/fpsyg.2019.00384] [Medline: 30846962]

Abbreviations

TPB: Theory of Planned Behavior

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Original Paper

The Role of Mental Well-Being and Perceived Parental Supportiveness in Adolescents’ Problematic Internet Use: Moderation Analysis

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Abstract

Background: Given the growing number of adolescents exhibiting problematic internet use (PIU) and experiencing its harmful consequences, it is important to examine the factors associated with PIU. Existing research has identified perceived parental supportiveness and adolescents’ subjective mental well-being as strong predictors of PIU. However, it is unknown how these factors work together in shaping adolescents’ engagement in PIU.

Objective: This paper aimed to examine the role played by adolescents’ perception of parental supportiveness in conjunction with their subjective mental well-being in shaping their PIU.

Methods: The study analyzed one of the Technology & Adolescent Mental Wellness (TAM) data sets that were collected from a nationally representative cross-sectional sample. Adolescents self-reported their internet use behavior, perceived parental supportiveness, and subjective mental well-being through an online research panel survey. Hierarchical linear regression analysis with an interaction term was performed.

Results: A total of 4592 adolescents, aged 12 to 17 years, completed the survey. Adolescents reported a mean age of 14.61 (SD 1.68) and were 46.4% (2130/4592) female and 66.9% (3370/4592) White. Findings revealed that, controlling for adolescents’ demographics and social media use, higher levels of perceived parental supportiveness (β=–.285, *P*<.001) and higher levels of subjective mental well-being (β=–.079, *P*<.001) were associated with a lower likelihood of adolescent PIU. The moderation analysis showed that the negative association between perceived parental supportiveness and PIU was stronger when adolescents reported high (vs low) levels of mental well-being (β=–.191, *P*<.001).

Conclusions: This study shows that perceived parental supportiveness was a stronger protective factor than adolescents’ mental well-being against PIU. The protective power of perceived parental supportiveness against PIU was strongest when adolescents had high mental well-being. The highest risk of PIU occurred when adolescents’ mental well-being was high, but parents were perceived as unsupportive. Our findings suggest that parental supportiveness should be targeted as part of PIU prevention efforts.

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KEYWORDS

problematic internet use; PIU; subjective mental well-being; perceived parental supportiveness; adolescents; well-being; young adult; internet; mental health; support; parent; engagement; social media

Introduction

Background

Internet use has become a major part of adolescents' daily life. A recent survey indicates that 45% of US adolescents aged 13 to 17 years are on the internet almost constantly [1], a figure that has nearly doubled from the 24% who reported being online on a near-constant basis in 2014-2015 [2]. Moderate internet use can be beneficial to adolescent development by facilitating social connectedness, providing useful information and entertainment, and helping with instrumental tasks (eg, [3,4]). However, excessive internet use can cause serious side effects, such as physical impairment, interpersonal problems, and poor academic performance [5,6].

A growing literature has conceptualized excessive internet use that leads to negative consequences in users' lives as problematic internet use (PIU) [6,7]. Despite some disagreement on terminology and defining criteria [8], PIU is generally described as users' excessive preoccupation with and loss of control over their internet use, resulting in negative personal and professional consequences [6,7]. Internet use refers to accessing the internet for information, entertainment, social connectedness, or other purposes using any device [9].

Adolescence is a particularly vulnerable period for the onset of PIU [10] because adolescents tend to exhibit lower levels of self-regulation [11]. Given the rewarding nature of internet use, low self-regulation is associated with increased risk for PIU [11-15]. In fact, one study found that PIU is more likely to occur in adolescents than in any other population [16]. Adolescent PIU is especially detrimental because it is likely to co-occur with other risky behaviors such as alcohol and drug use [10]. Thus, untreated adolescent PIU may transform into serious internet addiction in adulthood [15]. Given the prevalence and adverse outcomes of PIU among adolescents, it is important to identify the factors associated with PIU in this population. Below, we detail how two key factors—perceived parental supportiveness and adolescents' subjective well-being—are expected to shape the development of adolescent PIU, separately and jointly.

Perceived Parental Supportiveness and PIU

Adolescents are embedded into a family system that exercises tremendous influence over their lives. Thus, an extensive literature has examined adolescent PIU in the context of family interactions, especially parental supportiveness. Parental supportiveness is defined as "the extent to which parents intentionally foster individuality, self-regulation, and self-assertion by being attuned, supportive, and acquiescent to children's special needs and demands" ([17]; see also Eastin et al [18]). Supportive parents provide meaningful explanations when setting limits and prohibitions on behavior, as well as unconditional positive regard for the child even when behavior does not match parents' expectations or desires [19]. As a result, parental supportiveness helps children internalize and embrace their parents' rules and values, thereby engaging in more prosocial behaviors [20,21]. Parental supportiveness has been shown to be key in promoting adolescents' healthy social behaviors, such as volunteering and donating [21], and decreasing their problematic behaviors, such as cyberbullying [20] and affiliating with a deviant peer [22].

In the context of PIU, studies with US, European, and Asian samples show that supportive parenting practices, as indicated by high parent-child cohesion [23], high-quality parental relationships [24], parent-child bonding [25], and supportive parental monitoring [26], are protective factors against adolescent PIU. By the same token, unsupportive parental practices, as indicated by love withdrawal [27], authoritarian parenting style [28], high parent-child conflict [26], and rejecting, overprotective, or demanding parenting [28], substantially contribute to the development of adolescent PIU. Theoretically, the role played by parental supportiveness in the development of adolescent PIU has been explained through a compensation mechanism [29,30], whereby supportive parenting provides adolescents with a safe haven for sociopsychological development, but unsupportive parenting acts as a significant stressor, prompting adolescents to seek validation, support, and higher-quality relationships on the internet. In turn, adolescents' reliance on the internet for compensating for deficits in parental supportiveness [29] can lead to overuse and compulsive use, the hallmarks of PIU [6-8]. An additional benefit of supportive parenting is that it improves adolescents' emotional regulation skills, making it less likely that they will develop problems with impulse control [31,32].

An important note is that it is possible that unsupportive parents perceive themselves as supportive regardless of how the adolescents actually feel [33]. Since adolescents' compensatory use of the internet is driven by their own perceptions of the family environment, this construct should be measured from the adolescents' perspective. Hence, we hypothesize:

> *Hypothesis 1: Higher perceived parental supportiveness will be associated with lower PIU among adolescents.*

Subjective Mental Well-Being and PIU

Mental health can be conceptualized along two dimensions: psychopathology and subjective well-being [34]. Psychopathology refers to a severe disturbance in individuals' actions, emotions, motivations, and cognitive and regulatory processes, causing distress and impairment in daily functioning [35]. Psychopathology is professionally diagnosed and includes disorders such as depression and anxiety. Subjective mental well-being, on the other hand, refers to the extent to which individuals experience optimal psychological functioning and a sense of thriving in their everyday life [36]. Subjective mental well-being includes an affective component (ie, the extent to which individuals experience positive, as opposed to negative, affect in everyday life) and a cognitive component (ie, the extent to which individuals are satisfied with their lives and feel agentic in tackling the challenges of everyday life) [36]. High subjective well-being is the result of high levels of positive affect, low levels of negative affect, and a high assessment of one's own functioning.

While the two perspectives of mental health (ie, psychopathology and mental well-being) are related to each other, they are nonetheless distinct [34]. Simply put, the absence of mental illness does not mean individuals experience optimal psychological functioning and thriving. For example, it is possible that a nondepressed person (ie, absence of psychopathology) experiences low levels of positive affect in everyday life and may be dissatisfied with current life circumstances (ie, low subjective mental well-being).

An extensive literature has investigated the connections between adolescents' mental health and their PIU, focusing primarily on psychopathology indicators such as depression and anxiety, and finding that they are significant risk factors for the development of adolescent PIU [12,37-40]. Recently, studies have turned their attention to dimensions of subjective mental well-being, given that these are more applicable to the broad population, as opposed to just clinical samples. Furthermore, PIU is considered a precursor to addiction, and therefore it is not itself an indicator of psychopathology. A similar pattern emerged across international samples, where high subjective mental well-being was robustly associated with low adolescent PIU [41-43], while indicators of low mental well-being, such as low self-esteem [14], self-control [15], and life satisfaction [13], were linked with high adolescent PIU.

High subjective mental well-being is theorized to act as a protective factor against the development of adolescent PIU because high-functioning individuals have more adaptive coping skills when faced with the stressors of daily life and are therefore less likely to turn to the internet to alleviate negative affective states [44]. The experience of sustained positive emotions also enables adolescents to think and act in more flexible and efficient ways, creating a cascade that builds enduring resources, both psychological and interpersonal [45]. Among these resources are better emotional regulation and impulse control, which protect against problematic engagement with the internet [44]. Consistent with these arguments, we hypothesize:

> *Hypothesis 2: Higher subjective mental well-being will be associated with lower PIU among adolescents.*

Interaction Effects of Subjective Mental Well-Being and Perceived Parental Supportiveness on PIU

While parental supportiveness contributes to high mental well-being among adolescents [46-48], mental well-being is considered a more comprehensive construct that may be related to, but not limited to, parental supportiveness [49]. Indeed, adolescent mental well-being is linked with a variety of other factors, such as the quality of peer relationships [50], peer support [51], sibling relationships [52], teacher caring [53,54], and academic achievement [55]. For example, a social environment with supportive parents but with low-quality peer relationships tends to result in significant impoverishment in adolescents' subjective mental well-being [49].

Both parental supportiveness and mental well-being are expected to be protective factors against adolescent PIU, yet little is known about whether and how these factors work jointly in shaping PIU. We expect that the protective role of perceived parental supportiveness should be stronger for those adolescents with higher subjective mental well-being, since highly functioning adolescents more easily internalize the value and rules of positive social behaviors that their parents try to motivate [20,21]. Not only should adolescents high in subjective well-being be more responsive to parents' supportiveness, thus eschewing PIU, but high parental supportiveness and high subjective well-being indicate a lack of significant stressors in daily life, which should also make it less likely for adolescents to turn to the internet in a compensatory manner. In other words, it is likely that the combination of high perceived parental supportiveness and high mental well-being is least likely to be associated with adolescent PIU.

On the other hand, those with low mental well-being and unsupportive parents should be especially vulnerable to PIU. As reviewed, unsupportive parenting may prompt adolescents to engage in excessive use of the internet [26-28], in an effort to compensate for an invalidating home environment [29,30]. Adolescents with low mental well-being may be more prone to engaging in this maladaptive practice because they lack good coping strategies to deal with stressful situations. Thus, it is likely that the strength of the negative association between parental supportiveness and PIU is weaker among those with low mental well-being than those with high mental well-being. In other words, the combination of low parental supportiveness and low mental well-being should be associated with the highest levels of PIU among adolescents. Thus, we hypothesize:

> *Hypothesis 3: High subjective mental well-being will moderate the association between perceived parental supportiveness and PIU, such that the negative association between perceived parental supportiveness and PIU will be stronger for adolescents with high mental well-being.*

Methods

Data Collection

The study analyzed one of the Technology & Adolescent Mental Wellness (TAM) data sets that were collected from a nationally representative cross-sectional sample administered by Qualtrics between March and April 2019. The primary purpose for the data collection was to understand parents' and adolescents' technology use and mental health. The target population was English-speaking US residents aged 12 to 17 years. We set the parameters for Qualtrics to recruit a sample consistent with the race/ethnicity composition of the US census population for 12- to 17–year-old subjects. Recruitment and sampling approaches were modeled after previous youth and media studies using Qualtrics [56,57]. This study reports on data provided by adolescents, with the exception of two socioeconomic variables—family income and family structure—which were reported by their parents or guardians. This study was reviewed and approved by the Institutional Review Board at the University of Wisconsin-Madison.

Measures

Problematic Internet Use

Adolescents completed the short version of the Problematic and Risky Internet Use Screening Scale (PRIUSS-3) [58]. The PRIUSS-3 was developed based on the PIU conceptual framework [6] and validated for use among adolescents and young adults [58], with strong reliability [59]. The PRIUSS-3 includes the following items: “how often do you experience increased social anxiety due to your internet use?,” “how often do you feel withdrawal when away from the internet?,” and “how often do you lose motivation to do other things that need to get done because of the internet?,” scored on a 5-point Likert scale from 0 (never) to 4 (very often). Items were summed to create a PIU score for each participant, ranging from 0 to 12 (mean 4.72, SD 3.50; Cronbach α=.87).

Perceived Parental Supportiveness

Adolescents answered the following questions about their relationship with their parent or guardian who took the survey with them using a 5-point Likert scale from 0 (never) to 4 (always) [46]: “how often does she/he praise you for doing well?,” “how often does she/he criticize you or your ideas?,” “how often does she/he help you do things that are important to you?,” “how often does she/he blame you for her/his problems?,” and “how often does she/he make plans with you and cancel for no good reason?.” The questionnaire demonstrated good reliability in previous research [46]. Items were recoded to indicate higher values as higher supportiveness. We removed an item (“how often does she/he criticize you or your ideas?”), which caused weak reliability. Responses were summed to create a score for each participant, ranging from 0 to 16 (mean 12.38, SD 3.2; Cronbach α=.79).

Subjective Mental Well-Being

The short version of the Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS) was used to measure adolescents’ mental well-being (7 items) [60]. The WEMWBS is a measure of mental well-being focusing entirely on positive aspects of mental health and shows strong criterion and content validity [60]. Adolescents reported how they felt in the past 2 weeks about the following statements on a scale from 1 (none of the time) to 5 (all of the time): “I’ve been feeling optimistic about the future,” “I’ve been feeling useful,” “I’ve been feeling relaxed,” “I’ve been dealing with problems well,” “I’ve been thinking clearly,” and “I’ve been able to make up my own mind about things.” Responses were summed to produce a score for each participant, ranging from 1 to 30 (mean 22.73, SD 4.35; Cronbach α=.83).

Socioeconomic and Social Media Use Variables

Age, gender, race, family income, family structure, school type, and social media use were included as covariates in the analysis. Respondents were asked to indicate their age, ranging from 12 to 17 years. Gender was coded with 1 being female and 2 being male. Race was coded with 1 being Caucasian and 0 being others. School type was categorized into 1 being public schools and 0 being others. Family income was assessed using 12 increasing income ranges (1=less than $20,000 to 12=more than $150,000). Family structure was coded with 1 being a parent who is divorced, separated, or widowed and 0 being others. Finally, frequency of checking social media was assessed on a scale from 1 (less than once a week) to 8 (almost constantly) [61].

Analytic Strategy

The hypotheses were tested through a hierarchical linear regression analysis conducted using the *lmSupport* package in R (R Core Team). Perceived parental supportiveness and subjective mental well-being were entered as independent variables and PIU as a dependent variable. We controlled for age, gender, race, family income, family structure, school type, and the frequency of checking social media. Predictors were mean-centered before they were entered in the moderated regression model. Multicollinearity was not an issue, with the variance inflation factor statistic for the predictors ranging from 0.52 to 1.93.

Results

A total of 4592 parent-adolescent (aged 12-17 years) dyads completed the survey. Adolescents’ mean age was 14.61 (SD 1.68) years, and the sample consisted of 46.4% (n=2130) females and 66.9% (n=3370) White individuals. Table 1 presents more descriptive information. Bivariate Pearson correlations among all variables included in this analysis are presented in Table 2.

Most caregivers identified themselves as a biological parent (n=3934, 85.7%), followed by stepparent (n=246, 5.4%), parent’s partner (living together) (n=137, 3.0%), adoptive parent (n=120, 2.6%), grandparent (n=106, 2.3%), other relative or guardian (n=26, 0.6%), and foster parent (n=12, 0.3%).

Table 1. Descriptive characteristics (N=4592).

Characteristic	Participants
Age (years), mean (SD)	14.61 (1.68)
Gender, n (%)	
Female	2130 (46.4)
Male	2392 (52.1)
Nonbinary gender	23 (0.5)
Female-to-male transgender	25 (0.5)
Male-to-female transgender	5 (0.1)
Prefer not to answer	17 (0.4)
Race/ethnicity, n (%)	
White/Caucasian	3370 (66.9)
Black or African American	699 (15.2)
American Indian/Alaska Native	116 (2.5)
Asian	211 (4.5)
Asian Indian	17 (0.4)
Other Asian	7 (0.2)
Native Hawaiian/other Pacific Islander	36 (0.8)
Multiracial	221 (4.8)
Other	31 (0.7)
Prefer not to answer	82 (1.8)
Latino/Hispanic/Mexican	101 (2.2)
Family income (US$)[a], n (%)	
Less than $9,999	235 (5.1)
$10,000-$19,999	310 (6.8)
$20,000-$29,999	417 (9.1)
$30,000-$39,999	441 (9.6)
$40,000-$49,999	385 (8.4)
$50,000-$59,999	440 (9.6)
$60,000-$69,999	306 (6.7)
$70,000-$79,999	399 (8.7)
$80,000-$89,999	266 (5.8)
$90,000-$99,999	322 (7.0)
$100,000-$149,999	694 (15.1)
More than $150,000	368 (8.0)
Family structure[a], n (%)	
Married	2921 (63.6)
Living with a partner	440 (9.6)
Divorced	389 (8.5)
Separated	136 (3.0)
Widowed	94 (2.0)
Never married	568 (12.4)
Prefer not to answer	44 (1.0)

Characteristic	Participants
School type, n (%)	
Public school (middle or high school)	3585 (78.1)
Private school (middle or high school)	568 (12.4)
Home schooled	207 (4.5)
Online school	106 (2.3)
Public 4-year college	82 (1.8)
Not currently in school	23 (0.5)
Prefer not to answer	19 (0.4)
Social media use, mean (SD)	
Frequency of checking social media	5.15 (2.06)

[a] This item was answered by parents or guardians who took the survey with the adolescents.

Table 2. Pearson correlation coefficients for all variables.

Variables	1	2	3	4	5	6	7	8	9	10
1. Age	—[a]	—	—	—	—	—	—	—	—	—
2. Gender	–0.021	—	—	—	—	—	—	—	—	—
3. Race	0.059[b]	0.065[b]	—	—	—	—	—	—	—	—
4. Family income	0.026	0.115[b]	0.160[b]	—	—	—	—	—	—	—
5. Family structure	0.052[b]	–0.032[d]	–0.024	–0.218[b]	—	—	—	—	—	—
6. School type	0.007	–0.058[b]	–0.049[c]	–0.102[b]	–0.041[c]	—	—	—	—	—
7. Frequency of checking social media	0.047[c]	–0.048[e]	0.038[d]	0.059[b]	–0.069[b]	–0.069[b]	—	—	—	—
8. Mental well-being	–0.010	0.047[c]	0.046[c]	0.114[c]	–0.036[d]	–0.004	–0.005	—	—	—
9. Parental supportiveness	0.057[b]	–0.081[b]	0.011	–0.069[b]	0.079[b]	0.152[b]	–0.146[b]	0.228[b]	—	—
10. Problematic internet use	–0.045[c]	0.040[c]	0.083[b]	0.106[b]	–0.066[b]	–0.140[b]	0.353[b]	–0.104[b]	–0.366[b]	—

[a] The correlation coefficient is not displayed since it is shown in the asymmetrically diagonal position of the table.

[b] Correlations significant at the *P*=.001 level.

[c] Correlations significant at the *P*=.01 level.

[d] Correlations significant at the *P*=.05 level.

Standardized coefficients, standard errors, and *P* values for the independent variables and all covariates are summarized in Table 3. PIU was associated with being younger (β=–.072, *P*<.001), being White (β=.053, *P*<.001), having a higher family income (β=.050, *P*=.002), attending nonpublic school (β=–.060, *P*<.001), and using social media more often (β=.277, *P*<.001).

There was a statistically significant negative relationship between perceived parental supportiveness and PIU (β=–.275, *P*<.001), meaning that adolescents who perceived their parents as more supportive were less likely to engage in PIU. Thus, hypothesis 1 was supported. Similarly, there was a statistically significant negative association between subjective mental well-being and PIU (β=–.079, *P*<.001), meaning that adolescents with higher levels of subjective mental well-being were less likely to be engaged in PIU. Thus, hypothesis 2 was supported.

A statistically significant interaction effect of perceived parental supportiveness and subjective well-being on PIU also emerged (β=–.191, *P*<.001), meaning that the protective power of perceived parental supportiveness against PIU was strongest when adolescents had high mental well-being, supporting hypothesis 3.

Simple slope analyses for the association between perceived parental supportiveness and PIU were calculated at the mean (1 SD) level for subjective mental well-being, using the Johnson-Neyman techniques [62]. At mean – 1 SD of subjective mental well-being, the slope was b=–.12, SE 0.02, *t*=–4.98, *P*<.001. At mean + 1 SD of subjective mental well-being, the slope was b=–.49, SE 0.02, *t*=–20.88, *P*<.001. This revealed that the negative association between perceived parental supportiveness and PIU was significantly stronger for those with high subjective mental well-being than for those with low subjective mental well-being (Figure 1). Thus, the protective power of perceived parental supportiveness against PIU was highest when adolescents had high mental well-being.

Table 3. Hierarchical regression analysis examining the relationships between problematic internet use, perceived parental supportiveness, and subjective mental well-being (N=4592)[a].

Variable	Problematic internet use		*P* value	ΔR^2 (%) (total R^2=28.5%)
	β	SE		
Control variables				22.2
Age	–.072	0.032	<.001	
Gender[b]	.002	0.107	.90	
Race[c]	.053	0.115	<.001	
Family income	.050	0.016	.002	
Family structure[d]	–.020	0.160	.22	
School type[e]	–.060	0.135	<.001	
Frequency of checking social media	.277	0.027	<.001	
Independent variables				4.2
Perceived parental supportiveness	–.285	0.018	<.001	
Subjective mental well-being	–.079	0.011	<.001	
Interactions				2.2
Perceived parental supportiveness × subjective mental well-being	–.191	0.003	<.001	

[a] All coefficients are standardized. Predictors are mean-centered.

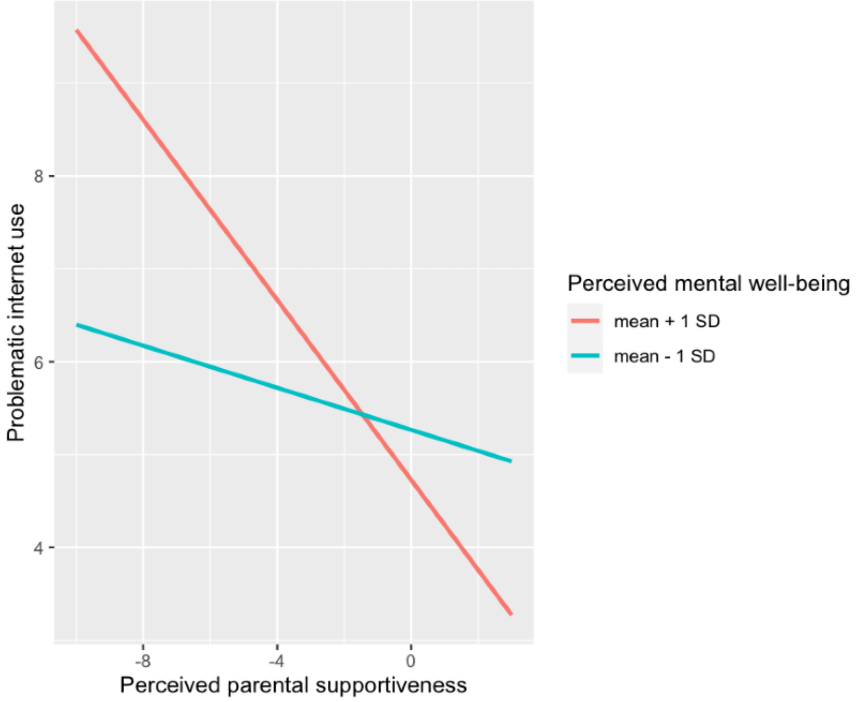
[b] Female=1, male=2.

[c] White=1, others=0.

[d] Divorced, separated, or widowed parent=1, others=0.

[e] Public school=1, others=0.

Figure 1. Interaction effect between perceived parental supportiveness and subjective mental well-being on problematic internet use.



Discussion

Principal Findings

PIU among adolescents is a public health concern due to its high prevalence and detrimental impact on adolescents' physical, social, and academic development [5,6]. The goal of this study was to examine the role played by two psychological factors in the development of adolescent PIU—perceived parental supportiveness and subjective mental well-being—through a large, nationally representative survey of US adolescents aged 12 to 17 years.

Our main findings can be summarized as follows: the more adolescents perceived their parents as supportive, the less PIU they reported, consistent with research that shows adolescents who perceive their parents as supportive internalize rules and values for prosocial behavior and do not need to resort to internet use to compensate for deficits in parental supportiveness. Similarly, better mental well-being among adolescents was associated with lower PIU, supporting claims by previous research [44,45] that high-functioning individuals have more adaptive coping skills, better emotional regulation, and more internal resources for coping with everyday stressors, without turning to the internet as a refuge or distraction. Notably, the effect of perceived parental supportiveness on PIU was quite large (β=–.278, P<.001) and substantially larger than the effect of subjective mental well-being on PIU (β=–.071, P<.001), indicating that perceived parental supportiveness may be a key driver of PIU in adolescents, and thus merits attention in future research.

Finally, the negative association between PIU and perceived parental supportiveness increased for adolescents with high mental well-being (Figure 1). PIU was lowest among adolescents with supportive parents and high mental well-being, which indicates that, unsurprisingly, those who are well adjusted and come from supportive environments are protected against risky behaviors such as PIU. However, an unexpected result emerged: PIU was highest among those with unsupportive parents and *high* mental well-being. While we do not have data on either adolescents' motivations for spending excessive amounts of time on the internet or on the specific activities they undertake online, we have argued that adolescents who perceive their parents as unsupportive turn to the internet to find solace, companionship, and understanding, consistent with the compensation mechanism articulated by prior research [29,30]. This finding suggests that it is highly functioning adolescents who are more likely to engage in this compensatory use of the internet. Those who have higher mental well-being may be better attuned to the opportunities provided by the internet to compensate for face-to-face deficits—in our case, a lack of parental supportiveness—and more agentic in pursuing those opportunities. Unfortunately, however, the more time they spend online, likely communicating with peers or seeking other opportunities for fun and relaxation (eg, video games), the more likely they are to rely on the internet to a problematic extent.

We conducted additional analyses to investigate the possibility that adolescents who perceive their parents as unsupportive seek social connections on the internet, potentially in an effort to foster relationships that compensate for low parental supportiveness. A regression model with social media use as the dependent variable and parental supportiveness and mental well-being as independent variables (Multimedia Appendix 1) confirmed that social media use was highest among those with unsupportive parents and high mental well-being. Since social media is a venue for fostering social connections, primarily with peers, this finding provides support for the social compensation hypothesis, whereby teens who perceive their parents as unsupportive parents go online to seek more meaningful social connections (see also Anderson and Jiang [1] and Barker [30]). Initially, this compensatory internet use may be an adaptive practice, but the rewarding nature of the internet can prompt increasing use and overreliance, putting adolescents on a slippery slope toward PIU and later on even internet addiction.

An intriguing issue that should be investigated by future research concerns the interplay between PIU/internet addiction and subjective mental well-being over time. While adolescents with unsupportive parents in our sample maintained high levels of subjective mental well-being even as they engaged in high PIU, it is likely that as PIU continues over time it can lead to a deterioration in subjective mental well-being, and even to psychopathology, supporting the large body of research that finds depression and anxiety to be strongly linked with PIU and internet addiction in young adults [12,37-40]. Although most studies to date are cross-sectional and treat PIU as the outcome of mental health indicators, it is likely that the causal relationship between PIU and mental health is bidirectional, with both variables influencing each other over time. Thus, it is possible that high levels of PIU will, in turn, negatively impact adolescents' mental well-being in the long run.

Given this state of affairs, we argue that adolescence is a tremendously important point for intervention, before PIU turns into full-blown internet addiction and before it leads to a deterioration in adolescents' well-being. Perceptions of parental unsupportiveness were the strongest driver of problematic usage, even among adolescents who otherwise experienced high well-being. Thus, perceived parental supportiveness is a key factor that should be targeted. For example, PIU prevention should include training for parents to improve their communication skills and provide appropriate discipline, but also validation and companionship, for their adolescents.

Limitations and Future Directions

This study has several limitations. While associations were observed between PIU and subjective mental well-being and perceived parental supportiveness, the cross-sectional nature of the study does not permit insight into temporal or causal relationships. Future longitudinal studies are necessary to understand what factors protect adolescents against PIU. This study did not differentiate between diverse types of internet use (eg, video gaming, chatting, social networking sites, etc). PIU in these different online contexts may relate differently to subjective mental well-being and perceived parental supportiveness. Furthermore, the measures are all self-reported by adolescents and thus are limited by their ability and willingness to recall and report information accurately.

Conclusion

Despite these limitations, this study contributes to the literature by finding a meaningful interplay between adolescents' mental well-being and their perception of parental supportiveness in shaping PIU. This helps illuminate the conditions under which adolescent PIU emerges.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Interaction effect between subjective mental well-being and perceived parental supportiveness on the frequency of checking social media.

[DOCX File , 89 KB - mental_v8i9e26203_app1.docx]

References

1. Anderson M, Jiang J. Teens, Social Media and Technology 2018. Pew Research Center. 2018 May 31. URL: https://www.pewresearch.org/internet/2018/05/31/teens-social-media-technology-2018/ [accessed 2021-06-11]
2. Lenhart A. Pew Research Center. 2015 Apr 9. URL: https://www.pewresearch.org/internet/2015/04/09/teens-social-media-technology-2015/ [accessed 2021-06-09]
3. Jackson LA, von Eye A, Witt EA, Zhao Y, Fitzgerald HE. A longitudinal study of the effects of Internet use and videogame playing on academic performance and the roles of gender, race and income in these relationships. Computers in Human Behavior 2011 Jan;27(1):228-239. [doi: 10.1016/j.chb.2010.08.001]
4. Liu Q, Fang X, Deng L, Zhang J. Parent–adolescent communication, parental Internet use and Internet-specific norms and pathological Internet use among Chinese adolescents. Computers in Human Behavior 2012 Jul;28(4):1269-1275. [doi: 10.1016/j.chb.2012.02.010]
5. D'Angelo J, Moreno MA. Screening for Problematic Internet Use. Pediatrics 2020 May;145(Suppl 2):S181-S185 [FREE Full text] [doi: 10.1542/peds.2019-2056F] [Medline: 32358209]
6. Moreno MA, Jelenchick LA, Christakis DA. Problematic internet use among older adolescents: A conceptual framework. Computers in Human Behavior 2013 Jul;29(4):1879-1887. [doi: 10.1016/j.chb.2013.01.053]
7. Cheever N, Moreno M, Rosen L. When does internet and smartphone use become a problem? In: Technology and Adolescent Mental Health. Cham: Springer International Publishing; 2018:121-131.
8. Spada MM. An overview of problematic internet use. Addict Behav 2014 Jan;39(1):3-6. [doi: 10.1016/j.addbeh.2013.09.007] [Medline: 24126206]
9. Lai FT, Kwan JL. Socioeconomic influence on adolescent problematic Internet use through school-related psychosocial factors and pattern of Internet use. Computers in Human Behavior 2017 Mar;68:121-136. [doi: 10.1016/j.chb.2016.11.021]
10. Gómez P, Harris SK, Barreiro C, Isorna M, Rial A. Profiles of Internet use and parental involvement, and rates of online risks and problematic Internet use among Spanish adolescents. Computers in Human Behavior 2017 Oct;75:826-833. [doi: 10.1016/j.chb.2017.06.027]
11. Li D, Zhang W, Li X, Zhen S, Wang Y. Stressful life events and problematic Internet use by adolescent females and males: A mediated moderation model. Computers in Human Behavior 2010 Sep;26(5):1199-1207. [doi: 10.1016/j.chb.2010.03.031]
12. Caplan S. Problematic internet use in the workplace. In: The Internet and Workplace Transformation. New York, NY: Routledge; 2006:63.
13. Cao H, Sun Y, Wan Y, Hao J, Tao F. Problematic Internet use in Chinese adolescents and its relation to psychosomatic symptoms and life satisfaction. BMC Public Health 2011 Oct 14;11:802 [FREE Full text] [doi: 10.1186/1471-2458-11-802] [Medline: 21995654]
14. Fioravanti G, Primi C, Casale S. Psychometric evaluation of the Generalized Problematic Internet Use Scale 2 in an Italian sample. Cyberpsychol Behav Soc Netw 2013 Oct;16(10):761-766. [doi: 10.1089/cyber.2012.0429] [Medline: 23742149]
15. Park S, Kang M, Kim E. Social relationship on problematic Internet use (PIU) among adolescents in South Korea: A moderated mediation model of self-esteem and self-control. Computers in Human Behavior 2014 Sep;38:349-357. [doi: 10.1016/j.chb.2014.06.005]
16. Karacic S, Oreskovic S. Internet Addiction Through the Phase of Adolescence: A Questionnaire Study. JMIR Ment Health 2017 Apr 03;4(2):e11 [FREE Full text] [doi: 10.2196/mental.5537] [Medline: 28373154]

17. Baumrind D. The Influence of Parenting Style on Adolescent Competence and Substance Use. The Journal of Early Adolescence 2016 Jul 26;11(1):56-95. [doi: 10.1177/0272431691111004]
18. Eastin M, Greenberg B, Hofschire L. Parenting the internet. Journal of Communication 2006;56(3):486-504. [doi: 10.1111/j.1460-2466.2006.00297.x]
19. Assor A, Roth G, Deci EL. The emotional costs of parents' conditional regard: a self-determination theory analysis. J Pers 2004 Feb;72(1):47-88. [doi: 10.1111/j.0022-3506.2004.00256.x] [Medline: 14686884]
20. Legate N, Weinstein N, Przybylski AK. Parenting Strategies and Adolescents' Cyberbullying Behaviors: Evidence from a Preregistered Study of Parent-Child Dyads. J Youth Adolesc 2019 Feb;48(2):399-409. [doi: 10.1007/s10964-018-0962-y] [Medline: 30478820]
21. Gagné M. The role of autonomy support and autonomy orientation in prosocial behavior engagement. Motivation and emotion 2003 Sep;27(3):199-223. [doi: 10.1023/A:1025007614869]
22. Soenens B, Vansteenkiste M, Niemiec C. Should parental prohibition of adolescents' peer relationships be prohibited? Personal Relationships 2009 Sep 08;16(4):507-530. [doi: 10.1111/j.1475-6811.2009.01237.x]
23. Park SK, Kim JY, Cho CB. Prevalence of Internet addiction and correlations with family factors among South Korean adolescents. Adolescence 2008;43(172):895-909. [Medline: 19149152]
24. Bleakley A, Ellithorpe M, Romer D. The Role of Parents in Problematic Internet Use among US Adolescents. MaC 2016 Jun 16;4(3):24-34. [doi: 10.17645/mac.v4i3.523]
25. Siomos K, Floros G, Fisoun V, Evaggelia D, Farkonas N, Sergentani E, et al. Evolution of Internet addiction in Greek adolescent students over a two-year period: the impact of parental bonding. Eur Child Adolesc Psychiatry 2012 Apr;21(4):211-219. [doi: 10.1007/s00787-012-0254-0] [Medline: 22311146]
26. Yen J, Yen C, Chen C, Chen S, Ko C. Family factors of internet addiction and substance use experience in Taiwanese adolescents. Cyberpsychol Behav 2007 Jun;10(3):323-329. [doi: 10.1089/cpb.2006.9948] [Medline: 17594255]
27. Li X, Li D, Newman J. Parental behavioral and psychological control and problematic internet use among Chinese adolescents: the mediating role of self-control. Cyberpsychol Behav Soc Netw 2013 Jun;16(6):442-447. [doi: 10.1089/cyber.2012.0293] [Medline: 23509987]
28. Xiuqin H, Huimin Z, Mengchen L, Jinan W, Ying Z, Ran T. Mental health, personality, and parental rearing styles of adolescents with Internet addiction disorder. Cyberpsychol Behav Soc Netw 2010 Aug;13(4):401-406. [doi: 10.1089/cyber.2009.0222] [Medline: 20712498]
29. Valkenburg PM, Peter J. Social Consequences of the Internet for Adolescents. Curr Dir Psychol Sci 2009 Feb 01;18(1):1-5. [doi: 10.1111/j.1467-8721.2009.01595.x]
30. Barker V. Older adolescents' motivations for social network site use: the influence of gender, group identity, and collective self-esteem. Cyberpsychol Behav 2009 Apr;12(2):209-213. [doi: 10.1089/cpb.2008.0228] [Medline: 19250021]
31. Sela Y, Zach M, Amichay-Hamburger Y, Mishali M, Omer H. Family environment and problematic internet use among adolescents: The mediating roles of depression and Fear of Missing Out. Computers in Human Behavior 2020 May;106:106226. [doi: 10.1016/j.chb.2019.106226]
32. Bulanda RE, Majumdar D. Perceived Parent–Child Relations and Adolescent Self-Esteem. J Child Fam Stud 2008 Jul 29;18(2):203-212. [doi: 10.1007/s10826-008-9220-3]
33. McNeely CA, Barber BK. How Do Parents Make Adolescents Feel Loved? Perspectives on Supportive Parenting From Adolescents in 12 Cultures. Journal of Adolescent Research 2010 Jan 27;25(4):601-631. [doi: 10.1177/0743558409357235]
34. Meier A, Reinecke L. Computer-Mediated Communication, Social Media, and Mental Health: A Conceptual and Empirical Meta-Review. Communication Research 2020 Oct 21. [doi: 10.1177/0093650220958224]
35. Lahey BB, Krueger RF, Rathouz PJ, Waldman ID, Zald DH. Validity and utility of the general factor of psychopathology. World Psychiatry 2017 Jun 12;16(2):142-144 [FREE Full text] [doi: 10.1002/wps.20410] [Medline: 28498590]
36. Diener E, Oishi S, Tay L. Advances in subjective well-being research. Nat Hum Behav 2018 Apr 12;2(4):253-260. [doi: 10.1038/s41562-018-0307-6] [Medline: 30936533]
37. Gámez-Guadix M. Depressive symptoms and problematic internet use among adolescents: analysis of the longitudinal relationships from the cognitive-behavioral model. Cyberpsychol Behav Soc Netw 2014 Nov;17(11):714-719 [FREE Full text] [doi: 10.1089/cyber.2014.0226] [Medline: 25405784]
38. Park S, Hong KM, Park EJ, Ha KS, Yoo HJ. The association between problematic internet use and depression, suicidal ideation and bipolar disorder symptoms in Korean adolescents. Aust N Z J Psychiatry 2013 Feb 09;47(2):153-159. [doi: 10.1177/0004867412463613] [Medline: 23047959]
39. Ceyhan AA, Ceyhan E. Loneliness, depression, and computer self-efficacy as predictors of problematic internet use. Cyberpsychol Behav 2008 Dec;11(6):699-701. [doi: 10.1089/cpb.2007.0255] [Medline: 19072150]
40. Tan Y, Chen Y, Lu Y, Li L. Exploring Associations between Problematic Internet Use, Depressive Symptoms and Sleep Disturbance among Southern Chinese Adolescents. Int J Environ Res Public Health 2016 Mar 14;13(3):313 [FREE Full text] [doi: 10.3390/ijerph13030313] [Medline: 26985900]
41. Odacı H, Çıkrıkçı. Problematic internet use in terms of gender, attachment styles and subjective well-being in university students. Computers in Human Behavior 2014 Mar;32:61-66. [doi: 10.1016/j.chb.2013.11.019]

42. Mei S, Yau YH, Chai J, Guo J, Potenza MN. Problematic Internet use, well-being, self-esteem and self-control: Data from a high-school survey in China. Addict Behav 2016 Oct;61:74-79 [FREE Full text] [doi: 10.1016/j.addbeh.2016.05.009] [Medline: 27249805]
43. Satici B, Yilmaz M. How Does Problematic Internet Use Mediate The Relation Between Belongingness And Mental Well-Being? Turkish Psychological Counseling and Guidance Journal 2020 Jun 19;10(57):277-295 [FREE Full text]
44. Casale S, Lecchi S, Fioravanti G. The association between psychological well-being and problematic use of Internet communicative services among young people. J Psychol 2015;149(5):480-497. [doi: 10.1080/00223980.2014.905432] [Medline: 25975575]
45. Park N. The Role of Subjective Well-Being in Positive Youth Development. The Annals of the American Academy of Political and Social Science 2016 Sep 08;591(1):25-39. [doi: 10.1177/0002716203260078]
46. Hair EC, Moore KA, Garrett SB, Ling T, Cleveland K. The Continued Importance of Quality Parent–Adolescent Relationships During Late Adolescence. J Research on Adolescence 2008 Mar;18(1):187-200. [doi: 10.1111/j.1532-7795.2008.00556.x]
47. Milevsky A, Schlechter M, Netter S, Keehn D. Maternal and Paternal Parenting Styles in Adolescents: Associations with Self-Esteem, Depression and Life-Satisfaction. J Child Fam Stud 2006 Sep 13;16(1):39-47. [doi: 10.1007/s10826-006-9066-5]
48. Bean RA, Barber BK, Crane DR. Parental Support, Behavioral Control, and Psychological Control Among African American Youth. Journal of Family Issues 2016 Jun 30;27(10):1335-1355. [doi: 10.1177/0192513x06289649]
49. Ryan RM, Deci EL. On happiness and human potentials: a review of research on hedonic and eudaimonic well-being. Annu Rev Psychol 2001 Feb;52(1):141-166. [doi: 10.1146/annurev.psych.52.1.141] [Medline: 11148302]
50. McMahon G, Creaven A, Gallagher S. Stressful life events and adolescent well-being: The role of parent and peer relationships. Stress Health 2020 Aug;36(3):299-310. [doi: 10.1002/smi.2923] [Medline: 31920010]
51. Rigby K. Effects of peer victimization in schools and perceived social support on adolescent well-being. J Adolesc 2000 Feb;23(1):57-68. [doi: 10.1006/jado.1999.0289] [Medline: 10700372]
52. Sherman AM, Lansford JE, Volling BL. Sibling relationships and best friendships in young adulthood: Warmth, conflict, and well-being. Personal Relationships 2006 Jun;13(2):151-165. [doi: 10.1111/j.1475-6811.2006.00110.x]
53. LaRusso MD, Romer D, Selman RL. Teachers as Builders of Respectful School Climates: Implications for Adolescent Drug Use Norms and Depressive Symptoms in High School. J Youth Adolescence 2007 Aug 24;37(4):386-398. [doi: 10.1007/s10964-007-9212-4]
54. DuBois DL, Silverthorn N. Natural mentoring relationships and adolescent health: evidence from a national study. Am J Public Health 2005 Mar;95(3):518-524. [doi: 10.2105/AJPH.2003.031476] [Medline: 15727987]
55. Duncan MJ, Patte KA, Leatherdale ST. Mental Health Associations with Academic Performance and Education Behaviors in Canadian Secondary School Students. Canadian Journal of School Psychology 2021 Feb 25. [doi: 10.1177/0829573521997311]
56. Moreno MA, Binger K, Zhao Q, Eickhoff J. Measuring Interests Not Minutes: Development and Validation of the Adolescents' Digital Technology Interactions and Importance Scale (ADTI). J Med Internet Res 2020 Feb 12;22(2):e16736 [FREE Full text] [doi: 10.2196/16736] [Medline: 32049068]
57. Heen MS, Lieberman JD, Miethe TD. A Comparison of Different Online Sampling Approaches for Generating National Samples. Center for Crime and Justice Policy. Nevada, LV: University of Nevada, Las Vegas; 2014. URL: https://www.unlv.edu/sites/default/files/page_files/27/ComparisonDifferentOnlineSampling.pdf [accessed 2021-06-18]
58. Moreno MA, Arseniev-Koehler A, Selkie E. Development and Testing of a 3-Item Screening Tool for Problematic Internet Use. J Pediatr 2016 Sep;176:167-172.e1 [FREE Full text] [doi: 10.1016/j.jpeds.2016.05.067] [Medline: 27395768]
59. Jelenchick L, Hawk S, Moreno M. Problematic internet use and social networking site use among Dutch adolescents. Int J Adolesc Med Health 2016 Feb;28(1):119-121. [doi: 10.1515/ijamh-2014-0068] [Medline: 25720115]
60. Tennant R, Hiller L, Fishwick R, Platt S, Joseph S, Weich S, et al. The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation. Health Qual Life Outcomes 2007 Nov 27;5:63 [FREE Full text] [doi: 10.1186/1477-7525-5-63] [Medline: 18042300]
61. Primack BA, Shensa A, Sidani JE, Whaite EO, Lin LY, Rosen D, et al. Social Media Use and Perceived Social Isolation Among Young Adults in the U.S. Am J Prev Med 2017 Jul;53(1):1-8 [FREE Full text] [doi: 10.1016/j.amepre.2017.01.010] [Medline: 28279545]
62. Johnson PO, Neyman J. Tests of certain linear hypotheses and their application to some educational problems. Statistical Research Memoirs 1936;1:57-93.

Abbreviations

PIU: problematic internet use
PRIUSS-3: Problematic and Risky Internet Use Screening Scale
SWEMWBS: Warwick-Edinburgh Mental Well-Being Scale–short version
TAM: Technology & Adolescent Mental Wellness
WEMWBS: Warwick-Edinburgh Mental Well-Being

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Original Paper

Young Sexual Minority Adolescent Experiences of Self-expression and Isolation on Social Media: Cross-sectional Survey Study

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Abstract

Background: Early adolescent years are marked by pervasive self- and peer-regulation regarding gender and sexuality norms, which can affect the mental well-being of sexual minority youth. During this developmental period, social media use is also emerging as a dominant mode of communication with peers, allowing for both risk and resilient behaviors that can impact well-being.

Objective: This exploratory study aims to examine how sexual minorities in middle school use social media, who they are connected to and for what purposes, and the associations between these behaviors and mental well-being compared with their heterosexual peers.

Methods: In our cross-sectional survey study of 1033 early adolescents aged between 10 and 16 years (average age 12.7, SD 1.21 years) from 4 middle school sites in the Northeastern United States, we conducted an exploratory study comparing sexual minorities (212/873, 24.3% of sample with known sexual orientation) with their heterosexual peers (n=661), obtaining an 84.46% (1033/1223; total possible) response rate.

Results: Sexual minorities reported having smaller networks on their favorite social media website (β=−.57; *P*<.001), less often responded positively when friends shared good news (β=−.35; *P*=.002), and less often tried to make friends feel better when they shared bad news (β=−.30; *P*=.01). However, sexual minorities more often reported joining a group or web-based community to make themselves feel less alone (β=.28; *P*=.003), unlike heterosexual youth. Sexual minorities had higher averages of loneliness and social isolation (β=.19; *P*<.001) than heterosexual students. Sexual minorities were also twice as likely to have tried to harm themselves in the past (β=.81; odds ratio [OR] 2.24, 95% CI 1.64-3.06; *P*<.001) and were more likely to have symptoms that reached the Center for Epidemiological Studies-Depression definition of depression (β=.15; OR 1.16, 95% CI 1.08-1.25; *P*<.001). About 39.1% (83/212) of sexual minorities had no one to talk to about their sexual orientation. Sexual minorities were 1.5 times more likely to have joined a social media website their parents would disapprove (β=.41; OR 1.50, 95% CI 1.14-1.97; *P*=.004) and more likely to report seeing videos related to self-harm (β=.33; OR 1.39, 95% CI 1.06-1.83; *P*=.02) on the web than heterosexual youth.

Conclusions: Given previous reports of supportive and safe web-based spaces for sexual minority youth, our findings demonstrated that sexual minority youth prefer to maintain small, close-knit web-based communities (apart from their families) to express themselves, particularly when reaching out to web-based communities to reduce loneliness. Future longitudinal studies could determine any bidirectional influences of mental well-being and social media use in sexual minorities during this difficult developmental period.

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KEYWORDS

social media; social networking sites; sexual minorities; cyberbullying; depression; loneliness; self-harm; social support; adolescents

Introduction

Background

Web-based communication opportunities via mobile devices, internet, and social media platforms remain a largely understudied context of sexual minority youth [1], defined in this study as youth who identify as gay, lesbian, bisexual, asexual, queer, questioning, or otherwise do not identify as heterosexual. Of these youth, 97% use at least one social media website. It is also known that adolescents are adopting social media at an earlier age, with YouTube, Instagram, and Snapchat surpassing Facebook as the most popular social media websites for youth aged from 13 to 17 years [2]. These web-based opportunities are particularly critical sources of risk and resilience to sexual minority youth given the disproportionate risks and limited access to social support they face in other contexts, such as home, school, and community [3]. Studies on sexual minority youths' use of web-based communication technologies are rarely compared with their heterosexual peers. The Gay Lesbian Straight Education Network [4] analyzed data from 2010 and 2011 demonstrating that lesbian, gay, bisexual, transgender, or queer (LGBTQ) youth (aged 13-18 years, n=1960) spend about 45 minutes longer on the web on a daily basis than their heterosexual peers. A recent large study of 6309 youth aged 14-29 years found that less traditional sexual minority categories, including pansexual, asexual, queer, and gender nonconforming youth, are more likely to spend time on the web compared with other youth [1]. Scholars have theorized that sexual minority youth may be avid social media users because of frequent social exclusion in their offline lives [4]. More recent research has revealed that social media can also enhance the well-being of sexual minority youth by providing safe and accessible contexts to develop social support networks, such as exploring emerging sexual minority identities, locating and coming out to other sexual minority peers, and accessing identity-specific web-based resources [1].

Early Adolescence as an Understudied Age Group

In the United States, the Federal Children's Online Privacy Protection Act prevents individuals aged younger than 13 years from signing up for social media accounts, such as Facebook, Instagram, Snapchat, or TikTok [5]. Despite this regulation, a recent study estimated that almost half (49%) of adolescents aged 11 years or younger had a social media account, and by age 14, this increased to 85% [6]. In a recent review of social media research [7], which provided a summary of systematic reviews across 371 studies, the vast majority of studies examining the effects of social media focused on either young children or adults; when adolescents were investigated, the developmental stages within adolescence were not delineated. The authors of this review argue that early adolescence is still the most neglected developmental period, despite the fact that it is likely one of the most relevant and consequential times to examine relationships between social media and mental health. As adolescents transition biologically and socially into new school and digital environments, they are often most susceptible to peer influence effects, primarily because of increased identity exploration, more unsupervised time spent with peers, and the need for peer validation and approval [8].

The early adolescent years are also marked by pervasive self- and peer-regulation regarding gender and sexuality norms [9]. Peer influence and opinion are especially salient during this developmental period when youth experience more prejudicial and homophobic behaviors [10], making it an especially difficult time to come out as a sexual minority [11]. As societal attitudes change and LGBTQ individuals are more socially accepted, the average age of *coming out* has also shifted. Russell et al [12] noted a trend moving from an average coming-out age of 20 years in the 1970s to around 16 years in the 1990s to approximately 14 years in 2010 [13]. Despite the decades-ago trend that adolescents are coming out at younger ages, the vast majority of studies on sexual minorities and their mental health focus on older adolescents [1,4] and young adults in college years [1], as opposed to the early stages of self-realization, in which young adolescents must decide when and where to come out, both on the web and offline. Thus, the studies described below that used the terms *youth* or *young adults* most often refer to those aged 18 years and older, unless otherwise indicated.

Sexual Minority Identity Development on the Web

Identity development in sexual minority populations refers to the process by which sexual minority adolescents learn to ascribe meaning and labels to their nonnormative experiences of sexuality [14,15]. As a new generation of youth come of age on the web, the internet serves as a major arena for forming and developing these identities. Fox and Ralston [16] found that participants in the process of LGBTQ identity formation often used social media as a tool to actively learn about themselves, their identities, and their communities, whether this engagement took the form of traditional information-seeking, experiential participation in the LGBTQ community, or observing the behaviors of LGBTQ role models on the internet. In a study of same-sex attracted youth aged from 14 to 21 years, Hillier and Harrison [17] also found that digital spaces served as arenas for discussing experiences of coming out, practicing same-sex dating, and forming friendships with other sexual minority youth, in relative safety compared with sexual minority youth's offline environments.

Recent research has suggested a developmental trajectory wherein younger adolescents spend time in web-based LGBTQ communities exploring their identities through sharing content, microblogging, and participating in fandom activities using websites such as Instagram, whereas older adolescents and young adults use traditional networking websites such as Facebook to establish professional, romantic, and social connections branching out beyond their identity communities [1]. Web-based fandoms, which media scholars define as an "imagined and imaginative community" [18] based around the participatory consumption of popular culture, have been found to be a particularly salient form of web-based community for youth newly identifying as sexual minority. Fandom communities allow users to explore and experiment both inwardly and outwardly with their emergent identities, providing low-risk, protected web-based spaces where sexual minority youth are not required to connect their fandom identities with their *real* names or even commit themselves to a particular sexual identity label [19]. For example, sexual minority users might prefer to look at artwork with characters that resonate with their developing selves, or they might write stories related to their identity development to share within fandom communities.

Social Media Networks, Settings, and Privacy

An ecosystem model has been suggested to understand the way in which many LGBTQ populations divide their time between different social media websites and categorize websites for different purposes depending on the affordances they offer regarding anonymity and content sharing [20]. Different platforms offer different opportunities for sexual minority youth to openly engage with identity-related content and form connections with peers. Tumblr, in particular, is a website that has been spotlighted for its ability to foster the queer community, in part because its design is not one of *default publicness* [21], and users can express themselves through multiple accounts and mediums, with less likelihood of being observed by offline networks [22]. These features are especially appealing to youth *in the closet* or developing a complex understanding of identity beyond what they would express to a primarily heterosexual audience.

Instagram, meanwhile, serves as a website of visual self-expression for many adolescents. It has been examined primarily as a platform where adolescents seek public social validation from their peer networks [23]. However, Instagram also has a particularly robust culture in which users create secondary accounts (called *Finstas*), which serve as private spaces on the internet where they can post illicit content, connect deeply with close friends, share more nuanced representations of themselves than might appear on their *real Instagrams*, and express negative emotions [24]. These features of Instagram use have not been examined through the lens of sexual identity but offer important insights into how adolescents negotiate privacy and self-presentation on websites that offer varying levels of visibility.

Research on how young adults approach the task of privacy management on various social media platforms has found that sexual minority and gender nonconforming youth face significant risks when disclosing their identity on the internet. The existence of *networked publics* means that youth active on the internet are often aware of the variety of audiences their content may be exposed to and develop strategies to make information legible only to audiences of their choosing [25]. Many adolescents aged as young as 13 years, although aware of the public nature of social media, are unwilling or disempowered to navigate complex privacy settings and find conflict between their desire to use a website and their inability to control the spread of their content on that website [26]. These issues can come to a head for LGBTQ youth, particularly when websites such as Facebook, which privileges single accounts and offline networks, lead young people to accidentally disclose their identities to unintended audiences, often with severe interpersonal and familial repercussions [21].

Adolescent Loneliness, Social Support, and Web-Based Interactions

Scholars have theorized that as modern social media websites allow us to maintain connections electronically, finding contacts across unrestricted distances, and creating web-only friendships, there is a greater risk of losing physical social connections and inviting new types of social exclusion [27]. Researchers have also noted that adolescents are more physically isolated today than previous generations, who satisfy their need for social connection through physical relationships. Adolescents today are more comfortable meeting their social needs through computer-mediated communication [28]. Therefore, measuring perceived loneliness might be more nuanced among young people when web-based peer and offline relationships are most salient, and exploring their social identities is a prominent developmental task [29]. Loneliness has been challenging to define but is often accompanied by feelings of emptiness, anxiety, and social isolation [30]. According to the cognitive discrepancy model by Perlman and Peplau [31], loneliness is realized when an individual's personal network of social relations is either quantitatively or qualitatively deficient; when they are disappointed with their expectations of interpersonal interactions, loneliness sets in. Studies have found that loneliness experienced in youth can have significant consequences for wellness [32], such as being more prone to problematic internet use [33] across multiple cultures or nationalities [34], poorer sleep quality, and lower immune response [35]. These wellness outcomes are of heightened concern for caregivers and practitioners of adolescents, especially while practicing social distancing during the COVID-19 pandemic.

For sexual minority youth, previous research has identified social support as the primary protective factor against negative mental health outcomes [36], including loneliness [37]. A large study (n=5542) of 13- to 18-year olds revealed that sexual minority adolescents believed that their internet friends were better than their in-person friends at providing social support [38]. Resilience, or patterns of positive adaptation to risk situations, has also been directly related to sexual minority youth's sense of positive identity, which in turn reduces the likelihood of negative mental health outcomes [39]. An example of this resiliency can be found in sexual minority youth who use social networking websites to develop their sexual identity, who were found to have lower levels of paranoia than their heterosexual peers [37]. Alternatively, internalized homonegativity is related to mental health problems, such as depression and anxiety [40]. According to the minority stress theory [41], exposure to stressors such as discrimination, social rejection, and sometimes violence is a central cause of mental distress among sexual minorities. These distal stressors are related to proximal stressors such as expectations of rejection and internalized homonegativity. A strong social support system, particularly from the LGBTQ community, can help buffer the impact of these stressors on mental health outcomes. Although other web-based resources, such as e-therapies, have the potential to provide mental health support to sexual minority youth, many of these technologies have not been tailored to the LGBTQ experience and thus fail to address the specific challenges these adolescents face [42].

Sexual minority youth are significantly more likely to experience depressive symptoms, substance use, and truancy, particularly when faced with homophobic harassment [43], both on the internet and offline [44]. Gay Lesbian Straight Education

Network [4] found that 42% of LGBTQ youth aged 13-18 years had been harassed on the internet, whereas 32% reported being sexually harassed on the internet; these percentages were significantly lower (15% and 8%, respectively) among non-LGBTQ youth. More recently, researchers have suggested that there is a relationship between the negative social media experiences of young sexual minority adults and their depressive symptoms [45]. Qualitative research has also examined the experiences of sexual minority youth with cyber-victimization, finding that it is often related to, although less common than, in-person harassment [38,46]. Across the many forms that cyber-victimization of sexual minority youth may take, they face particular vulnerability because of their often complex relationships with privacy, family, and closeted identity [47]. Sexual minority youth are also twice as likely as heterosexual youth to attempt suicide [48], particularly those who face family rejection [49]. Recent research analyzing Reddit posts classified as displaying loneliness showed that these posts were associated with future posting activity on the suicide subreddit threads [50]. This predictive modeling of social media activity can be useful when trying to understand how loneliness manifests itself through web searches and postings and when certain patterns in an adolescent's social media behaviors put them at risk of self-harm or suicidality.

Due to the publicness, availability, and permanence of typical social media environments, peer influence effects can be heightened in terms of speed, volume, and scale, with adolescents sharing and viewing content with multiple networks within and outside their peer group [51,52]. Adolescents are socialized to adopt the web-based behaviors of their peers. For instance, their decisions about web privacy are shaped by peer norms regarding privacy settings [53]. Adolescents also tend to imitate their peers in the risky web-based content they post; for instance, adolescents who report more of their friends sharing alcohol references on social media are more likely to post about alcohol themselves [54]. Research has found that risky social media content can influence perceptions of peer norms as well, such as eating and weight-related attitudes and behaviors [55] and risky sexual norms [56]. Social media may encourage adolescents with mental health dilemmas to share their experiences with weight management or nonsuicidal self-injury on the internet as a way of receiving social support that is not accessible to them offline, which may reinforce or normalize such behaviors within some web-based communities [57]. Few studies have examined suicide contagion effects on social media, despite the existence of readily accessible self-injury content on platforms such as Instagram through the use of ambiguous hashtags [58] and Tumblr through communities that make visible and sometimes glorify self-harm practices [22]. There is a scarcity of research on the web-based peer influences of adolescent sexual minority populations, which may be similar or different from their heterosexual peers.

Rationale for Exploratory Study

To date, there are no studies of sexual minority adolescents aged as young as 11 years (who are in the early stages of identifying as a sexual minority), their social media preferences and behaviors, potential influences of peer interactions, and how these preferences and web-based interactions are associated with their mental health. The vast majority of studies conducted on the effects of loneliness or social isolation focus on young or older adult populations; less is known about early adolescents, and studies on sexual minority youth are even more scarce. A recent review of studies on social media use, sexual minorities, and depression found that most studies broadly defined social media use, limiting their understanding to the quantity of time spent rather than analyzing the types of activities undertaken [59]. Literature on privacy management and socially supportive behaviors on social media often fails to incorporate the perspectives of sexual minority youth. Past studies have also focused on social networking platforms that young adults typically use, such as Facebook or Tumblr. This study included more current websites used by those in early adolescence, such as YouTube, TikTok, Snapchat, Instagram, and Discord.

Objectives

This study has the following objectives:

1. Understand the differences and similarities between how early adolescent sexual minorities use social media compared with their heterosexual counterparts, including platforms, privacy settings, motivations for use, and secretive behaviors;
2. Investigate the web-based connections of early adolescent sexual minorities, whether they engage in socially supportive web-based behaviors, and whether they are motivated to connect with others to reduce social isolation compared with heterosexual peers;
3. Examine whether there are increased vulnerabilities in loneliness, depressive symptoms, and self-harm among early adolescent sexual minority social media users compared with their heterosexual counterparts.

Methods

Data Collection Procedures

Data were collected as part of a larger pilot and ongoing longitudinal survey of early adolescent social media use and behavioral health [60] since 2017. This human subject research study obtained institutional review board approval from Wellesley College. As there were no existing measures that had been piloted in our early adolescent population for key constructs related to social media use, the purpose of the mixed methods pilot study conducted in 2017-2018 was to integrate what past literature has indicated as key constructs and conduct key informant interviews with middle school students and their parents to test age appropriateness and comprehension of terminology. This informed our measurement development for the 2017-2018 pilot survey, which was iteratively adapted based on multiple data collections at diverse pilot middle school sites. In 2019, we launched a longitudinal survey study based on extensive piloting conducted in a previous study with brand new middle school sites. We used data from wave 2 of this ongoing data set collected from October to December 2019. The data set was collected using the Qualtrics Qualtrics (Qualtrics, Provo, UT) software. Surveys were optimized for both computers and mobile devices.

Overall, 4 middle school sites (3 public and 1 private) of varying sizes and diverse demographics within urban and suburban areas of the Northeastern United States agreed to participate in a study of social media use and health for fifth to ninth graders. This region of the United States is politically and socially tolerant of sexual minorities, as evidenced in the history of legalizing gay marriage in the region and the recent regional policy review conducted by the Movement Advancement Project of the Transgender Law Center [61]. The original survey was in English and was translated into Spanish and Portuguese at the request of the participating schools because of the demographics of the region to improve reading comprehension for their English-language learning student populations. Trained research assistants proctored web-based surveys in person during a designated advisory or break period during an in-school or afterschool session. Parents could opt out their children from participating in the study. Students were told that the study was voluntary, and they could choose not to take the survey, which would not affect their academic standing either way. Their answers would be kept confidential, and they did not have to answer any questions they found uncomfortable. Students provided web-based assent before participating in the survey. Participation rates ranged from 42% in the afterschool programs to 94.8% in the whole school data collection, including 5.2% parent or student opt-out or absence on the day the survey was administered. The total response rate across sites was 84.5%. All students were given embossed pens whether they participated or not, and the names of students who completed the survey were entered into a raffle prize drawing to win a US $25 gift card incentive at each school site for each day of data collection. School sites were provided with a small honorarium to provide access to their students. A total of 1033 students completed the survey between October and December 2019. The participant descriptions have been provided in Table 1.

Table 1. Participant demographic data (N=1033).

Characteristic	Participants
Age (years)	
Value, range	10-16
Value, mean (SD)	12.7 (1.21)
Gender, n (%)	
Female	513 (49.6)
Male	505 (48.9)
Other	15 (1.5)
Sexual minority (yes; n=873 with known sexual orientation), n (%)	212 (24.3)
Not sure or questioning	109 (51.4)
Attracted to both sexes	41 (19.3)
Not attracted to either sex	23 (10.8)
Attracted to the same sex	19 (8.9)
Other	20 (8.9)
Grade, n (%)	
Fifth	19 (1.8)
Sixth	261 (25.3)
Seventh	263 (25.5)
Eighth	261 (25.3)
Ninth	222 (21.5)
Missing information	7 (0.7)
Race or ethnicity, n (%)	
White	484 (46.9)
Hispanic	183 (17.7)
Black	102 (9.9)
Asian American	68 (6.5)
Multiracial	48 (4.6)
Native American	18 (1.7)
Other	98 (9.5)
Missing information	37 (3.6)
Free or reduced-price lunch eligibility, n (%)	232 (22.5)

Measures

Sexual Orientation

Sexual attraction was used to categorize students as either heterosexual or sexual minorities. Students who reported that they were attracted to the opposite sex were categorized as *heterosexual* (0) and those reporting they were attracted to both sexes, the same sex, not sure or questioning, other, or not attracted to either sex were categorized as *sexual minorities* (1).

Types and Motivations for Social Media Websites Joined

Social Media Platform Use

Students reported which social media websites they had joined. On the basis of our pilot studies of websites currently popular among middle school students, we included the following options: Snapchat, Instagram, YouTube, Facebook, Tumblr, TikTok, Facebook, Twitter, Pinterest, Reddit, House Party, Discord, Steam, ooVoo, Zepeto, WhatsApp, Kik, Twitch, and VSCO. Students who reported joining one of these websites were assigned a score of 1 (yes), and those who did not join these websites were assigned a score of 0 (no).

Motivation for Social Media Use

Students were asked about the reasons for joining social media. Responses included finding a place to express themselves, sharing things with friends, seeing what everyone was posting, and using social media to make new friends. Students were allowed to check all that applied. If a student selected a reason, they were coded as 1 (yes), and if they did not select a reason, they were coded as 0 (no).

Second Instagram Status

Students who joined Instagram were asked whether they had a second Instagram page or a *fake Finsta*. For students who reported having a *Finsta*, a follow-up question asked why they had more than one page. Reasons included “I want to share a different side of myself to some of my friends,” “I only want some people to know how I really feel,” “I want to be funny with my friends,” and “I don’t want my family to see what I post.” Students were allowed to check all that applied. If a student selected a reason, they were coded as 1 (yes), and if they did not select a reason, they were coded as 0 (no).

Social Media Settings and Support System

Communication About Sexual Identity

Students categorized as sexual minorities were asked a follow-up question about who they talked about their sexual orientation. Students were asked to check all that applied. Responses included no one, LGBTQ club or group, parents, family members, friends, and people they do not know on the internet. Students who reported talking to one of these people were assigned a score of 1 (yes).

Privacy Settings

Privacy settings were measured using a single item asking students to report whether the settings for their favorite social media website were set as *public* (1), *private* (2), or they *don’t know* (3). *Don’t know* responses were coded as missing data.

Web-Based Curation

For social media behaviors, students were asked to report whether they did any of the following on their favorite social media website: “Posted updates, comments, photos or videos that you later regret sharing,” “Deleted comments that other have made on your page,” “Posted fake or false information,” “Deleted or block people from your network or friend list,” or “Removed almost all prior posts or deactivated an account.” Students were allowed to check all that applied. If a student selected a behavior, they were coded as 1 (yes), and if they did not select any behavior, they were coded as 0 (no).

Web-Based Network Size

The number of friends was measured using a single item “Thinking about your favorite social media site, about how many friends do you have on that site?” Responses ranged from *Less than 50* (1) to *Over 1000* (6).

Participating in Web-Based Social Support

A total of 3 individual items, responding positively when friends share good news, trying to make friends feel better when sharing bad news, or joining a web-based group to feel less alone, were used to measure how often students used social media as a support system. These items ranged from *Never* (1) to *Always* (5). An open-ended response was requested for those indicating that they joined a web-based group to feel less alone.

Composition of Web-Based Networks

Students reported who they were friends with or who they followed on social media. They were allowed to check all that applied. Responses included parents, siblings or cousins, other family members, classmates or friends from school, other known adults, celebrities, and people they had never met. If a student selected a friend type, they were coded as 1 (yes), and if they did not select any friend type, they were coded as 0 (no).

Risky Behaviors on Social Media

Parent Disapproval of Joining Social Media Websites

Students were asked whether they had joined a social media website their parents would not approve of (yes or no). If they answered *Yes*, they were provided a follow-up question about the reasons why their parents would disapprove of their website. The forced choice options derived from our pilot studies, included “I am too young,” “I am not ready to handle it emotionally,” “I would spend too much time on it,” “My parents would have limited control over it,” and “They don’t want me to have bad influences.” Participants were also able to write additional reasons.

Risky Peer Web-Based Behavior

Students reported the content of social media posts and websites they had seen in the past 12 months, including ways to be thin, hate messages, drugs or alcohol, or self-harm. Students checked all that applied. A value of 1 (yes) was assigned to any student who selected that content, whereas nonselection was assigned a value of 0 (no).

Web-Based Peer Harassment

Adapted from a web-based victimization scale developed by Ybarra et al [62], this scale asked participants how often their web-based peers made rude or mean comments, spread rumors on the internet, or were hurt by someone excluding them on the internet. These three items were reported on a 4-point scale ranging from 1 (*Never*) to 4 (*Often*; Cronbach α=.77).

Mental Wellness

Loneliness

A 3-item loneliness scale, the revised University of California, Los Angeles Loneliness Scale [63], was used as a brief measure of loneliness for young respondents, which has been shown to be internally consistent with both discriminant and concurrent validity compared with the full measure. The 3-item scale asks, “How often do you feel...” (1) that you lack companionship, (2) left out, and (3) isolated from others (Cronbach α=.80). These items used a 3-point response scale: *Hardly ever* (1), *Some of the Time* (2), and *Often* (3).

Depressive Symptoms

Depressive symptoms were measured using the Center for Epidemiological Studies-Depression (CES-D) 10-item scale [64], which has been shown to have strong internal consistency, test-retest reliability, convergent validity, and divergent validity. Participants were asked to indicate how often they felt this way during the past week. Items were rated on a 4-point response scale format ranging from *rarely or less than 1 day* (1) to *All* *of the time 5-7 days* (4; Cronbach α=.75). Items were summed, and scores of 10 or above were assigned a value of 1; students with scores less than 10 were assigned a value of 0. A score equal to or greater than 10 was considered depression.

Self-harm

The frequency of self-harm was measured using a single item about whether the student had ever tried to harm themselves, eg, cutting, hitting, poisoning, deliberate risk-taking, etc. This was a dichotomous variable of either *Never tried* (0) or *Tried once or twice* (1).

Data Analysis

Regression analyses were conducted to understand the associations between sexual orientation and social media settings, uses, behaviors, and mental well-being. Web-based harassment and loneliness were analyzed using a structural equation modeling (SEM) framework using multiple indicators. In these SEM models, the outcomes were treated as latent variables, which allowed us to account for measurement errors within the modeling process. These models were estimated using the maximum likelihood estimation. Dichotomous indicators, such as joining social media websites and reasons for social media use, were analyzed using a logistic regression framework. Continuous or ordinal outcomes, such as responding positively when friends share good news and the number of friends on social media, were analyzed using a linear regression framework. To reduce the risk of omitted variable bias, all models controlled for the effects of age, gender, and mother's highest level of education.

Of the 1033 students who completed the survey, 873 (84.51%) were categorized into either the heterosexual (661/873, 75.7%) or sexual minority (212/873, 24.3%) groups. A total of 14.7% (128/873) were missing covariate information related to mothers' education (116/873, 13.3%) or identified themselves as a nonbinary gender (12/873, 1.4%). For SEM models, missing data were handled using the full information maximum likelihood estimation. Before interpreting the results of SEM models, we required the models to meet at least three of the following four criteria regarding fit indices: comparative fit index ≥0.90, Tucker-Lewis fit ≥0.90, root mean square error of approximate ≤0.08, and standardized root mean square residual ≤0.05. Both the web-based harassment and loneliness models met these requirements. Samples were further reduced because of the amount of missing data on the outcomes. Most model sample sizes ranged from 637 to 745, suggesting that 14.7% (128/873) to 27% (236/873) (sample size range of 637-745 out of 873 students) of data were missing because of the outcome. A few models had more missing data since fewer students answered questions related to privacy settings (n=556), having an Instagram page (n=515), and follow-up questions related to Instagram use (n=200).

Open-ended responses to the survey were analyzed using a structured tabular thematic analysis on brief texts [65], where a coder inductively generated initial codes and themes for data segments and a second coder verified codes and discussed final codes until agreement was reached.

Results

Types of Social Media Websites Joined

Sexual minorities were 1.5 times more likely to have joined Tumblr (β=.44; odds ratio [OR] 1.56, 95% CI 1.13-2.14; *P*=.007) or Steam (β=.45; OR 1.57, 95% CI 1.16-2.12; *P*=.003) and 33% more likely to have joined Discord (β=.28; OR 1.32, 95% CI 1.00-1.73; *P*=.05), but 50% less likely to have joined TikTok (β=−.50; OR 0.61, 95% CI 0.49-0.76; *P*<.001), Snapchat (β=−.60; OR 0.55, 95% CI 0.44-0.70; *P*<.001), or VSCO (β=−.53; OR 0.59, 95% CI 0.45-0.77; *P*<.001), 40% less likely to have joined House Party (β=−.47; OR 0.63, 95% CI 0.50-0.79; *P*<.001), and 14% less likely to join Instagram (β=−.51; OR 0.60, 95% CI 0.48-0.76; *P*<.001) compared with heterosexual students. There were no significant group differences in the likelihood of joining YouTube, Facebook, Twitter, Pinterest, Reddit, ooVoo, Zepeto, WhatsApp, Kik, or Twitch (Multimedia Appendix 1).

Joining Web-Based Communities to Feel Less Lonely

A total of 25.9% (55/212) of the sexual minority participants indicated that they had joined a web-based group to feel less socially isolated. More than half of these participants (29/55, 53%) provided an example web-based group to which they belonged in the open-ended response. Of these 29 responses, 23 (79%) were usable responses. Out of these responses, a thematic analysis [65] revealed that 4 were explicitly related to the LGBTQ community, including the Reddit subgroup LGBT and a location-based, in-person support group for LGBTQ youth of color, with additional web-based opportunities for engagement. Other students wrote about web-based communities focused on fandom interests, such as gaming servers, art-sharing websites, or book discussion groups, whereas others referred to group chats designed to communicate with close friends (responses are shown in detail in Textbox 1).

Textbox 1. Open-ended responses from sexual minority youth: joining web-based communities to feel less lonely.

Lesbian, Gay, Bisexual, Transgender, Queer, or Other (LGBTQ+) Specific

- GLASS
- Groups for lesbian, gay, bisexual, transgender, or other issues or mental health things
- LGBT Reddit forum
- Some LGBTQ+ Instagram accounts

Shared Interests or Identities

- A group chat with people who also have Crohn disease
- A reading and writing community just to share books I've read and see what other books people liked
- Robotics
- Gacha community
- Roblox group
- Amino
- An art group on Pinterest, The Drawing Crew
- Anime
- Any occasion (eg, Halloween, matching outfits, and help for homework)
- Discord-Dragon Ball Z: Final Stand
- Episode community and fandoms of shows
- Fortnite group chat called THE FORTNITERS
- Littlest pet shop
- Meme team
- Teenager-focused Reddit forum

Friend Group Chats

- Best friends group chat
- Just a group chat with most of my friends

Motivations for Social Media Use

Sexual minorities were 1.5 times more likely to report that a reason for joining social media was finding a place to express themselves (β=.45; OR 1.57, 95% CI 1.20-2.06; *P*=.001) and 25% less likely to report joining to share things they enjoy with friends (β=−.28; OR 0.76, 95% CI 0.60-0.95; *P*=.02) than heterosexual students. There were no significant group differences in the use of social media to see what everyone was posting or make friends.

Sexual minorities were 50% less likely to report having a *Finsta* to be funny with friends (β=−.66; OR 0.52, 95% CI 0.31-0.85; *P*=.01). Heterosexual and sexual minorities did not significantly differ for any other reasons for having a second Instagram page.

Social Media Settings and Social Support System

Sexual minorities were asked who they talked to about their sexual orientation; 39.1% (83/212) reported talking to no one, 6.6% (14/212) talked to a Gay-Straight Alliance club or LGBTQ support group, 26.9% (57/212) talked to their mothers, 13.2% (28/212) talked to their father, 8% (17/212) talked to a female sibling or cousin, 7.1% (15/212) talked to a male sibling or cousin, 7.1% (15/212) talked to another female family member, and 2.8% (6/212) reported talking with another male family member. A total of 30.7% (65/212) of sexual minorities reported talking to friends, and 7.1% (15/212) reported talking to people they did not know on the internet.

Sexual minorities were 30% less likely to report that their social media privacy settings were set to *Private* (β=−.33; OR 0.72, 95% CI 0.54-0.96; *P*=.03) than heterosexual students. Sexual minorities were also less likely to have deleted or blocked people in their network (β=−.28; *P*=.03), but heterosexual and sexual minority youth were equally likely to report social media behaviors such as posting things they later regret, deleting comments, posting fake information, or removing previous posts.

Sexual minorities reported having smaller networks on their favorite social media websites (β=−.57; *P*<.001), less often responded positively when friends shared good news (β=−.35; *P*=.002), and less often tried to make friends feel better when they shared bad news (β=−.30; *P*=.01). However, sexual minorities more often reported joining a group or web-based community to make themselves feel less alone (β=.28; *P*=.003), unlike heterosexual youth.

Sexual minorities were less likely to include on their social media their parents (mom: β=−.26; OR 0.77, 95% CI 0.61-0.98; *P*=.03 and dad: β=−.27; OR 0.76, 95% CI 0.59-0.98; *P*=.04), siblings or cousins (β=−.49; OR 0.62, 95% CI 0.49-0.78; *P*<.001), classmates of the same or younger (β=−.43; OR 0.65, 95% CI 0.52-0.82; *P*<.001) or older (β=−.67; OR 0.51, 95% CI 0.40-0.65; *P*<.001) grades, friends from afterschool or a team (β=−.57; OR 0.57, 95% CI 0.45-0.71; *P*<.001), or friends of other friends (β=−.58; OR 0.56, 95% CI 0.44-0.71; *P*<.001) than heterosexual youth. Sexual minorities were also less likely to follow any celebrities (sports: β=−.73; OR 0.48, 95% CI 0.37-0.63; *P*<.001; actors or actresses: β=−.48; OR 0.62, 95% CI 0.49-0.79; *P*<.001; fashion or beauty: β=−.40; OR 0.67, 95% CI 0.49-0.91; *P*=.01, health or fitness: β=−.85; OR 0.43, 95% CI 0.25-0.72; *P*=.001). Heterosexual and sexual minority youth did not differ in their likelihood of being friends with an adult extended family, teachers, coaches, or people they have never met.

Risky Behaviors in Web-Based Networks

Sexual minorities were 1.5 times more likely to have joined a social media website their parents would disapprove of (β=.41; OR 1.50, 95% CI 1.14-1.97; *P*=.004), and they were more likely to report seeing videos on the internet related to self-harm (β=.33; OR 1.39, 95% CI 1.06-1.83; *P*=.02) than heterosexual youth. There were no significant group differences in watching videos related to being thin, hate messages, experiences of drugs or drinking, or frequency of web-based harassment.

When invited to share why they thought their parents would not approve of their presence on specific social media websites, many sexual minority youth referenced the proliferation of mature content, whether it came from other users or their own activity on the website. A total of 54% (20/37) of sexual minority youth who answered this question said that their parents would disapprove because they were too young to be using a certain website, whereas 40% (15/37) thought their parents would primarily be concerned with *bad influences* on the web and 19% (7/37) perceived their parents' concerns as related to their children's emotional immaturity. Open-ended answers corroborated these concerns, describing fears about people who "say inappropriate stuff" on web and "people you haven't met...who want to steal my information." Time was also a significant concern; 35% (13/37) of sexual minority youth who answered this question thought their parents worried about them spending too much time on the internet, with a participant specifically referencing the quantity of time spent playing Fortnite as a reason for their parent's disapproval. Limited parental control was another facet of parental disapproval, which was identified by 16% (6/37) of sexual minority youth who answered this question and highlighted in open-ended responses.

Mental Wellness

Sexual minorities had higher averages of loneliness and social isolation (β=.19; *P*<.001) than heterosexual students. They were also twice as likely to have tried to harm themselves in the past (β=.81; OR 2.24, 95% CI 1.64-3.06; *P*<.001) and more likely to have symptoms that reached the CES-D-based definition of depression (β=.15; OR 1.16, 95% CI 1.08-1.25; *P*<.001).

Discussion

Principal Findings

Our study is among the first to examine the social media behaviors and mental health patterns of early adolescent sexual minorities aged as young as 11 years when early sexual identity questioning is more prominent and can influence one's sense of belonging and mental wellness. The first objective of our study was to understand how sexual minority youth use social media differently than their heterosexual counterparts. Contrary to the general finding that Snapchat, Instagram, and TikTok are the most popular social media websites in early adolescence, we found that sexual minorities gravitate to less popular websites, such as Tumblr and Discord, and were significantly more interested in web-based self-expression than their heterosexual counterparts. Sexual minority youth were also less likely to use *Finstas* or *fake Instagram* accounts. In addition, sexual minority youth were more likely to sign up for social media websites that parents would not approve of and were also less likely to include parents in their web-based networks.

Our second objective was to understand the role of internet peers and socially supportive web-based behaviors. Sexual minority youth tended to have significantly smaller web-based networks, which may partly explain why they were less concerned about privacy settings. In terms of social support, sexual minority youth were less likely to unfriend peers or remove previous posts, presumably because of negativity on the internet. At the same time, they were also less likely to offer social support to their web networks. One of our key findings regarding web-based social support was that sexual minorities were significantly more likely than heterosexual peers to report that they join web-based communities to feel less alone.

Our third objective was to examine any mental health patterns that could help explain the differences in social media behaviors. We found that sexual minority youth were more likely to experience loneliness, depressive symptoms, and even acts of nonsuicidal self-harm than their heterosexual counterparts, which underscores the overall pattern of web-based isolation and the continued struggle to find safe outlets for self-expression.

Types and Motivations for Different Platforms

Our finding that sexual minority youth were 1.5 times more likely to use Tumblr is corroborated by other research that analyzes Tumblr's design and community structure, which is especially conducive to identity development and privacy management for LGBTQ youth [21,22]. Although Tumblr's community makeup changed in 2018 as a result of its adult content ban, which particularly affected the LGBTQ community on the website [66], our data (collected a full year after the content ban went into effect) indicate that Tumblr is still a relevant social media platform that sexual minority youth gravitate toward to express themselves—one that offers a community that other popular websites (eg, Instagram and Snapchat) may not at this early adolescent stage. The accompanying finding that sexual minority youth were 50% less likely to use TikTok is surprising, given that journalistic sources have documented blossoming queer communities on

TikTok [67,68]. As a new and continuously evolving platform, it is possible that sexual minority youth might have begun to use TikTok differently during the onset of the COVID-19 pandemic, after these data were collected (in October-December 2019). Although TikTok has proven successful in fostering safe spaces in certain cases, its connotations as a website for funny content might limit its utility for sexual minority youth who are primarily looking for sources of self-expression rather than entertainment in their social media use.

In our qualitative responses, the web-based communities sexual minority youth participated in to reduce loneliness and isolation were tailored around social connections based on identity or interests. The community offered by the Reddit subgroup r/LGBT, for instance, centers around information and experience sharing rather than comedic relief. Other responses reflected the tendency of sexual minority to use digital media to engage with a curated network of close friends, usually in the format of a group chat. Although these responses did not address how they might have formed these friendships initially, it can be partially contextualized by findings from the study by Ybarra et al [38] that internet friends offered higher levels of social support for sexual minority youth. The inclusion of a web-based community that is an extension of a place-based group (GLASS, Boston-based service provider for LGBTQ youth of color and their allies) in open-ended responses is also notable, and further evidence of the Fox and Ralston [16] finding that LGBTQ youth may use the internet to connect with local LGBTQ community spaces.

Sexual minority youth prioritizing self-expression over entertainment was further evidenced by their motivations for social media use. Our sexual minority participants reported being more likely to have joined social media for expressive purposes and less likely to have joined to share things they enjoyed with friends. This use pattern is also supported by the lower likelihood of sexual minority youths using Finstas to be funny. Although some research suggests that humor is a primary function of Finstas for many young adults [69], the sexual minority youth that we surveyed were less likely to share funny content. These results suggest that sexual minority youth may enjoy the more reflective and unidirectional aspects of self-expression on the web, such as having an audience to explore different sides of themselves, rather than being a vessel for an interactive exchange of social support.

Privacy Settings and Social Support

Our unexpected finding of sexual minority youth being significantly less likely to have private social media settings contradicts previous research that describes web-based spaces as places to control information for a *networked public* [25] or fear of being accidentally outed by automated privacy controls [21]. A possible explanation for this result may be that the smaller networks sexual minority youth already maintain on social media limit their need for explicit forms of privacy control; in other words, their intended audience is only their direct friends or followers, and although they may be aware of and concerned about the use or spread of their personal data, they are unmotivated or powerless to navigate the complex privacy structures of different platforms, as described by Pangrazio and Selwyn [26]. They may also be encoding information using methods other than privacy controls—for instance, engaging in the culture of *subtweeting* detailed by Marwick and boyd [25], where Twitter users allude to interpersonal conflict without revealing details or the identities of individual actors.

The findings that sexual minority youth are less likely to report their nuclear family members as friends on their *networked publics* and that they tend to sign up for social media websites that their parents would disapprove of are possible indicators of fear of revealing their web-based identities to their family members. We hypothesize that this could be because of sexual minority adolescents not being comfortable or ready to *out* themselves to their families in terms of what they post and who it reaches. Being more likely to have joined a social media website without parental approval may also indicate that sexual minority adolescents do not have as much close internet supervision. Although our findings did not show that sexual minority youth are exposed to more mature content than their heterosexual counterparts, except for content relating to self-harm, age and appropriateness of content are typically common concerns for parents. This discrepancy between parents' and adolescents' understanding of social media use may be explained by the finding that the time adolescents spend on the web displaces the time they could spend communicating with their families about their behaviors on the web, a pattern that may include sexual identity explorations [70].

Almost 40% of participants in our study disclosed that they had never talked to anyone about their sexual orientation, and two-thirds did not even discuss it with their friends. Given the backdrop of the loneliness and poor mental health outcomes that we uncovered, we also found an overarching pattern of social media use that had a tone of social isolation (eg, not responding when friends share good or bad news and being less motivated to share what they enjoy with friends). These observations may not necessarily be deleterious, as studies have found that having smaller web-based networks or tighter privacy controls to be protective against negativity on the web [71] and having family members find out about identity prematurely when sexual minorities are in the coming out phase may limit youth's ability to explore their emerging sexual and gender identities. From a different perspective, our findings demonstrate that sexual minority youth have smaller networks, do not share what they enjoy with their internet friends, and are less socially supportive on the internet, all signal forms of passive viewing and disengagement with at least some aspects of social media. According to the minority stress theory, adaptive coping mechanisms may be at play, either through engagement (eg, responding to negativity) or disengagement (eg, avoiding negative spaces) [72]. Active engagement forms of coping often lead to a greater sense of control, whereas disengagement coping can lead to heightened depressive symptoms in offline contexts [73]. Previous research has also established that passive viewing and noninteractive browsing (eg, *lurking*) of social media walls are associated with poor well-being outcomes [74]. An alternative explanation is that sexual minority youth may want to avoid web-based drama by limiting their interactions with a select trusted few [71].

Risky Behaviors, Mental Wellness, and Harassment

Our study demonstrated significant mental wellness disparities in sexual minorities, such as depressive symptoms, loneliness, and self-harm, in the understudied early adolescent years when they are just exploring their sexual identity statuses. Given the dearth of studies relating sexual minority adolescent social media use and mental health, we conducted exploratory analyses of their web-based behaviors at this stage, including how, why, and with whom they interact on the web, in hopes of understanding any notable preliminary patterns to explore in a future study. For instance, we found that sexual minorities saw significantly more posts about self-harm in their peers' posts compared with their heterosexual counterparts. We do not know which peers were posting (ie, whether they were a sexual minority peer or not), and we cannot ascertain whether sexual minorities were better able to recognize and remember these types of posts than their heterosexual counterparts. However, the finding that early adolescents significantly view more web-based posts about self-harm and are also significantly more likely to have ever self-harmed is a cause for concern and should be investigated in future studies.

Surprisingly, our study did not corroborate previous research that sexual minority youth are harassed on the web at higher rates than their heterosexual peers [4,38,75]. A reason is that there is possibly more social acceptance of sexual minorities in this generation, given the relatively high proportion of middle school students who identified as sexual minority. Another explanation could be that the sexual minorities in our sample were less willing to disclose this information. Researchers have found that heterosexual individuals are more likely than their sexual minority counterparts to tell their parents and school staff about cyberbullying incidents, partly because sexual minority youth are significantly more afraid of their technology privileges being taken away compared with their heterosexual peers [47]. Our participants also reported low rates of cyber-victimization overall (Multimedia Appendix 1), which may relate to the setting of our study being school-based rather than a convenience sample of LGBTQ-identified youth, which would more likely be self-selected.

Limitations

The strengths of this cross-sectional data set include racial, ethnic, and socioeconomic diversity and a relatively high number of participants identifying as sexual minority, as it was a highly representative school-based sample of several communities across the New England area. Limitations include the lack of potential generalizability beyond this region of the Northeastern United States. The study did not include gender minority participants as a comparison category because of the low prevalence in our sample (12/873, 1.4%). A recent study using the National Youth Risk Behavior Survey found that bisexual adolescents were more cyberbullied than gay or lesbian adolescents [76]. This could be another alternative explanation for our relatively low cyber-victimization findings, as we had a low proportion of bisexually identified participants, and we were unable to disaggregate our findings by category of sexual minority in our sample. Although previous samples of sexual minority adolescents have been larger, our sample is unique in that it is younger than these other samples (eg, ages 13-18 years and 14-29 years), with our participants averaging 12.7 years. Given that several measures were developed for this study, limitations in establishing the reliability and validity of such measures are acknowledged. For the items measuring privacy of favorite social media websites, participants were only allowed to indicate public, private, or do not know responses, which would be appropriate for some websites with a binary option but may not completely account for websites with partial privacy options.

Conclusions and Future Directions

Access to online social support systems is critical for sexual minority youth, who often experience discrimination from offline service providers because of their sexual minority status [77]. This potential barrier is particularly true for sexual minority youth living in nonurban areas or those who fear being outed by being seen at LGBTQ organizations. Given the ability to selectively choose who you are *out to* on the web, mental health professionals working with sexual minority youth who express fear of stigmatization or violence for coming out in their offline lives may consider exploring with whom their clients feel comfortable and can turn to online social support. As part of these considerations, further research on new and evolving digital media platforms, such as Discord and TikTok, could aid providers.

Future longitudinal studies could determine any bidirectional influences of mental well-being and social media use in early adolescent sexual minorities. Future studies that include larger samples of early adolescent sexual minorities would allow for analyzing the subgroups of sexual identity separately and distinguishing sexual orientation from gender identity when reporting results. Although this study did not examine data collected from gender nonbinary or nonconforming youth, research is necessary to explore the similarities and differences in their social media use and mental health compared with sexual minorities, especially in early adolescence when peer acceptance is crucial. More research on parental supervision of sexual minority adolescent social media use may unravel why these adolescents tend to avoid *public* social media audiences that include their own parents and siblings while also not using available privacy settings. Much research on peer influence effects through social media has centered on risk behaviors; therefore, more research on the positive spread of resilient behaviors in sexual minority web-based networks is also needed.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Regression results by sexual orientation.
[DOCX File , 24 KB - mental_v8i9e26207_app1.docx]

References

1. McInroy LB, Craig SL, Leung VW. Platforms and patterns for practice: LGBTQ+ youths' use of information and communication technologies. Child Adolesc Soc Work J 2018 Oct 19;36(5):507-520. [doi: 10.1007/s10560-018-0577-x]
2. Anderson M, Smith A, Caiazza T. Pew Research Center. 2018 May 31. URL: https://www.pewresearch.org/internet/2018/05/31/teens-social-media-technology-2018/ [accessed 2020-11-05]
3. Craig SL, McInroy L, McCready LT, Alaggia R. Media: a catalyst for resilience in lesbian, gay, bisexual, transgender, and queer youth. Journal of LGBT Youth 2015 Jul 6;12(3):254-275. [doi: 10.1080/19361653.2015.1040193]
4. Out Online: the Experiences of Lesbian, Gay, Bisexual and Transgender Youth on the Internet. GLSEN. 2013. URL: https://www.glsen.org/sites/default/files/2020-01/Out_Online_Full_Report_2013.pdf [accessed 2020-11-05]
5. Children's Online Privacy Protection Act (COPPA). Protecting Children's Privacy Under COPPA: A survey on compliance. Federal Trade Commission. 2002 Apr 01. URL: https://www.ftc.gov/reports/protecting-childrens-privacy-under-coppa-survey-compliance [accessed 2020-11-19]
6. George MJ, Jensen MR, Russell MA, Gassman-Pines A, Copeland WE, Hoyle RH, et al. Young Adolescents' Digital Technology Use, Perceived Impairments, and Well-Being in a Representative Sample. J Pediatr 2020 Feb 11;219:180-187 [FREE Full text] [doi: 10.1016/j.jpeds.2019.12.002] [Medline: 32057438]
7. Odgers CL, Jensen MR. Annual research review: adolescent mental health in the digital age: facts, fears, and future directions. J Child Psychol Psychiatry 2020 Mar;61(3):336-348 [FREE Full text] [doi: 10.1111/jcpp.13190] [Medline: 31951670]
8. Prinstein M, Giletta M. Peer relationsdevelopmental psychopathology. In: Developmental Psychopathology. Hoboken, NJ: Wiley; 2016:1-53.
9. Mulvey KL, Killen M. Challenging gender stereotypes: resistance and exclusion. Child Dev 2015;86(3):681-694. [doi: 10.1111/cdev.12317] [Medline: 25382748]
10. Poteat VP, Anderson CJ. Developmental changes in sexual prejudice from early to late adolescence: the effects of gender, race, and ideology on different patterns of change. Dev Psychol 2012 Sep;48(5):1403-1415. [doi: 10.1037/a0026906] [Medline: 22250998]
11. D'Augelli AR. Mental health problems among lesbian, gay, and bisexual youths ages 14 to 21. Clin Child Psychol Psychiatry 2016 Jul 26;7(3):433-456. [doi: 10.1177/1359104502007003010]
12. Russell ST, Fish JN. Mental health in lesbian, gay, bisexual, and transgender (LGBT) youth. Annu Rev Clin Psychol 2016;12:465-487 [FREE Full text] [doi: 10.1146/annurev-clinpsy-021815-093153] [Medline: 26772206]
13. D'Augelli A, Grossman A, Starks M, Sinclair K. Factors associated with parents' knowledge of gay, lesbian, and bisexual youths' sexual orientation. J GLBT Fam Stud 2010 May 5;6(2):178-198. [doi: 10.1080/15504281003705410]
14. Gordon LE, Silva TJ. Inhabiting the sexual landscape: toward an interpretive theory of the development of sexual orientation and identity. J Homosex 2015;62(4):495-530. [doi: 10.1080/00918369.2014.986417] [Medline: 25397814]
15. Robertson M. 'How do I know I am gay?': understanding sexual orientation, identity and behavior among adolescents in an LGBTQ youth center. Sex Culture 2013 Oct 15;18(2):385-404. [doi: 10.1007/s12119-013-9203-4]
16. Fox J, Ralston R. Queer identity online: informal learning and teaching experiences of LGBTQ individuals on social media. Comput Hum Behav 2016 Dec;65:635-642 [FREE Full text] [doi: 10.1016/j.chb.2016.06.009]
17. Hillier L, Harrison L. Building realities less limited than their own: young people practising same-sex attraction on the internet. Sexualities 2016 Nov 7;10(1):82-100. [doi: 10.1177/1363460707072956]
18. Jenkins H. Afterword: the future of fandom. In: Fandom: Identities and Communities in a Mediated World. New York, USA: New York University Press; 2007:357-364.

19. McInroy LB, Craig SL. 'It’s like a safe haven fantasy world': online fandom communities and the identity development activities of sexual and gender minority youth. Psychol Popular Media 2020 Apr;9(2):236-246. [doi: 10.1037/ppm0000234]
20. DeVito MA, Walker AM, Birnholtz J. 'Too gay for Facebook'. Proc ACM Hum-Comput Interact 2018 Nov 1;2(CSCW):1-23. [doi: 10.1145/3274313]
21. Cho A. Default publicness: queer youth of color, social media, and being outed by the machine. New Media Soc 2017 Dec 12;20(9):3183-3200. [doi: 10.1177/1461444817744784]
22. Cavalcante A. Tumbling into queer utopias and vortexes: experiences of LGBTQ social media users on tumblr. J Homosex 2019;66(12):1715-1735 [FREE Full text] [doi: 10.1080/00918369.2018.1511131] [Medline: 30235077]
23. Yau JC, Reich SM. 'it's just a lot of work': adolescents' self-presentation norms and practices on Facebook and Instagram. J Res Adolesc 2019 Mar;29(1):196-209. [doi: 10.1111/jora.12376] [Medline: 29430759]
24. Xiao S, Metaxa D, Park J, Karahalios K, Salehi N. Random, Messy, Funny, Raw: Finstas as Intimate Reconfigurations of Social Media. In: Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems. 2020; Honolulu, HI, USA. 2020 Mar Presented at: CHI'20; March 2-5, 2020; Honolulu, HI, USA. [doi: 10.1145/3313831.3376424]
25. Marwick AE, boyd D. Networked privacy: How teenagers negotiate context in social media. New Media Soc 2014 Jul 21;16(7):1051-1067. [doi: 10.1177/1461444814543995]
26. Pangrazio L, Selwyn N. 'It’s not like it’s life or death or whatever': young people’s understandings of social media data. Soc Media Soc 2018 Jul 19;4(3):205630511878780-205630511878789 [FREE Full text] [doi: 10.1177/2056305118787808]
27. Kushlev K, Proulx JD, Dunn EW. Digitally connected, socially disconnected: the effects of relying on technology rather than other people. Comput Hum Behav 2017 Nov;76:68-74. [doi: 10.1016/j.chb.2017.07.001]
28. Clark DM, Loxton NJ, Tobin SJ. Declining loneliness over time: evidence from American colleges and high schools. Pers Soc Psychol Bull 2015 Jan;41(1):78-89 [FREE Full text] [doi: 10.1177/0146167214557007] [Medline: 25422313]
29. Brown B, Larson J. Peer relationships in adolescence. In: Handbook of Adolescent Psychology. Hoboken, NJ: John Wiley & Sons; 2009:74-103.
30. Stein JY, Tuval-Mashiach R. The social construction of loneliness: an integrative conceptualization. J Construct Psychol 2015 Jan 28;28(3):210-227. [doi: 10.1080/10720537.2014.911129]
31. Perlman D, Peplau L. Toward a social psychology of loneliness. In: Personal Relationships. London, UK: Academic Press; 1981:31-56.
32. Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. Perspect Psychol Sci 2015 Mar;10(2):227-237. [doi: 10.1177/1745691614568352] [Medline: 25910392]
33. Kuss DJ, Griffiths MD, Karila L, Billieux J. Internet addiction: a systematic review of epidemiological research for the last decade. Curr Pharm Des 2014;20(25):4026-4052. [Medline: 24001297]
34. Savolainen I, Oksanen A, Kaakinen M, Sirola A, Paek H. The role of perceived loneliness in youth addictive behaviors: cross-national survey study. JMIR Ment Health 2020 Jan 2;7(1):e14035 [FREE Full text] [doi: 10.2196/14035] [Medline: 31895044]
35. Pressman SD, Cohen S, Miller GE, Barkin A, Rabin BS, Treanor JJ. Loneliness, social network size, and immune response to influenza vaccination in college freshmen. Health Psychol 2005;24(3):297-306. [doi: 10.1037/0278-6133.24.3.297]
36. Hatzenbuehler ML. The social environment and suicide attempts in lesbian, gay, and bisexual youth. Pediatrics 2011 May;127(5):896-903 [FREE Full text] [doi: 10.1542/peds.2010-3020] [Medline: 21502225]
37. Ceglarek PJ, Ward LM. A tool for help or harm? How associations between social networking use, social support, and mental health differ for sexual minority and heterosexual youth. Comput Hum Behav 2016 Dec;65:201-209. [doi: 10.1016/j.chb.2016.07.051]
38. Ybarra ML, Mitchell KJ, Palmer NA, Reisner SL. Online social support as a buffer against online and offline peer and sexual victimization among U.S. LGBT and non-LGBT youth. Child Abuse Neglect 2015 Jan;39:123-136. [doi: 10.1016/j.chiabu.2014.08.006]
39. Bruce D, Harper GW, Bauermeister JA. Minority stress, positive identity development, and depressive symptoms: Implications for resilience among sexual minority male youth. Psychol Sex Orientat Gend Divers 2015 Sep;2(3):287-296. [doi: 10.1037/sgd0000128]
40. Newcomb ME, Mustanski B. Internalized homophobia and internalizing mental health problems: a meta-analytic review. Clin Psychol Rev 2010 Dec;30(8):1019-1029. [doi: 10.1016/j.cpr.2010.07.003]
41. Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. Psychol Bull 2003 Sep;129(5):674-697 [FREE Full text] [doi: 10.1037/0033-2909.129.5.674] [Medline: 12956539]
42. Lucassen M, Samra R, Iacovides I, Fleming T, Shepherd M, Stasiak K, et al. How LGBT+ young people use the internet in relation to their mental health and envisage the use of e-therapy: exploratory study. JMIR Serious Games 2018 Dec 21;6(4):e11249 [FREE Full text] [doi: 10.2196/11249] [Medline: 30578194]
43. Birkett M, Espelage DL, Koenig B. LGB and questioning students in schools: the moderating effects of homophobic bullying and school climate on negative outcomes. J Youth Adolesc 2009 Aug;38(7):989-1000. [doi: 10.1007/s10964-008-9389-1] [Medline: 19636741]

44. Sinclair KO, Bauman S, Poteat VP, Koenig B, Russell ST. Cyber and bias-based harassment: associations with academic, substance use, and mental health problems. J Adolesc Health 2012 May;50(5):521-523. [doi: 10.1016/j.jadohealth.2011.09.009] [Medline: 22525118]
45. Escobar-Viera CG, Shensa A, Sidani J, Primack B, Marshal MP. Association between LGB sexual orientation and depression mediated by negative social media experiences: national survey study of us young adults. JMIR Ment Health 2020 Dec 3;7(12):e23520 [FREE Full text] [doi: 10.2196/23520] [Medline: 33270041]
46. Varjas K, Meyers J, Kiperman S, Howard A. Technology hurts? Lesbian, gay, and bisexual youth perspectives of technology and cyberbullying. J School Violence 2012 Oct 3;12(1):27-44. [doi: 10.1080/15388220.2012.731665]
47. Cooper RM, Blumenfeld WJ. Responses to cyberbullying: a descriptive analysis of the frequency of and impact on LGBT and allied youth. J LGBT Youth 2012 Apr;9(2):153-177. [doi: 10.1080/19361653.2011.649616]
48. Russell ST, Joyner K. Adolescent sexual orientation and suicide risk: evidence from a national study. Am J Public Health 2001 Aug;91(8):1276-1281. [doi: 10.2105/ajph.91.8.1276]
49. Ryan C, Huebner D, Diaz RM, Sanchez J. Family rejection as a predictor of negative health outcomes in white and Latino lesbian, gay, and bisexual young adults. Pediatrics 2009 Jan;123(1):346-352. [doi: 10.1542/peds.2007-3524] [Medline: 19117902]
50. Mazuz K, Yom-Tov E. Analyzing trends of loneliness through large-scale analysis of social media postings: observational study. JMIR Ment Health 2020 Apr 20;7(4):e17188 [FREE Full text] [doi: 10.2196/17188] [Medline: 32310141]
51. Ehrenreich SE, Underwood MK. Peer coercion and electronic messaging. In: The Oxford Handbook of Coercive Relationship Dynamics. Oxford, UK: Oxford University Press; 2016.
52. Nesi J, Choukas-Bradley S, Prinstein MJ. Transformation of adolescent peer relations in the social media context: part 2-application to peer group processes and future directions for research. Clin Child Fam Psychol Rev 2018 Sep 7;21(3):295-319 [FREE Full text] [doi: 10.1007/s10567-018-0262-9] [Medline: 29627906]
53. Saeri AK, Ogilvie C, La Macchia ST, Smith JR, Louis WR. Predicting Facebook users' online privacy protection: risk, trust, norm focus theory, and the theory of planned behavior. J Soc Psychol 2014;154(4):352-369. [doi: 10.1080/00224545.2014.914881] [Medline: 25154118]
54. Geusens F, Beullens K. Strategic self-presentation or authentic communication? Predicting adolescents' alcohol references on social media. J Stud Alcohol Drugs 2017 Jan;78(1):124-133. [doi: 10.15288/jsad.2017.78.124] [Medline: 27936372]
55. Holland G, Tiggemann M. A systematic review of the impact of the use of social networking sites on body image and disordered eating outcomes. Body Image 2016 Jun;17:100-110. [doi: 10.1016/j.bodyim.2016.02.008] [Medline: 26995158]
56. van Oosten JM, Peter J, Vandenbosch L. Adolescents' sexual media use and willingness to engage in casual sex: differential relations and underlying processes. Hum Commun Res 2017 Jan 1;43(1):127-147 [FREE Full text] [doi: 10.1111/hcre.12098]
57. Reid D, Weigle P. Social media use among adolescents: benefits and risks. Adolesc Psychiatry 2014 Jul;4(2):73-80 [FREE Full text] [doi: 10.2174/221067660402140709115810]
58. Moreno MA, Ton A, Selkie E, Evans Y. Secret society 123: understanding the language of self-harm on Instagram. J Adolesc Health 2016 Jan 1;58(1):78-84 [FREE Full text] [doi: 10.1016/j.jadohealth.2015.09.015] [Medline: 26707231]
59. Escobar-Viera CG, Whitfield DL, Wessel CB, Shensa A, Sidani JE, Brown AL, et al. For better or for worse? A systematic review of the evidence on social media use and depression among lesbian, gay, and bisexual minorities. JMIR Ment Health 2018 Jul 23;5(3):e10496 [FREE Full text] [doi: 10.2196/10496] [Medline: 30037786]
60. Equality Maps Snapshot: LGBTQ Equality By State. Movement Advancement Project. URL: https://tinyurl.com/54dfwcum [accessed 2021-03-17]
61. Charmaraman L, Richer AM, Moreno MA. Social and behavioral health factors associated with violent and mature gaming in early adolescence. Int J Environ Res Public Health 2020 Jul 11;17(14):4996 [FREE Full text] [doi: 10.3390/ijerph17144996] [Medline: 32664533]
62. Ybarra ML, Espelage DL, Mitchell KJ. The co-occurrence of Internet harassment and unwanted sexual solicitation victimization and perpetration: associations with psychosocial indicators. J Adolesc Health 2007 Dec;41(6 Suppl 1):S31-S41. [doi: 10.1016/j.jadohealth.2007.09.010] [Medline: 18047943]
63. Russell D, Peplau LA, Cutrona CE. The revised UCLA Loneliness Scale: concurrent and discriminant validity evidence. J Pers Soc Psychol 1980 Sep;39(3):472-480. [doi: 10.1037//0022-3514.39.3.472] [Medline: 7431205]
64. Björgvinsson T, Kertz SJ, Bigda-Peyton JS, McCoy KL, Aderka IM. Psychometric properties of the CES-D-10 in a psychiatric sample. Assessment 2013 Aug;20(4):429-436. [doi: 10.1177/1073191113481998] [Medline: 23513010]
65. Robinson OC. Conducting thematic analysis on brief texts: the structured tabular approach. In: Qualitative Psychology. Washington, DC: Educational Publishing Foundation; Mar 18, 2021.
66. Sybert J. The demise of #NSFW: contested platform governance and Tumblr’s 2018 adult content ban. New Media Soc 2021 Feb 26:146144482199671. [doi: 10.1177/1461444821996715]
67. Carey E. TikTok's Queer ?It Girls? Are Creating New LGBTQ+ Safe Spaces. Them.US. 2020 Oct 01. URL: https://www.them.us/story/tiktoks-queer-it-girls-create-lgbtq-safe-spaces [accessed 2020-11-01]
68. Ohlheiser A. TikTok has become the soul of the LGBTQ Internet. Washington Post. 2020 Jan 28. URL: https://www.washingtonpost.com/technology/2020/01/28/tiktok-has-become-soul-lgbtq-internet/ [accessed 2020-11-09]

69. Kang J, Wei L. Let me be at my funniest: Instagram users' motivations for using Finsta (a.k.a., fake Instagram). The Social Science Journal 2020 Jan 27;57(1):58-71. [doi: 10.1016/j.soscij.2018.12.005]
70. Kayany JM, Yelsma P. Displacement effects of online media in the socio-technical contexts of households. J Broadcast Electron Media 2000 Jun;44(2):215-229. [doi: 10.1207/s15506878jobem4402_4]
71. Craig SL, Eaton AD, McInroy LB, D'Souza SA, Krishnan S, Wells GA, et al. Navigating negativity: a grounded theory and integrative mixed methods investigation of how sexual and gender minority youth cope with negative comments online. Psychol Sex 2020 Jul;11(3):161-179 [FREE Full text] [doi: 10.1080/19419899.2019.1665575]
72. Miller CT, Kaiser CR. A theoretical perspective on coping with stigma. J Social Isssues 2001 Jan 17;57(1):73-92 [FREE Full text] [doi: 10.1111/0022-4537.00202]
73. Evans LD, Kouros C, Frankel SA, McCauley E, Diamond GS, Schloredt KA, et al. Longitudinal relations between stress and depressive symptoms in youth: coping as a mediator. J Abnorm Child Psychol 2015 Feb 5;43(2):355-368 [FREE Full text] [doi: 10.1007/s10802-014-9906-5] [Medline: 24993312]
74. Underwood MK, Ehrenreich SE. The power and the pain of adolescents' digital communication: cyber victimization and the perils of lurking. Am Psychol 2017 Feb;72(2):144-158 [FREE Full text] [doi: 10.1037/a0040429] [Medline: 28221066]
75. Abreu RL, Kenny MC. Cyberbullying and LGBTQ youth: a systematic literature review and recommendations for prevention and intervention. J Child Adolesc Trauma 2018 Mar 24;11(1):81-97 [FREE Full text] [doi: 10.1007/s40653-017-0175-7] [Medline: 32318140]
76. Angoff H, Barnhart W. Bullying and cyberbullying among LGBT and heterosexual youth from an intersectional perspective: findings from the 2017 national youth risk behavior survey. J School Violence 2021 Jul;20(3):274-287. [doi: 10.1080/15388220.2021.1879099]
77. Coker TR, Austin SB, Schuster MA. The health and health care of lesbian, gay, and bisexual adolescents. Annu Rev Public Health 2010 Mar;31(1):457-477. [doi: 10.1146/annurev.publhealth.012809.103636] [Medline: 20070195]

Abbreviations

LGBTQ: lesbian, gay, bisexual, transgender, or queer
OR: odds ratio
SEM: structural equation modeling

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Viewpoint

Opportunity, Challenge, or Both? Managing Adolescent Socioemotional and Mental Health During Web-Based Learning

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Abstract

The transition to web-based learning during the COVID-19 pandemic has highlighted the need to consider the benefits of and the risks associated with web-based technology for education, media use, and access to resources. Prior to the pandemic, children and adolescents had in-person access to peers; social relationships; educators; health care providers; and, in some cases, mental health resources and medical care in schools and community settings. Due to the introduction of universal masking and physical distancing guidelines to prevent the spread of COVID-19 in early 2020, methods for accessing these resources have shifted dramatically, as people now rely on web-based platforms to access such resources. This viewpoint will explore equity in access to technology for web-based learning, mental health (with a focus on students of color), and the challenge of cultivating meaningful relationships on web-based platforms. Challenges and possible solutions will be offered.

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KEYWORDS

pandemic; technology; media; bullying; mental health; distance learning

Equity in Web-Based Learning

Navigating physical isolation during the lockdown phases of the COVID-19 pandemic has created new challenges for individuals, particularly for children and adolescents who were required to rapidly adapt to distance learning by using technology to replace in-person schooling and daily social interactions. Prior to the pandemic, some students, such as those with serious or chronic medical conditions that require intermittent hospitalization, were homeschooled or had tutors as a regular part of their education. However, for the vast majority of school-age children in the United States, the transition to at-home web-based learning was abrupt. Due to the advent of the pandemic, old norms no longer exist. The pandemic has created a great disruption in more than education, as schools often provide meals; conduct various special education–based evaluations and therapies; facilitate physical activity and socialization; and offer career guidance, supervision, and sometimes even basic medical and mental care free of charge within their walls.

Although in-person schooling can be valuable for multiple children in multiple ways, not all schools are as well resourced as others. Among medical professionals and child advocates, there have been multiple concerns raised regarding the physical and mental health effects of in-person learning versus those of distance learning. Each side acknowledges child and community health but focuses on separate parts of the challenge (eg, prioritizing standard academics or prioritizing socioemotional learning) rather than seeing the whole picture and the impact that using technology for schooling has on children and families.

The reopening of schools may have further exacerbated the risks of morbidity and mortality from COVID-19 in some communities, including immigrant communities and communities of color [1].

In a holistic approach to the technologic integration of learning in which health equity is the central goal, one should consider the following suggestions for addressing remote education:

- Educators, law makers, and medical institutions should incorporate feedback from the most affected communities, including parents and teachers of color in underresourced settings [1], in order to address inequities in education, including inequities in access to teachers, digital technology and equipment, and other services that were historically provided at school.
- Invest in infrastructure to provide reliable broadband internet to all students
- Create an equitable web-based learning experience for students who were previously excluded from full-time in-person learning due to medical conditions or other reasons

Mental Health: Special Focus on Youth From Black, Indigenous, and Persons of Color Communities

In December 2019, a National Institute of Mental Health director's message discussed alarming updates on Black youth suicide [2]. In the message, data from the Emergency Taskforce on Black Youth Suicide and Mental Health were discussed. Suicide rates among Black youth have been increasing [3]. In a group that has long faced inequities in access to mental health services and ongoing oppressive systems in school discipline, justice, and education, this seemingly resilient group of youths has started to exhibit increases in suicidality [4,5]. In 2020, continued trauma and stress have added up for Black youth and youth of color. This includes, but is not limited to, increased morbidity and mortality from COVID-19 among Americans in Black, Indigenous, and Persons of Color (BIPOC) communities [6]. In addition, unprecedented exposure through traditional and social media to the murders of Black citizens at the hands of law enforcement and the inhuman caging of immigrant children has taken a toll [7].

BIPOC youth, who are strong and resilient, are also hurting. The pandemic has magnified the inequities faced by all youth of color in the United States, and Black, Latino, and Indigenous communities are experiencing higher mortality rates [6,8] from infection, higher rates of unemployment, and disproportionate stressors related to housing and food insecurity [9,10]. Mental health and health care experts in Western Washington have also reported an increase in the number of youth of color expressing anxiety. Further, parents and caregivers are seeking advice on how to cope with stress themselves and how to guide their children through symptoms of anxiety, despair, and powerlessness.

Concurrent with the increased amount of stressors, the availability of mental health professionals has also been further strained. School closures have resulted in the loss of a key resource for mental health services that aim to help children and adolescents [11]. The number of licensed mental health providers with experience and expertise in working with youth from Black, Latino, and Indigenous communities was limited before the pandemic [4]. Now, families may face longer waiting times for mental health services, payment challenges (as providers may have switched to only accepting out-of-pocket payments), and limited in-person availability during the transition to telehealth services that promote safety during the pandemic.

In order to address the need for mental health support services, particularly those with a specific focus on BIPOC youth, one should consider the following possible solutions:

- Encourage patients and families to seek support from a health care provider for concerns about mental health
    - Due to potential delays in access or longer-than-normal wait times, individuals should be encouraged to seek mental health resources early instead of waiting until symptoms affect their activities of daily living.
- Providers should actively screen all patients for depression [12,13] and anxiety if they present to a clinical setting for nonmental health concerns.
- Education and health care institutions should ask about the mental health impacts of race-based violence that children witness on traditional and social media.

Opportunities: Curating Web-Based Friendships

As previously stated, the COVID-19 pandemic has unfortunately resulted in multiple school closings in the United States since March 2020. This has had subsequent and variable consequences among different racial, ethnic, cultural, and socioeconomic groups. The American Academy of Pediatrics recognizes that essential development is best achieved in person and supports efforts for having children return to socializing and learning in the same space. To meet the future needs of students undergoing web-based learning, people must acknowledge that children are not monolithic and that the impacts of web-based learning are variable. The idealized model in which students are well resourced, are popular, and are involved in extracurricular activities ignores the students who were struggling in the social environment of school before the pandemic. The social pressure of school was relieved for some students who experienced regular bullying and microaggressions prior to the enforcement of web-based learning, while the high-achieving students experienced less social reinforcement and a lower sense of belonging [14]. However, for other students, the transition to web-based schooling resulted in the loss of their only safe place away from the troubles and trauma at home [15].

Although some of the negative impacts of social media can be unrelenting (eg, influences on body image, mood, and cyberbullying), there are children and teenagers who are discovering that they have the ability to conscientiously curate their friend groups and social experiences on web-based platforms. There are also youth finding their "online voice" through individual advocacy, like Mari Copeny, who continues to highlight the Flint, Michigan water crisis, and through group advocacy, like Future Coalition, a national network and community for youth-led organizations and youth leaders [16]. Current digital natives are learning how to mute, block, and unfriend people with expertise and engage with people on their terms. Prior to the pandemic, social media and digital platforms offered a sense of community, allowed for the exploration of identity, and offered a social forum for expanding friendships beyond physically proximate peers. During the pandemic, youth have relied on digital spaces to maintain and create social connections. These digital spaces provide parents and school-age children with the ability to make their web-based interactions positive, and future remote learning may be an option for families that require a safe or physically distanced environment.

One should consider the following suggestions to aid youth in building supportive friendships in web-based settings:

- Researchers can explore the incidence of students building supportive web-based relationships and their ability to avoid cyberbullying and negative peer influences.
- Adults in the education sphere can provide guidance to students on setting boundaries in web-based relationships. This includes avoiding hostile digital spaces, discontinuing social media profiles that induce stress and poor self-esteem, and reviewing aspects of positive peer relationships (eg, mutual respect, trust, empathy, and support) that can be sought in both web-based and in-person interactions.
- Medical providers can provide resources to families to help students build social skills for both web-based and in-person encounters that are applicable to encounters beyond the classroom [10].

Conclusion

As the ongoing pandemic presents unprecedented challenges to pediatricians, mental health professionals, educators, and families, it is also important to remember that ingenuity can result in unique ways to cope, connect, and coordinate care. It is also important to make solid investments in infrastructure, such as access to broadband internet, mental health, and positive social connection, to minimize inequities. As care providers who care for children and adolescents, we must plan how to improve and sustain the education of youth and their socioemotional and mental health. We must also place specific focus on BIPOC communities, which have been disproportionately affected by the pandemic. Further, we must consider the widening of the digital divide as we develop methods for keeping children and adolescents engaged socially and educationally while considering the wider social impact on the hardest hit communities. The internet can be a great tool for supporting marginalized adolescents when it is available and is intentionally used. Physicians and educators should be prepared to equip families with the tools needed to explore the internet in healthy ways that open minds and promote self-studying and making connections [17]. The experiences and lessons gained from remote learning during the pandemic can be used to provide people with better learning outcomes as we face future challenges.

Conflicts of Interest

None declared.

References

1. Dernbach BZ. ‘I can’t teach if I’m dead’: Minnesota teachers of color say distance learning is best option for fall. Sahan Journal. 2020 Jul 28. URL: https://sahanjournal.com/education/minnesota-schools-reopen-teachers-color/ [accessed 2021-07-08]
2. Gordon J. Addressing the crisis of Black youth suicide. National Institute of Mental Health. 2020 Sep 22. URL: https://www.nimh.nih.gov/about/director/messages/2020/addressing-the-crisis-of-black-youth-suicide.shtml [accessed 2021-07-09]
3. Ring the alarm: The crisis of Black youth suicide in America. Emergency Taskforce on Black Youth Suicide and Mental Health. URL: https://watsoncoleman.house.gov/uploadedfiles/full_taskforce_report.pdf [accessed 2021-07-09]
4. U.S. Department of Health and Human Services. Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services; 2001.
5. Garland AF, Lau AS, Yeh M, McCabe KM, Hough RL, Landsverk JA. Racial and ethnic differences in utilization of mental health services among high-risk youths. Am J Psychiatry 2005 Jul;162(7):1336-1343. [doi: 10.1176/appi.ajp.162.7.1336] [Medline: 15994717]
6. Feldstein L, Tenforde M, Friedman K, Newhams M, Rose EB, Dapul H, Overcoming COVID-19 Investigators. Characteristics and outcomes of US children and adolescents with multisystem inflammatory syndrome in children (MIS-C) compared with severe acute COVID-19. JAMA 2021 Mar 16;325(11):1074-1087. [doi: 10.1001/jama.2021.2091] [Medline: 33625505]
7. Tynes BM, Willis HA, Stewart AM, Hamilton MW. Race-related traumatic events online and mental health among adolescents of color. J Adolesc Health 2019 Sep;65(3):371-377 [FREE Full text] [doi: 10.1016/j.jadohealth.2019.03.006] [Medline: 31196779]
8. Gold JAW, Rossen LM, Ahmad FB, Sutton P, Li Z, Salvatore PP, et al. Race, ethnicity, and age trends in persons who died from COVID-19 - United States, May-August 2020. MMWR Morb Mortal Wkly Rep 2020 Oct 23;69(42):1517-1521 [FREE Full text] [doi: 10.15585/mmwr.mm6942e1] [Medline: 33090984]

9. Couch KA, Fairlie RW, Xu H. Early evidence of the impacts of COVID-19 on minority unemployment. J Public Econ 2020 Dec;192:104287 [FREE Full text] [doi: 10.1016/j.jpubeco.2020.104287] [Medline: 32952224]
10. Selden T, Berdahl T. COVID-19 and racial/ethnic disparities in health risk, employment, and household composition. Health Aff (Millwood) 2020 Sep;39(3):1624-1632. [doi: 10.1377/hlthaff.2020.00897] [Medline: 32663045]
11. Golberstein E, Wen H, Miller BF. Coronavirus disease 2019 (COVID-19) and mental health for children and adolescents. JAMA Pediatr 2020 Sep 01;174(9):819-820. [doi: 10.1001/jamapediatrics.2020.1456] [Medline: 32286618]
12. Siu AL, US Preventive Services Task Force. Screening for depression in children and adolescents: US Preventive Services Task Force Recommendation Statement. Pediatrics 2016 Mar;137(3):e20154467. [doi: 10.1542/peds.2015-4467] [Medline: 26908686]
13. Zuckerbrot RA, Cheung A, Jensen PS, Stein REK, Laraque D, GLAD-PC STEERING GROUP. Guidelines for adolescent depression in primary care (GLAD-PC): Part I. Practice preparation, identification, assessment, and initial management. Pediatrics 2018 Mar;141(3):e20174081 [FREE Full text] [doi: 10.1542/peds.2017-4081] [Medline: 29483200]
14. Hughes JN, Im MH, Allee PJ. Effect of school belonging trajectories in grades 6-8 on achievement: Gender and ethnic differences. J Sch Psychol 2015 Dec;53(6):493-507 [FREE Full text] [doi: 10.1016/j.jsp.2015.08.001] [Medline: 26563601]
15. Marsh S, Dobson R, Maddison R. The relationship between household chaos and child, parent, and family outcomes: a systematic scoping review. BMC Public Health 2020 Apr 22;20(1):513 [FREE Full text] [doi: 10.1186/s12889-020-08587-8] [Medline: 32316937]
16. Mari Copeny. Mari Copeny. URL: https://www.maricopeny.com/ [accessed 2021-07-30]
17. Family media plan. American Academy of Pediatrics.: American Academy of Pediatrics URL: https://www.healthychildren.org/English/media/Pages/default.aspx [accessed 2021-07-07]

Abbreviations

BIPOC: Black, Indigenous, and Persons of Color

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Original Paper

Adolescent Health on Social Media and the Mentorship of Youth Investigators: Five Content Analysis Studies Conducted by Youth Investigators

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Abstract

Although the literature on adolescent health includes studies that incorporate youth perspectives via a participatory design, research that is *designed*, *conducted*, and *presented* by youth remains absent. This paper presents the work of 5 youth investigators on the intersecting topics of adolescent health and social media. Each of these youths was equipped with tools, knowledge, and mentorship for scientifically evaluating a research question. The youths developed a research question that aligned with their interests and filled a gap that they identified in the literature. The youths, whose projects are featured in this paper, designed and conducted their own research project, drafted their own manuscript, and revised and resubmitted a draft based on reviewer input. Each youth worked with a research mentor; however, the research questions, study designs, and suggestions for future research were their own.

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social media; anxiety; depression; self-esteem; Instagram; Reddit; Twitter; YouTube; content analysis; adolescent

Introduction

No Research About Us Without Us

Most scientists who work with human subjects are familiar with this tenet, which implies that study participants, including the youth, should not be treated merely as *passive subjects and beneficiaries* of research but rather as active contributors to the research process [1]. Indeed, a growing body of research suggests that youths and their communities alike benefit from youth participation in research [2-4]. However, one systematic review of youth participatory action research found that youths are seldom engaged in the earliest phases of the research process, including the assessment of needs and formation of research questions [3]. Another systematic review on youth participatory action research found that none of the 45 studies reviewed included youth as authors [4]. Thus, despite increased recognition of the need for youth inclusion in research, instances of youth defining research questions and authoring empirical manuscripts are rare.

In June 2020, partially in response to the COVID-19 pandemic, the *Journal of Adolescent Health* published a call to “transform the way that young people engage with designing and implementing adolescent health programs and policies” [5]. This empirical compilation extends this prerogative to suggest that youth should also be invited to author research. This suggestion may raise additional considerations and concerns. For example, teaching and mentoring youth through the basics of the research process is time-intensive, and many research teams do not prioritize the allocation of staff toward training youth. In addition, youths are often unfamiliar with processes that the scientific community has deemed crucial to legitimate scientific contributions, and thus, research produced by youth may differ from that produced by scholars with more training and resources. In this study, given the youths’ early stage in their research careers, certain expectations of typical empirical research articles were adjusted. For example, the youths received permission from mentors to collect smaller sample sizes, use simpler analytic approaches, and retain a few instances of less-scientific language to allow their unique voices to be present. These approaches are similar to professional researchers’ early investigations or pilot work, which often focus on detecting early findings to fuel larger hypothesis-driven studies [6,7]. We suggest that the need for adjustments such as these is not a sufficient reason to exclude youth from publishing research; rather, youths’ developmental and educational stages should be considered as important context for evaluating their work.

This compilation of youth research presents the work of five young investigators; 4 of the youth authors were in high school at the time of writing (JJ, EK, AM, and OT), and one was in her first semester of college (SG). All youth participated in the Summer Research Scholars (SRS) program, a program that uses a tested and empirically supported curriculum to guide adolescents through the steps of the research process to complete and present their own independent research project [8]. The youths whose projects were featured here experienced 3 months of training in the SRS program. They were provided with tools, knowledge, mentorship, and supervision to scientifically evaluate a research question. They selected their questions through a review of the literature, incorporation of their own areas of interest, and discussions with their peers and mentors. The youths then had approximately 6 months to design and conduct their own research project, draft their own manuscript, and revise and resubmit that draft based on reviewer input. Although each youth worked with a research mentor, the research questions, study designs, and suggestions for future research are their own.

Common Methods Across Projects

Natural Language Processing

In this compilation, two of the five studies used natural language processing to evaluate the text. For these analyses, the Linguistic Inquiry and Word Count (LIWC) program was used [9]. This software program analyzes bodies of text for the frequency of keywords associated with psychologically meaningful categories, including thinking styles, attentional focus, and emotionality in a variety of experimental settings. LIWC builds on several decades of research to understand narrative voice in health [10-15] and uses validated internal dictionaries developed by a rigorous process—in which groups of judges reviewed 2000 words or word stems and determined how the reviewed words related to specific categories (eg, word count, total first-person usage, and negative emotion). During the LIWC analysis of a document, every word is compared with *dictionaries* of up to 74 dimensions across these categories. LIWC calculates the proportion of words falling into different categories, ranging from emotional words to words about social context [16]. LIWC has been validated for content and construct validity [11,17]. Interrater reliability discrimination of categories has been found to range from 86% to 100% depending on the dimension being assessed, supporting content validity.

Content Analysis

All five studies included content analyses as all or part of the approach. Content analysis is a systematic technique for developing categories into which data are sorted based on explicit rules [18]. Content analysis allows for the examination and quantification of social media content, such as original posts (text, images, and videos) and engagement with such posts (likes, comments, and shares). Content analysis has previously been used to evaluate discussions of health-related topics on social media [19,20]. Content analysis may produce more objective data on social media behavior than, for example, self-reports or interviews, which may be vulnerable to social desirability or recall bias. Content analysis approaches allow for the testing of hypotheses through the development of a deductive codebook based on theory or clinical guidelines. Content analysis also allows for the exploratory evaluation of novel phenomena through the inclusion of inductive codes. Furthermore, the content analysis of publicly available social media data is often granted exempt status by institutional review boards, as was the case with each of these projects. This research method allowed adolescents to conduct research on an accelerated timeline.

The studies below are grouped by method, with the two studies using natural language processing appearing first, followed by the three studies that used content analysis alone. For each study, the youth authors are listed first, and the second author is the adult research mentor.

Study 1

This study was prepared by Joshua Jerisha and mentor Reese Hyzer

COVID-19, Social Distancing, and Adolescent Mental Health on Twitter: Web-Based Content Analysis

Introduction

Background

As of February 26, 2021, the COVID-19 pandemic was associated with more than 2.5 million deaths globally, with 508,127 confirmed deaths in the United States alone [21]. Nonpharmaceutical interventions have been used to curb the spread of the virus. Social distancing measures (physical distancing, quarantines, and remote work or school) have been found to be one of the most effective methods for reducing COVID-19 transmission [22], and in compliance with these measures, many communications have shifted to a virtual format. In turn, social media may play a significant role in communication regarding the risks associated with COVID-19 and social distancing measures.

In the early days of the first outbreak (January 31, 2020, to February 2, 2020), social media use among Chinese citizens aged 18 years or older was correlated with a 22.6% increase in anxiety and a 48.3% increase in depression [23]. Before the pandemic, anxiety and depression were not uncommon among adolescents, with 16.5% of US youth aged 6-17 years experiencing a mental health condition in 2016 [24]. In 2020, 98.1% of US adolescents reported compliance with social distancing [25]. Adolescents may be at a unique risk for mental health challenges because of a combination of social media use, prepandemic rates of anxiety and depression, and reduced social contact.

The World Health Organization (WHO) declared COVID-19 a global pandemic on March 11, 2020. By April 2, 2020, the WHO launched their #HealthyAtHome campaign, followed by advice on the use of face masks by April 6, 2020. All these announcements were communicated in a tweet from the WHO [26].

Objectives

Currently, associations among social media use, mental health, and the language surrounding COVID-19–related posts remain unclear. The shifting state of the institutional response to COVID-19 may be reflected in the broader discussion of the pandemic on Twitter. Thus, changes in information found on social media may be associated with related shifts in mental health. In light of this, our study aims to explore the independent and co-occurring mentions of social distancing and mental health on Twitter between March and April 2020, as well as the content and language featured in these posts.

Methods

Study Design

We conducted an exploratory content analysis and linguistic analysis of Twitter. Our social media unit of analysis was the *tweet*, which we defined as a single post created by a user account containing between 1 and 280 characters of text. This study was exempt from human subjects review by the University of Wisconsin-Madison Institutional Review Board.

Search and Sampling Strategy

We sought to obtain a representative sample of COVID-19–related tweets from March 2020 to April 2020. We manually sampled posts from the *Top* category of a custom Twitter search for *#COVID19* from both months. We selected the first 50 tweets from the list for each month. Twitter's proprietary sorting algorithm governs the retrieval of tweets via this mechanism. This design sought to replicate how adolescents might encounter COVID-19–related tweets available to the general public. Tweets favored by the Twitter algorithm are given more exposure on the platform and thus are most relevant to the average adolescent Twitter user.

Social Media Inclusion Criteria

Sampled tweets were included for analysis if they contained English language text and the hashtag #COVID19. If either of these criteria were not met, the corresponding tweet was excluded from the analysis. Similarly, duplicate tweets were eliminated from the sample set.

Measures

Our study examined the following three categories of data: descriptive profile data, post content, and LIWC scores.

Descriptive Profile Data

Descriptive profile data for each tweet included its post date, number of likes, number of account followers, and account verification status. These data points offer context regarding the size of the audience and the types of accounts posting the tweets. Verified accounts usually belong to users of public interest, ranging from celebrities to institutions such as the WHO and accredited professionals, including epidemiologists.

Post Content

Post content data consisted of the multimedia attached to the tweet in the form of a hyperlink, image, or video, as well as references to social distancing and mental health.

Multimedia data were recorded to provide context for social media engagement (interaction with posts through likes, comments, and other means), and by extension, its weighting by the algorithm. In previous research, social media users reported that they would preferably engage with posts containing an image (68%), a video (50%), and a hyperlink (16%) [27]. Thus, greater multimedia presence indicates more relevance to typical adolescent users because of the relationship between high social media engagement and Twitter's algorithm.

References to social distancing and mental health were based on keywords established in the codebook, which are defined in Table 1.

Table 1. Study 1—social distancing and mental health reference coding criteria and results for March and April tweets (N=100).

Reference	Codebook keywords	Example tweet verbatim	March tweets (n=50), n (%)	April tweets (n=50), n (%)
Social distancing	*Social distancing*, *physical distancing*, *stay home*, *shelter in place*, *lockdown*, *shutdown*, *quarantine*, *isolation*, *self-isolate*, *remote learning*, *remote work*, and *flatten the curve*		11 (22)	21 (42)
Mental health	*Mental health*, *anxiety*, *depression*, *anxious*, *depressed*, *stressed*, *frustrated*, *angry*, *sad*, *scared*, and *afraid*, *resilient*		13 (26)	5 (10)
Both	One or more keywords from social distancing and mental health		11 (22)	6 (12)

The LIWC Program

We used the most recent version of the LIWC program, which is a text analysis program described in the Introduction section of this compilation [28]. LIWC has previously been used in studies on news media coverage of cyberbullying [29], gender differences in pediatric residency personal statements [30], and linguistic convergence among friend groups [31]. Output variables, referred to as *LIWC scores* in this paper, represent the frequency of keyword occurrence. Each of these numerical scores can be compared between datasets to illustrate the relative trends in the written materials. The only LIWC score that differs from this design is *emotional tone*, which is evaluated as a percentile between 0% and 100% [28]. Sample keywords from LIWC dictionaries are listed in Table 2. Our LIWC dictionaries of interest were *anger* and *sadness* (emotions), *anxiety* and *risk* (perceptions), and *first-person singular* and *first-person plural* (pronouns). The *emotions* and *perceptions* dictionaries correspond to several relevant components of adolescent mental health (eg, symptoms of stress, anxiety, and depression), whereas the singular and plural *pronoun* dictionaries provide insight into the framing of tweets. All these factors help inform our understanding of the possible mental health implications for adolescent users.

Table 2. Study 1—Linguistic Inquiry and Word Count (LIWC) dictionary, example terms, and LIWC scores for March and April tweets with two-tailed t test results.

LIWC dictionary	LIWC example terms	LIWC scores		*P* value (adjusted)
		March tweets, mean (SD)	April tweets, mean (SD)	
Emotional tone	N/A[a]	50.25 (37.85)	38.98 (33.04)	.12
I	*I, me*, and *mine*	2.23 (4.32)	0.77 (1.66)	.03
We	*We, us*, and *our*	1.49 (2.56)	1.61 (2.39)	.80
Anxiety	*Worried* and *fearful*	0.67 (1.33)	0.75 (1.41)	.77
Anger	*Hate, kill*, and *annoyed*	0.68 (1.52)	0.49 (1.27)	.51
Sadness	*Crying, grief*, and *sad*	0.77 (1.76)	0.77 (1.85)	.99
Risk	*Danger* and *doubt*	0.99 (1.74)	1.60 (2.51)	.16

[a] N/A: not applicable.

Data Collection Procedures

Data collection began with Twitter's *Advanced search* under the *Search filters* section of the website. This type of search allows a user account to filter tweets using hashtags and dates. *#COVID-19* was input into the hashtag field, with *March 1, 2020*, as the start date and *March 31, 2020*, as the end date for March. For April, we switched the data parameters to *April 1, 2020*, for the start date and *April 30, 2020*, for the end date. Age-related filters were not available, so our selected tweets were produced by accounts associated with organizations and individuals of various ages. Tweet text verbatim was copied into a spreadsheet before the number of the tweet's likes, the number of account followers, and account verification status were recorded. Tweet text was analyzed using the LIWC program to determine LIWC scores. We did not collect any personally identifiable data, such as full names or Twitter handles. Data were collected between July 22, 2020, and July 26, 2020.

Analyses

Data were separated by month to represent March 2020 and April 2020 to interpret our findings through comparisons. Descriptive statistics were conducted and included means and SDs for tweet likes and followers, percentages for account verification, and percentages for multimedia. A chi-square test was used to assess the relationship between the month and the proportion of mentions of social distancing, mental health, and both or none. Independent *t* tests were conducted to compare LIWC scores between tweets posted in March and April. Statistical analyses were conducted using the software STATA 15.1 (StataCorp LLC), and statistical significance was set at *P*<.05.

Results

Descriptive Profile Data

We identified a national sample of 100 tweets associated with the COVID-19 pandemic, with 50 sourced from March 2020 and another 50 sourced from April 2020. The March tweets averaged 586.3 likes (SD 1950.7) and 100,103.5 account followers (SD 167,936.8), whereas the April tweets averaged 358.5 likes (SD 550.3) and 482,775.2 account followers (SD 1,208,351). Of the 50 tweets sampled, 31 (62%) from March and 30 (60%) from April were posted by verified accounts.

Post Content

Among the 50 March tweets, 9 (18%) contained a hyperlink, 20 (40%) contained an image, 8 (16%) contained a video, and 13 (26%) contained no media. Among the 50 April tweets, 12 (24%) contained a hyperlink, 23 (46%) contained an image, and 6 (12%) contained a video, whereas 9 (18%) did not contain any media. We found that the frequency of social distancing mentions was greater in April tweets (21/50, 42%) than in March tweets (11/50, 22%; *P*=.04). There were more mental health mentions in March tweets (13/50, 26%) than in April tweets (5/50, 10%; *P*=.04). Tweets that included mentions of both social distancing and mental health were present more in March tweets (11/50, 22%) than in April tweets (6/50, 12%; *P*=.04). Finally, tweets that mentioned none of these categories were less prevalent in March tweets (15/50, 30%) than in April tweets (18/50, 36%; *P*=.04; see Table 1 for further details).

LIWC Results

An independent sample *t* test showed that March 2020 tweets had significantly more singular (I) pronouns (mean 2.23, SD 4.32) than April 2020 tweets (mean 0.77, SD 1.66; t_{98}=2.24; *P*=.03). All other results were statistically insignificant (*P*>.05). The complete list of LIWC scores and *t* test results are listed in Table 2.

Discussion

Principal Findings

We found that references to social distancing increased, whereas references to mental health and both categories decreased between March and April. In addition, *first-person singular* pronoun usage decreased significantly during the same timeframe. On the basis of these findings, we drew cautious inferences regarding adolescent mental health amid the COVID-19 pandemic.

Social Media Discourse

Our results suggest that social distancing may have become a more salient topic of social media discourse as the pandemic progressed. In the early months of the crisis, fears surrounding the coronavirus remained relatively consistent, supported by the lack of significant differences between the March and April data sets of *anxiety* and *risk*. In addition, social distancing remained prominent between both months, whereas references to mental health decreased from March to April. These findings may provide some insight into adolescent mental health amid the COVID-19 pandemic. Previous studies have shown that adolescents are especially sensitive to changes in social stimuli, particularly in the reduction of interaction with peer groups [32]. References to social distancing may emphasize this unfulfilled need. Adolescents who increasingly come into contact with social media content involving social distancing may be at an elevated risk of mental health consequences.

Individualism Versus Collectivism

The decrease in the prevalence of *I* pronouns suggests less frequent usage of an individualistic language as the pandemic progressed. However, our findings do not support an increase in the prevalence of *we* pronouns. One possible explanation is a shifting focus to more factual and objective content phrased in the third person (eg, public health statements). In the future, larger studies may be able to detect trends in language to examine changes in individualistic or collectivist sentiment over time or across groups. Collectivism emphasizes the priorities of the group over the individual [33], which may reduce the frequency with which individual mental health is referenced. For this reason, fewer references to mental health may indicate a societal paradigm shift away from the perspective of individuals. The collectivist perspective is associated with positive mental wellness under certain circumstances. In a study, cultural collectivism was correlated with a reduction in suicidal ideation among grieving women [32]. In contrast with the isolation associated with social distancing measures, a collectivist outlook may have a positive effect on adolescent mental health.

Limitations

A few considerations must be taken into account when interpreting the results of our study. The breadth of our content analysis provides insight into macrolevel social trends, although our sample size was small. For a few of our LIWC measures, statistical significance may have been achieved in a larger sample. Similarly, selected posts were prioritized by the Twitter algorithm rather than being produced or shared by the adolescent population. With these caveats in mind, our data can be used to draw cautious inferences regarding specific population segments, although they are not a perfect metric of individual attitudes and perceptions. In the future, surveys or focus groups can be used to corroborate the content analysis findings. In addition, the web-based or offline divide may have played a role in our study. Opinions expressed on the web can differ from personal beliefs offline. Interviews with adolescents would provide an understanding of offline perceptions of social distancing and mental health.

Conclusions

In light of our study, clinicians should consider the type of content being consumed on social media when addressing adolescents' mental health during the COVID-19 pandemic. Mass media sources (television and newspaper stories) have the capacity to shape public responses to crises. Previous research has demonstrated that as few as 4.6% of these sources *express empathy* in response to crises [34]. Mass media messaging is related to social media, as Twitter serves as a platform that forwards these sources to a wider audience. When discussing mental health challenges, clinicians should ask their adolescent patients about the tone of the media they consume and how it affects their mood and thought processes. These considerations will be especially relevant in treating the long-term mental health consequences of the pandemic. Future studies should investigate the offline mental health implications of COVID-19 on social media using more targeted methods, such as interviews and focus groups. These studies can be regularly administered for a timeframe longer than 2 months to better track the evolution of the adolescent mental health response to COVID-19.

Study 2

This study was prepared by Shreya Godishala and mentor Anna Jolliff

Pro- and Antiopioid Posts on Reddit: Content Analysis

Introduction

Opioid Use Among Adolescents

In 2018, almost 70,000 people died from drug overdose [35]. Two out of three overdose deaths involved opioids such as prescription opioids, heroin, or synthetic opioids (eg, fentanyl). A large number of opioid users are adolescents [36]. Research suggests that 5.5% of those aged 17 years endorse opioid misuse [37]. Investigating opioid-related content on social media platforms commonly used by adolescents has the potential to reveal patterns of opioid abuse at a national scale, understand the opinions of adolescents and young adults, and provide insight to support prevention and treatment [38].

Social Media and Opiate Use

Despite the large number of adolescents who misuse opioids [36], little is known about how social media influences adolescents' use or misuse of opiates. One study found an association between a participant tweeting about opioids and offline opioid overdoses [39]. Furthermore, previous research has shown that engagement with alcohol-related and e-cigarette–related social media is associated with more offline use of these substances [40,41]. Therefore, it is important to understand the messages that adolescents view on social media regarding the risky behavior of using opiates, as these messages may predict their behavior.

Reddit is a forum-based social media platform in which subcommunities, or *subreddits*, are built based on people's interests [42]. A study on regular news consumers found that about half of Reddit users were young adults aged between 18 and 29 years [43]. To date, few empirical studies have discussed opioid use in Reddit communities. A previous study evaluated posts from anonymous and nonanonymous users in an opioid-related Reddit thread [44]. This study found that nonanonymous users were more likely to use words related to the past than anonymous users, who may have felt more comfortable discussing present actions. This study supports the usefulness of applying linguistic analysis to Reddit posts in an effort to understand opioid users. However, this study did not examine differences between pro- and antiopioid Reddit posts, which may further reveal attitudes among opioid users.

This Study

Little is known about how Reddit users post about opioids in web-based communities, the degree to which engagement occurs, and the themes present in pro- versus antiopioid posts. The aim of this study is to conduct a content analysis evaluating engagement and linguistic elements of pro- and antiopioid use posts on Reddit.

Methods

Study Design

We conducted a content analysis using the natural language processing of publicly available Reddit posts. This study was exempt from human subjects review by the University of Wisconsin-Madison Institutional Review Board.

Reddit Post Selection

We identified a sample of Reddit posts by searching for *opioid* on Reddit and clicked on the first subreddit, which also had the largest membership. This selection approach allowed us to replicate how an adolescent might naturally look for information about opioid use on Reddit.

Posts within this subreddit were sorted by the most recent, and the first 100 posts were pulled for analysis. Posts were included for analysis if they discussed opioid use and took a positive or negative stance regarding opioid use. Neutral posts were excluded from the analysis. To determine whether posts were pro- or antiopioid use, we developed a codebook based on previous research [45]. Pro-opioid posts mentioned usage of drugs, questions about usage and sourcing, and addiction without a stated intent or desire to recover. Antiopioid posts mentioned seeking help for recovery, withdrawal, and sobriety. One investigator (SG) categorized posts as positive or negative using a deductive approach. A second investigator coded a 19.61% (20/102) subsample of both Reddit (n=10) and Twitter (n=10) posts to calculate the interrater agreement. Interrater agreement was calculated as the percentage of Reddit and Twitter posts referencing each category, ranging between 85% (17/20) and 100% (20/20), with a mean of 92.7% (SD .05%)

The LIWC Program

Pro- and antiopioid posts were evaluated using the LIWC software described in the Introduction section of this compilation [28]. LIWC software scans text and calculates the percentage of text words that fall within a given dictionary. LIWC has been used in previous studies to evaluate publicly available text and understand differences in content and tone [29].

Measures

LIWC Dictionaries

The selected LIWC variables were aligned with the specific aims of our study. Previous research has shown that the results of opiate use include changes in physical and mental health, isolation from family and friends, and financial difficulties [46]. Therefore, we included variables related to tone, positive emotion, negative emotion, health, relationships, and focus (past, present, and future). The three focus variables show whether the text describes past events (*used*, *ago*), present events (*now*, *today*), or future events (*will*, *soon*). These variables were selected based on their relevance to opioid use [47]. Table 3 shows the full list of LIWC variables, with example words coded for those variables.

Table 3. Study 2—LIWC[a] variables included with example words.

LIWC variable	LIWC example words
Tone	—[b]
Ipron	*It*, *to*, and *no*
Posemo	*Love* and *nice*
Negemo	*Hurt* and *ugly*
Anxious	*Worried*
Anger	*Hate* and *kill*
Sad	*Crying* and *grief*
Family	*Dad* and *aunt*
Friend	*Buddy* and *neighbor*
Body	*Cheeks* and *hand*
Health	*Clinic*, *flu*, and *pill*
Focus past	*Ago*, *did*, and *talked*
Focus present	*Today*, *is*, and *now*
Focus future	*May*, *will*, and *soon*
Work	*Job*, *major*, and *xerox*
Money	*Audit*, *cash*, and *owe*

[a] LIWC: Linguistic Inquiry and Word Count.

[b] Not available. The LIWC 2015 development manual does not provide example words for Tone.

Engagement

We collected data on how individuals may interact with pro- or antiopioid posts by logging the number of upvotes and comments on each post. The upvote feature on the Reddit platform is typically used as an indication of the support or approval of a post.

Data Collection Procedure

Data were collected on Reddit posts from July 11 to 12, 2020. Interrater agreement for positive posts was 80% (8/10). All posts were copied and pasted verbatim into Google sheets.

Analysis

Descriptive statistics were used to understand the engagement with pro- and antiopioid posts. A two-tailed *t* test was used to compare LIWC scores for each variable between pro- and antiopioid Reddit posts. Statistical significance was set at $P<.05$.

Results

Sample Characteristics

At the time of the analysis, this subreddit had approximately 116,000 members. A total of 100 posts were included in the analysis. All posts were dated between July 8, 2020, and July 26, 2020. In this sample, 65% (65/100) of the posts were pro-opioids, and 35% (35/100) were antiopioid. There were more comments on antiopioid posts (mean 14.88, SD 16.37) than on pro-opioid posts (mean 9.06, SD 12.22; t_{81}=2.79; *P*=.05). Similarly, there were more upvotes for antiopioid posts (mean 41.67, SD 103.43) than for pro-opioid posts (mean 1.58, SD 1.98; t_{81}=16.84; *P*=.002).

An example pro-opioid post was the following, "Hey guys, was just wondering based on your experiences, what is the best oxycodone brand."

An example antiopioid post was the following:

> *Hi I'm new on here and I'm happy I have found a place to talk about my addiction, I really need help. I've been on 200 mg of Diazepam and 900mg of Codeine Phosphate. I am very scared I might overdose and I just want to be sober!*

LIWC Results

The scores on the LIWC variable *Focus Present* were significantly higher for antiopioid posts (mean 15.58, SD 9.81) than for pro-opioid posts (mean 11.19, SD 5.79; t_{98}=2.82; *P*=.02). The *Focus Future* variable was also significantly higher for antiopioid posts (mean 1.63, SD 1.86) than for pro-opioid posts (mean 0.83, SD 0.96; t_{98}=2.84; *P*=.02). There were no other statistically significant differences between pro- and antiopioid posts (Table 4).

Table 4. Study 2—engagement and linguistic differences between pro- and antiopioid posts on Reddit.

Variable	Antiopioid (score), mean (SD)	Pro-opioid (score), mean (SD)	*P* value
Focus present	15.58 (9.82)	11.19 (5.80)	.02
Focus future	1.63 (1.86)	0.83 (0.97)	.02
Upvotes	41.67 (103.43)	1.58 (1.98)	.002
Comments	14.48 (16.37)	9.06 (12.22)	.05

Discussion

Principal Findings

The purpose of this study was to examine the differences between pro- and antiopioid posts on Reddit. We found that there were more comments and upvotes on antiopioid posts than on pro-opioid posts. Antiopioid posts were more likely to contain linguistic elements related to the present and future than pro-opioid posts. Our results show that there may be differences in how antiopioid and pro-opioid Reddit users relate to the present and the future. Our results further show that although pro-opioid posts may be more common in some Reddit communities, antiopioid users who post in these communities are likely to experience support (in the form of upvotes) and engagement (in the form of comments).

Most posts on the Reddit opioid community were pro-opioid. However, there were more upvotes for antiopioid content than for pro-opioid content. As the upvote feature is typically used to indicate support or approval, this finding suggests that users who wish to discuss the negative effects of opioid use may find support (in the form of upvotes) on Reddit. More frequently, upvoted posts are sorted to the top by the Reddit algorithm. Therefore, antiopioid posts, which received more upvotes in this study, may also be seen by more users of this subreddit.

There were also fewer comments under pro-opioid posts than antiopioid posts. Comments are a primary way for users to interact with each other in the community and may indicate engagement, support, and discussion. Our results suggest that people who share pro-opioid posts may be met with less conversation than those who share antiopioid posts. However, in this study, only the number and not the content of comments were evaluated. Future studies should examine whether comments on antiopioid posts are positive or negative.

Of the 16 LIWC variables measured, only the *Focus Present* and *Focus Future* variables were significantly different between pro- and antiopioid use posts. This finding is somewhat consistent with a previous study that found differences in time focus between anonymous and nonanonymous Reddit users [44]. We found that nonanonymous users used more words related to the past, which may be due to concerns about nonanonymously disclosing current or planned activities. In this study, a difference in focus was also identified. Words such as *today*, *now*, and *will* were more frequent in antiopioid posts than pro-opioid posts. It may be that antiopioid Reddit users are more likely to comment on the negative present or anticipated future outcomes associated with opioid use.

No other variables were significantly different between pro-opioid and antiopioid posts. This finding was surprising, as the variables were chosen based on outcomes of opioid use, and social media displays of drug use have been shown to reflect real-life use [41]. We had expected that antiopioid posts, for example, would describe negative emotions (*scared*) or describe the topics of family, friends, or financial problems [46]. It may be that pro-opioid users chose to focus on other aspects of drug use. For example, past research on e-cigarette use shows that Reddit conversations are dominated by conversations about how to access these products [48]. In contrast, antiopioid Reddit users may have chosen not to share negative outcomes related to health, family, or work.

Limitations

This study's external validity was limited by the small sample size and the relatively short length of the period for which the posts were collected. Reddit does not provide demographics for its users, so we cannot confirm that the study participants were adolescents or young adults; however, research suggests that Reddit is more popular among young adults than any other demographic [43]. Therefore, young people are likely to encounter the pro- and antiopioid content described in this study.

Conclusions

This study was one of the first to examine the engagement and linguistic elements of opioid use in a popular subreddit. This study showed that there is still much that needs to be researched about how individuals engage in web-based communities about opiates. The findings of this study indicate that, except for verb tense, word usage in posts about opiates may not distinguish pro- from antiopioid Reddit users. Future studies should investigate how members of opioid discussion groups on Reddit and other social media interact with opioid-related content, including through likes or upvotes and in the comment sections. If Reddit's algorithm can identify youths who misuse opioids, Reddit can suggest resources and assist its users in finding help.

Study 3

This study was prepared by Anjali Mathur and mentor Bradley Kerr

References to Positive and Negative Self-esteem on the Comments of Beauty-Related YouTube Videos: Content Analysis

Introduction

Self-esteem in Adolescence

Adolescence is the stage between 11 and 21 years of age, and it is a critical period for the development of self-esteem [49]. Self-esteem is defined by how one positively or negatively views oneself, and low self-esteem is associated with depression, anxiety, and suicidal ideation [50-53]. In adolescence, self-esteem is especially vulnerable to protective or harmful influences [54]. Therefore, it is important to understand influences on adolescent self-esteem, and social media may present one such influence. Previous studies have found that social media use is associated with lower self-esteem [55,56].

Social Media Influencers and Self-esteem

One way in which social media influences adolescents' self-esteem is through social media influencers. Social media influencers are content creators with a large social media following. Individuals with low self-esteem are more likely to make upward comparisons between themselves and influencers [54,57]. Beauty-related YouTube content creators are influencers that share aspects of their personality, esthetics, and preferences, allowing viewers to relate to them [57]. Specifically, beauty-related YouTube content creators post videos that review and promote makeup products while also entertaining their viewers through sharing tutorials and trends [57,58]. Such content may potentially impact adolescent viewers' self-esteem, given the focus on physical appearance and that YouTube is used by 77% of adolescent internet users [59]. These youths may seek advice on purchases, enjoy video entertainment, or watch videos to relax [60]. In addition, the popularity of beauty-related videos on YouTube has increased drastically as the annual viewership increased from 59 billion in 2016 to 169 billion in 2018 [58]. This large viewership suggests that these videos have the potential to reach and influence a wide audience, which may include many adolescents. Thus, it is important to understand the influence of viewing beauty-related YouTube content creators' videos on adolescents' self-esteem.

This Study

Previous studies have examined content shared by beauty-related YouTube content creators and identified methods creators use to gain followers and influence their viewers [57]. Beauty-related YouTube videos may affect the self-esteem of viewers, and it is possible that these viewers describe the effects on their self-esteem in comments on these videos. However, previous studies have shown that Instagram users may post positively toned comments while self-reporting negative effects on their body image [61]. Thus, the presence of self-esteem-related discussions in beauty-related YouTube content creators' video comment sections and their tone remain unclear. The aim of this study was to examine the expression of and overlap between self-esteem and tone in comments on beauty-related YouTube videos.

Methods

Study Design

We conducted a content analysis of publicly available YouTube comments, which is described in the Introduction section of this compilation. This method allowed for the objective evaluation of conversations in beauty-related YouTube video comment sections. This study was exempt from human subjects review by the University of Wisconsin-Madison Institutional Review Board.

Search Strategy

We identified a sample of 6 beauty-related YouTube content creators whose content focuses on makeup. To identify beauty-related YouTube content creators likely to be viewed by adolescents, we used the search term *most popular makeup youtubers* in the Google search engine. The first four relevant results were reviewed, and beauty-related YouTube content creators who were represented on more than one website were selected [62]. Beauty-related YouTube content creators were included if, within their top 16 most recently posted videos, at least two videos included *makeup* or *palette* in the title of the video. For each beauty-related YouTube content creators, the two most recent videos including the word *makeup* or *palette* in the title were included in this study.

Comment Inclusion Criteria

The 20 most recent comments for each beauty-related YouTube content creator's selected video were evaluated if they contained more than a username, were written in English, and included words (not just emojis). For comments that received responses, only the initial comments were included, not the responses.

Measures

Positive and Negative Self-esteem

We developed a codebook adapted from the Rosenberg Self-Esteem questionnaire to evaluate the presence of positive and negative self-esteem references [63]. The 10 items from the questionnaire were used to define positive and negative self-esteem references. The questionnaire included both positively and negatively framed statements. Each item was used for both positive self-esteem and negative self-esteem codes by reframing the statements. The positive self-esteem code was created using positively framed statements and by converting negative questionnaire items to positive statements. Similarly, the negative self-esteem category was developed using negatively framed statements and by converting the positive questionnaire items to negative statements. Table 5 shows the full definitions of positive and negative self-esteem.

Table 5. Study 3—codebook values and definitions.

Codebook values	Definition
Self-esteem	
Positive	Satisfied with self, thinking they are good, having good qualities, feeling they are just like or better than others, feel proud of themself, feeling important, feeling worthy, respects themself, feels successful, and positive about self or life
Negative	Unsatisfied with self, thinking they are no good at all, feeling they have little/no good qualities, feeling nothing compared with others, having little to be proud of, feeling useless, feeling like a person of little worth, disrespectful to self, thinks they are a failure, and negative attitude toward self
Tone	
Positive	Good, pleasant, happy, joyful, contented, commenter offers a suggestion, impressed, love, gratitude, inspiration, fabulous, and constructive suggestions offered by commenters
Negative	Bad, unpleasant, sad, afraid, angry, dislike, out of control, boring, disgusted, hate, terrible, canceled, and corrections offered by commenters

Positive and Negative Tone

We developed a codebook adapted from the Positive and Negative Experience Scale to evaluate tone [64]. The initial codebook was pilot tested and refined using the study data. The initial codebook defined positive tone using the following adjectives from the scale: good, pleasant, happy, joyful, and contented. Additional phrases suggesting a positive tone were added to the codebook after pilot testing, including adjectives (impressed, love, gratitude, inspiration, and fabulous) and constructive suggestions offered by commenters. Negative tone was also defined using adjectives from the Scale of Positive and Negative Experience, including bad, unpleasant, sad, afraid, angry, and dislike. Additional phrases suggesting a negative tone were added to the codebook after pilot testing, including adjectives (out of control, boring, disgusted, hate, terrible, and canceled) and corrections offered by commenters.

Audience Engagement

We recorded the number of likes, dislikes, comments, and views on each video, as well as the follower count for each beauty-related YouTube content creator's channel.

Data Collection Procedures

Data were collected from each video, and comments were coded in October 2020. A second investigator coded a 10% (24/240) subsample of the comments. Interrater agreement was calculated for each codebook measure as the percentage of YouTube comments coded the same between the two investigators. Interrater agreement ranged between 88% (21/24) and 100% (24/24), with a mean of 95.8% (SD 0.06).

Analysis

Descriptive statistics were calculated to assess the prevalence of references to self-esteem and tone.

Results

YouTube Videos and Creators Characteristics

A total of 12 videos were included, two videos from each of the 6 beauty-related YouTube content creators. Likes per video ranged from 7000 to 634,000 with an average of 129,925.0 likes (SD 191,029.8), whereas dislikes ranged from 109 to 85,000 with an average of 14,538.4 dislikes (SD 29,260.2). Comments ranged from 424 to 37,724, with an average of 13,279.3 comments per video (SD 16,159.9). Views per video ranged from 107,437 to 10,168,197, with an average of 2,362,004.0 views (SD 3,211,374.3). The beauty-related YouTube content creators had a range of 4.8 million to 23.1 million subscribers to their channel.

Positive and Negative Self-esteem

A total of 240 comments were evaluated. Among these comments, 5.4% (13/240) reported positive self-esteem. An example of a positive self-esteem comment was:

I'm not really a brand...yet.But, I do want to take over the world of vintage clothing. You're an inspiration. [beauty-related YouTube content creator's name]

Of all the comments, 6.3% (15/240) referenced negative self-esteem. For example, a person commented:

> *I would be terrible friends with them, I don't like make-up on me, I'm broke, I'm not popular, and I don't keep up with trends.*

No comments referenced both positive and negative self-esteem. Of the comments, 88.3% (212/240) did not refer to self-esteem.

Positive and Negative Tone

Among the comments evaluated, 65.4% (157/240) exhibited a positive tone. An example of a comment with a positive tone included, "HE LOOKS GOOD WTF." Of all comments, 17.5% (42/240) displayed a negative tone. For example, a person said, "You look like You did an absolutely terrible kawaii Makeup." Of the comments evaluated, 3.3% (4/240) exhibited both positive and negative tone. For example, a commenter wrote:

> *As a victim of the One Chip Challenge...DON'T DO IT! hahahahaha!!! I am a wuss and totally had a panic attack...I did get some pretty funny footage though LMAO.*

Of all comments, 18.7% (45/240) displayed neither positive nor negative tone.

Overlap in Self-esteem and Tone

Among the comments that referenced positive self-esteem, 100% (13/13) reflected a positive tone. Positive self-esteem was referenced in 8% (1/13) of positive-toned comments. Among the comments that referenced negative self-esteem, 54%

(7/13) reflected a positive tone, and 69% (9/13) reflected a negative tone. Negative self-esteem was referenced in 4.5% (7/157) of positive-toned comments and 21% (9/42) of negative-toned comments.

Discussion

Principal Findings

Through this study, we found that few comments on beauty-related YouTube videos referenced self-esteem. Among the self-esteem comments, a similar number of positive self-esteem and negative self-esteem comments were observed. Most comments on the sampled beauty-related videos showed a positive tone.

The first main finding was that 11.7% (28/240) of comments referenced self-esteem. A possible explanation for this finding is that many feel uncomfortable discussing self-esteem on the web. Previous research suggests that social media users feel pressured to only post what would make them, as an individual, look good [65], which may influence viewers to avoid commenting negatively about their self-esteem. It is also possible that the viewer avoids commenting on their self-esteem if the rest of the comment section appears to include few comments referencing others' self-esteem. Finally, it may be that few viewers experienced changes in their self-esteem.

Our second main finding was that there were a similar number of comments that referenced positive and negative self-esteem. One possible reason for this finding is that beauty-related YouTube videos can impact a viewer's self-esteem both positively and negatively. This finding aligns with a previous study that suggested that YouTube videos can both hurt and help the viewer's self-esteem based on their understanding and relatability to the beauty-related YouTube content creators [66]. However, another possibility is that YouTube users comment on their existing self-esteem levels when viewing YouTube content and may not be influenced by the videos themselves. Therefore, it is not clear what prompts positive and negative self-esteem discussions within the comments of beauty-related YouTube content creator videos.

An additional finding was that most comments displayed a positive tone. This aligns with previous studies that suggest that beauty-related YouTube content creators build their platform to spread positivity [67] and that viewers are more likely to comment with supportive material [68]. A positive tone may indicate a positive viewing experience and positive influences on self-esteem; however, research conducted on Instagram suggests that users may comment positively on a post but self-report negative effects on their own body image [61]. Thus, it is possible that a positive tone may not reflect a positive change in the viewer's self-esteem. In addition, it is possible that the positive tone conveyed in the comment section may influence the viewer to avoid commenting negatively or commenting on their self-esteem.

Limitations

One limitation of this study was that self-reported self-esteem was not measured. Future work should examine the self-reported self-esteem of adolescents who view beauty-related videos on YouTube. In addition, those who comment on YouTube videos may not be representative of all viewers of the video, and it is not clear how findings generalize across all video viewers. In an attempt to review a broader set of viewer comments, multiple beauty-related YouTube content creators were included in this study. Similarly, the ages of the commenters are unknown; thus, it is possible that there are comments not shared by adolescent viewers. Nonadolescent viewers may be less vulnerable to negative self-esteem as a result of watching beauty-related YouTube content creators. However, as there are a large number of adolescent viewers on YouTube [69], it is possible that many comments were posted by adolescents. Furthermore, we excluded emojis from our coding processes as emojis may have multiple interpretations based on their context and may be difficult to code objectively.

Conclusions

Despite these limitations, our study has several important implications. Given the high frequency of comments on beauty-related YouTube videos with a positive tone, coupled with the low frequency of self-esteem disclosures, it is possible that adolescents would feel uncomfortable discussing negative effects on their self-esteem in this web-based environment. Future studies should examine avenues in which adolescents discuss their self-esteem in connection with beauty-related videos on YouTube. Future research should also explore effective approaches for parents to engage in conversations with their children about beauty-related videos on YouTube. Furthermore, some self-esteem references in comments suggests the possibility that these videos could affect adolescents' self-esteem. Further studies should investigate the effects of beauty-related YouTube videos on viewers' self-reported self-esteem.

Study 4

This study was prepared by Ethan Kaji and mentor Maggie Bushman

Comparing the Representation of Depression on Reddit and Twitter Social Media Platforms: Content Analysis Study

Introduction

Social Media and Depression

The most prominent mental illness affecting adolescents is depression, with 4%-5% of adolescents impacted worldwide each year [70]. If depression symptoms are not treated, it can lead to recurrence later in life [70]. The most extreme cases of depression can also lead to suicide, a major cause of death among adolescents [71,72]. Oftentimes, people with depression will post their feelings and inner thoughts on social media platforms, giving others a chance to respond and support them [73]. A study of Facebook accounts found that participants who showed symptoms of depression on the web also self-reported symptoms of depression [74]. Previous research has evaluated how depression is discussed on social media and has investigated ways to identify users with depression [75]. Computer algorithms can detect depression-related content in posts on social media with an accuracy of more than 90% [75]. Being able to consistently identify symptoms of depression on social media could lead to earlier treatment for adolescents.

Reddit Versus Twitter

Social media platforms, such as Reddit and Twitter, provide spaces for adolescents to discuss the triumphs and tribulations of their daily lives on the web, including personal information about their school, family, and friends [76]. Reddit is a social media platform divided into distinct communities to foster discussions among users [42]. These communities, often called subreddits, are created and moderated by users rather than the Reddit platform itself. Users can post specific subreddits, and others can respond by continuing the thread. Previous research has suggested that an anonymous platform such as Reddit encourages the discussion of more emotional or sensitive information [77].

In contrast to Reddit, Twitter is a platform designed around short statements made by users to convey information in real time [78]. A study from 2017 found that users who tweet about mental health do so because Twitter provides a sense of community, a safe space for expression, and means of coping [79]. Users also use Twitter to spread awareness. Little is known about the differences in how adolescents talk about their depression on an anonymous, forum-based platform such as Reddit compared with a personal, newsfeed platform such as Twitter. Therefore, this study aims to compare depression posts on Reddit, a forum-based platform, and Twitter, a newsfeed platform, to understand how users talk about depression on the web.

Methods

Study Design

We conducted a content analysis of publicly available Reddit and Twitter posts on October 28, 2020, to determine the number of posts that showed symptoms of depression and other themes related to youth. Reddit posts were defined as the first posts in the depression subreddit *r/depression*. Twitter posts were defined as posts that used the hashtag #depression. This study was exempt from human subjects review by the University of Wisconsin-Madison Institutional Review Board.

Search Strategy

We identified a national sample of publicly available Reddit and Twitter posts. Reddit posts were taken directly from the subreddit r/depression. Posts were evaluated under the *new* tab to view a wide range of recent posts, rather than only the most popular. Twitter posts were collected using the search term #depression. The *latest* tab was used on Twitter to ensure a variation of posts. Using the search terms r/depression and #depression, we sought to replicate search strategies adolescents would use when discussing depression on social media.

Post Inclusion Criteria

Reddit posts were included if they were the most recent posts in r/depression. Twitter posts were included if they were some of the most recent posts made with #depression. On Twitter, posts were included if they contained content in addition to hashtags. Posts with pictures were considered on both platforms. However, posts written in a language other than English, with videos, and made by accounts that stated that they were bots were not considered. Duplicate posts or identical posts published by either the same or different accounts were excluded from the sample.

Measures

An investigator categorized Reddit and Twitter posts into major topic categories using deductive and inductive approaches. The investigator reviewed each post to determine if symptoms of depression and youth topics were discussed. Open coding was used to generate codes for promotional posts and medical topics, as these themes emerged while coding these posts. A codebook that used the Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV criteria from a previous study was adapted to determine whether posts contained symptoms of depression [74]. A full list of codes and their prevalence is shown in Table 6.

Each post included in the study was coded for the following categories: at least one symptom of depression; at least one youth topic; promotional posts; and medical topics. A symptom of depression was defined by mentioning at least one of the nine DSM-IV criteria, including categories such as *depressed mood*, *insomnia or hypersomnia*, and *recurrent thoughts of death*. A complete list of DSM-IV categories can be found in Table 6. Youth topic variables included specific references to school, family, and social activities. Youth topic variables were included to discern whether adolescents were likely posting using #depression and r/depression. Adolescents might also discuss topics such as school, family, and social activities. Promotional posts included posts endorsing any material or content. Examples included promotions for blogs on exercise, books on veterans, and seminars on meditation. Finally, medical topics included medical references, such as medications, hospital visits, and therapy. An investigator coded the samples of the Reddit and Twitter posts. A second investigator coded a 10% (n=40) subsample of both Reddit (n=20) and Twitter (n=20) posts to calculate the interrater agreement.

Table 6. Study 4—codebook categories, definitions, and percent of posts.

Categories	Definitions and examples	Reddit posts referencing code (n=53), n (%)	Twitter posts referencing code (n=49), n (%)
Depressed mood	Sad, empty, crying, tearful, distressed, and down (unless context clarifies otherwise)	47 (89)	8 (16)
Decreased interest or pleasure in activities or anhedonia	Not having fun, do not feel like doing anything, giving up, lack of purpose, and not caring	17 (32)	0 (0)
Changes in weight or appetite	No appetite, do not feel like eating, cannot stop eating, and eating everything in sight	0 (0)	0 (0)
Insomnia or hypersomnia	Tired, exhausted, sleepy, need a nap, easily tired, not sleeping well, restless sleep, cannot sleep, cannot get to sleep, falling asleep in an unusual place, and insomnia	4 (8)	0 (0)
Agitation or slowing down of movement	Inability to sit still or feeling slow	2 (4)	1 (2)
Fatigue or loss of energy	Cannot get anything done and cannot get motivated due to fatigue	8 (15)	1 (2)
Feelings of worthlessness or guilt	Feel guilty or worthless, "I am stupid," "I'm not cool," "I'm average," "I'm crazy" or "I'm insane," regretting something, being a failure, or failing	20 (38)	1 (2)
Difficulty concentrating or indecisiveness	Cannot study, cannot finish work, cannot concentrate because of emotion, cannot decide on something, do not feel like deciding, cannot make up your mind, and not knowing what to do	7 (13)	0 (0)
Recurrent thoughts of death	Thinking of ways to commit suicide, references to jumping, referencing death of self, and thinking about death	23 (43)	1 (2)
School	Specifically references school-related events, goals, and extracurricular activities	13 (25)	0 (0)
Family	Specifically references parents, guardians, siblings, and other family members	20 (38)	4 (8)
Social activity	Specific references to social life	20 (38)	2 (4)
Promotional content	Promoting any material or content, that is, blogs, studies, and podcasts	0 (0)	26 (53)
Medical topics	Medical content appears within the post	15 (28)	9 (18)

Data Collection Procedures

Data were collected on each Reddit and Twitter feed on October 28, 2020. Interrater agreement was calculated as the percentage of Reddit and Twitter posts referencing each category, ranging between 85% (34/40) and 100% (40/40), with a mean of 92.7% (SD .05%)

Analysis

Descriptive statistics were calculated for all measures. A chi-square test was used to analyze the relationship between each platform and the following main categories: the proportion of mentions of at least one symptom of depression; at least one youth topic; promotional content; and medical topics. Statistical significance was set at *P*<.05. The average DSM-IV scores were calculated by calculating the total number of DSM-IV symptoms that appeared on each platform and dividing by the number of posts collected from each of them.

Results

Overview

A total of 53 posts were selected from the subreddit r/depression. At the time of coding (October 2020), this subreddit had approximately 700,000 members. A total of 49 tweets were selected from the social media platform Twitter.

Symptoms of Depression and Youth Codes

We found that 92% (49/53) of posts on Reddit and 24% (12/49) of posts on Twitter contained at least one symptom of depression (*P*<.001). *Depressed mood* was referenced by 89% (47/53) of Reddit posts and 16% (8/49) of Twitter posts. Common phrases that denoted *depressed mood* included terms such as *crying* and *sad*. *Recurrent thoughts of death* was the second most common depression symptom and was referenced by 43% (23/53) of Reddit posts and 2% (1/49) of Twitter posts. The average Reddit post received a DSM-IV score of 2.4, whereas the average Twitter post received a DSM-IV score of 0.2. Similarly, we found that the percentage of posts that mentioned at least one youth code was 62% (33/53) on Reddit and 10% (5/49) on Twitter (*P*<.001).

Promotional and Medical Codes

We found that promotional content appeared in 0% (0/53) of Reddit posts and 53% (26/49) of Twitter posts (*P*<.001). We also found that the percentage of posts referencing medical topics was 28% (15/53) on Reddit and 18% (9/49) on Twitter (*P*=.24). For the full results describing the codes and frequency, see Table 6.

Discussion

Principal Findings

This study compared Reddit and Twitter posts discussing depression. Results suggested that the discussion of depression was significantly more common on Reddit than on Twitter, with 92% (49/53) of Reddit posts and 24% (12/49) of tweets mentioning at least one symptom of depression. Furthermore, Reddit posts received an average DSM-IV score of 2.4, whereas Twitter posts received an average DSM-IV score of 0.2. This difference in expression fits with existing literature that adolescents are more or less willing to reveal certain emotions based on the type of social media platform they are using [80]. Our results also suggested that Reddit posts may be more likely to be posted by adolescents, with 62% (33/53) of posts on Reddit referencing and discussing at least one youth code compared with 10% (5/49) of posts on Twitter mentioning such subjects. Another important finding is that Twitter posts were significantly more likely to contain promotional content than Reddit posts. None of the Reddit posts investigated contained promotional content. In comparison, 53% (26/49) of tweets contained promotional content.

Our findings may help understand the potential differences in discussions of depression on Reddit and Twitter. These findings suggest that users are more likely to elaborate on their experiences with depression when posting on the subreddit r/depression rather than with #depression on Twitter. This may be because of the anonymity of r/depression [77].

Reddit communities are also moderated by users who volunteer as *moderators*. Moderating powers include the ability to remove posts, comments, and users from the community. It is possible that the heavy moderation of r/depression by users compared with Twitter encourages others to be more open with their posts on Reddit [42]. A moderated Reddit thread could become a safe place for adolescents to discuss mental health and depression. They might find it comforting that a moderator would be able to remove hurtful or harmful posts or users from the subreddit. Both Reddit and Twitter have features to report posts or messages; however, having a moderator could take the burden of reporting off the shoulders of adolescents and onto a third party. Another possibility could be that subreddit moderators can remove posts that do not align with the subreddit's mission, such as promotional content, resulting in longer posts in which users can expand on their experiences with depression.

The finding that more Reddit posts referenced at least one youth code compared with Twitter could suggest that there is a wider audience of adolescents using r/depression to discuss mental health than Twitter. This finding is consistent with the demographics of each platform. In recent years, Reddit's age demographic has been trending younger, with 21% of users aged between 18 and 24 years [81]. Conversely, Twitter's age demographic has been trending older, with 28% aged between 35 and 49 years [82].

Finally, the larger percentage of posts with promotional content on Twitter than on Reddit suggests that tweets with symptoms of depression are diluted by tweets from other topics such as promotions for blogs on exercise or seminars on meditation, sometimes unrelated to clinical depression. The promotional nature of the content on Twitter could be why references to youth-based topics such as school, family, and social activity were more common on Reddit than on Twitter. There is a chance that the promotional use of #depression could deter adolescents experiencing symptoms of depression from discussing their experiences on Twitter.

Limitations

The sample of Reddit and Twitter posts included in this study was small. However, patterns in the data were still identified. Another limitation was the timeframe for the collection of posts. All posts were collected during the COVID-19 pandemic, where stay-at-home orders and isolation could have influenced the data. Although this limitation might skew the number of posts that show at least one symptom of depression, it should affect both platforms equally without affecting the overall comparison.

Conclusions

Future studies should consider investigating other moderated communities for users experiencing depression, such as Facebook groups. Future studies should also consider comparing Instagram, a photo-based social media platform, with Reddit, a forum-style platform, which could yield important information on how the inclusion of photographs makes users more or less likely to discuss mental health topics. Comparisons should also be made with platforms that target foreign audiences, as both Reddit and Twitter have a majority of US users. Further understanding of how adolescents discuss depression on the web could help inform guidelines for social media support communities. Although computer algorithms could be used to detect posts about depression, supporting web-based communities where human detection is taking place could provide adolescents with the resources they need to get help. It could also help clinicians understand youth experiences with depression, what web-based resources they access for support, and lead to earlier treatments.

Study 5

This study was prepared by Owen Tsao and mentor Anna Jolliff

Mental Health Sentiments in the Comment Sections of Climate Change Posts on Instagram: Content Analysis

Introduction

Climate Change and Adolescent Mental Health

Climate change can result in mental illnesses, such as depression, anxiety, and posttraumatic stress disorder [83]. Climate change can impact mental health directly through exposure to traumas, such as forest fires and floods, and indirectly, as people hear news about climate change and its associated deaths [83,84]. The effects of climate change will disproportionately affect the youth and young people. Some of the decisions and mistakes made by previous generations (some necessary, some not) have, in turn, led to the ill effects of climate change. It is the younger and future generations who will have to answer for the mistakes of the past and live a greater proportion of their lives in a steadily degrading environment [85]. However, young people also have the ability to advocate against climate change.

Climate Change Advocacy on Social Media

Young people can advocate against climate change through new technological developments. Currently, the younger generation uses social media as a context to promote climate change activism [86,87]. Research shows that climate change advocacy on social media promotes knowledge and behavioral changes around climate change [88]. Social media *personalizes* the issue of climate change by adding photographs, conveying information through friends, and catering to users' preferences for receiving information [88]. However, it is unknown whether climate change advocacy on social media is associated with depression or anxiety, as viewers are exposed to negative news and messages. Furthermore, research on climate change advocacy on social media disproportionately focuses on Twitter, excluding popular sites such as Instagram [89]. It is crucial to study Instagram because it is one of the most popular social media platforms among adolescents [90].

This Study

Previous studies have confirmed the negative mental health effects of climate change and studied climate change activism on social media. However, it is unknown whether positively versus negatively framed posts receive more engagement in the form of likes, comments, or followers on the posters' accounts. It is also unknown whether comment sections of positively and negatively framed posts include sentiments consistent with depression, anxiety, or positive affect. The aim of this study is to evaluate whether positively or negatively framed climate change Instagram posts receive more engagement and whether their comment sections demonstrate sentiments consistent with depression, anxiety, and/or positive affect.

Methods

Study Design

We conducted a content analysis of publicly available, positively and negatively framed climate change Instagram posts to understand whether sentiments consistent with depression and anxiety as well as sentiments consistent with positive affect could be found in their comment sections. This study was exempt from human subjects review by the University of Wisconsin-Madison Institutional Review Board. We selected Instagram because many adolescents actively use it. Although we could not confirm that commenters were adolescents, 37.1% of Instagram users are aged between 13 and 24 years, and Instagram is the most widely used social media platform among American teens [90,91].

Search Strategy and Post Eligibility

Our goal was to identify a sample of positive and negative posts on Instagram to evaluate the comments on these posts. We chose to search for posts using a hashtag page instead of a single Instagram profile so that we could see a variety of posts from different users. We performed a series of pilot tests to identify the most popular hashtags. From these pilot tests, we selected the hashtag #climatechange, as it is highly popular and contains a mix of positively and negatively framed posts on climate change. Next, we identified a sample of both positively and negatively framed posts by opening Instagram and searching using the hashtag #climatechange. Posts were sorted by the *most popular* feature on Instagram and considered for inclusion in chronological order, with the most recent viewed first to replicate how an adolescent might come across such posts.

We defined a negatively framed post as a post that expressed a negative event or consequence of climate change (Figure 1). Inversely, a positively framed post was not one that advocated against climate change but rather gave good news about climate change, provided a solution, or was explicitly uplifting (Figure 2). Each selected post had to be identified as *positive* or *negative* by two investigators (OT and AJ) to be eligible for comment evaluation. Posts for which two investigators did not reach the same verdict, neutral posts, and duplicate posts were not included. Posts with fewer than five comments were excluded. The top five comments below each post, regardless of whether they earned a code, were included in the analyses.

Figure 1. Example of a negatively framed climate change post.

@bambooherb

US and UK citizens are world's biggest sources of plastic waste

bambooherb The US and UK produce more plastic waste per person than any other major countries, according to new research.

The analysis also shows the US produces the most plastic waste in total and that its citizens may rank as high as third in the world in contributing to plastic pollution in the oceans. Previous work had suggested Asian countries dominated marine plastic pollution and placed the US in 20th place, but this did not account for US waste exports or illegal dumping within the country.

Plastic waste has polluted the whole planet, from the deepest

Figure 2. Example of a positively framed climate change post.

Morgan Freeman converted his 124-acre ranch into a giant sanctuary to protect honey bees

@globalpositivenews

earth.beyond Follow @reterraform a non-profit spreading awareness

What a hero! Save the bees at all costs 🐝🖤 .

.

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#regram #ecofriendly #bees #greentips #ecology #zerowaste #zerowasteliving #zerowastelifestyle #zerowastelife #greenliving #sustainableliving #climatechange #globalwarming #reuse #reducereuserecycle #zerowastetips #savetheplanet #savethebees #savetheearth #greenideas #veganlife #ecoideas #ecofriendlyproducts #ecofriendlyliving #environment

Measures

Audience Engagement

We documented the number of likes and comments on each post. We also documented the number of followers for each account that shared a post.

Depression and Anxiety

We developed a codebook adapted from the DSM-V criteria to define criteria for sentiments consistent with depression and anxiety [92]. Emojis that expressed sentiments consistent with depression or anxiety were added inductively. For example, a crying emoji reflected the *sad* or *tearful* sentiment within depression, and the *nervous* emoji reflected the *worry* or *feeling on edge* sentiment of anxiety (see Table 7 for the full codebook).

Table 7. Study 5—codebook and example comments.

Sentiment type	Example sentiments	Emojis added during coding
Depression	Depressed mood, tearful, sad, empty, hopeless, irritable, less interest or pleasure in doing things, decrease or increase in appetite, too much or too little sleep, fatigue or loss of energy, and worthlessness or guilt	
Anxiety	Anxiety; worry; restlessness; feeling on edge; easily fatigued; difficulty concentrating; mind going blank; irritability; difficulty falling or staying asleep; and distress or impairment in social, occupational, or other areas	
Positive affect	Determined, enthusiastic, excited, inspired, interested, proud, strong, happy, joyful, cheerful, lively, energetic, proud, confident, bold, and daring	

Positive Affect

We developed a measure of positive affect based on sentiments consistent with positive affect items from the Positive and Negative Affect Schedule–expanded form [93]. Emojis that expressed sentiments consistent with positive affect were added inductively. For example, the *applause* emoji was considered to reflect the *enthusiasm* sentiment within positive affect (see Table 7 for the full codebook).

Procedures

Data were collected for each post from October 29, 2020, to November 2, 2020. An investigator (OT) coded all comments using a combination of deductive and inductive approaches. A second investigator (AJ) coded a 10% (10/100) subsample of comments. Interrater agreement was calculated as the percentage of comments on which both coders agreed (9/10, 90% of all comments).

Analysis

Two-sided *t* tests were used to understand differences in the number of likes and comments between positively and negatively framed posts and the number of followers of accounts that shared positively versus negatively framed posts. Statistical significance was set at $P<.05$. Descriptive statistics were used to describe the prevalence of mental health sentiments in the comments.

Results

Post Characteristics

A total of 100 comments on climate change posts were selected from Instagram, with 50 comments coming from 10 positively framed posts and 50 comments coming from 10 negatively framed posts across 18 separate accounts. The average number of likes on positive posts was 5591.7 (SD 5435.2), whereas negatively framed posts had an average of 3400.3 likes (SD 4292.1), but this difference was not statistically significant (t_{18}=1.00; P=.33). Positively framed posts’ average number of comments was 60.2 (SD 47.8), whereas the average number of comments on negatively framed posts was 74.8 (SD 72.3), and this difference was not statistically significant (t_{18}=0.53; P=.60). Positive accounts had a range of 4125-342,000 followers, whereas negative accounts had 43,200-591,000 followers. Positively framed post accounts averaged 81,263.3 (SD 112,940.5) followers, whereas negatively framed post accounts had an average of 155,120 followers (SD 175,216.3). This difference was not statistically significant (t_{18}=1.12; P=.27).

Mental Health Sentiments in Comments

Of the 100 comments, 17 (17%) referenced sentiments consistent with depression. An example comment was, “Yes we are and Shame on us.” Furthermore, 5% (5/100) referenced sentiments consistent with anxiety; an example was, “You’re *[sic]* weekly posts always make me feel so much better about my eco anxiety.” This post was also coded for positive affect. Finally, 32% (32/100) referenced sentiments consistent with positive affect, and an example was, “Good work !!” Table 8 shows the frequency of depression, anxiety, and positive affect sentiments in comments under positively and negatively framed climate change posts.

Table 8. Study 5—frequency of mental health sentiments in comments of positively and negatively framed climate change posts (N=100).

Sentiment type	Positive post comments, n (%)	Negative post comments, n (%)
Depression	2 (2)	15 (15)
Anxiety	2 (2)	3 (3)
Positive affect	26 (26)	6 (6)

Discussion

Principal Findings

This study examined positively and negatively framed climate change posts and their comment sections on Instagram. Overall, both positively and negatively framed posts received thousands of likes and an average of >50 comments. There were no statistically significant differences between the number of likes or comments on positively versus negatively framed posts. This finding suggests that climate change posts can reach thousands of adolescents and positively influence young people, raising awareness without negative mental health consequences.

First, we found that all posts received thousands of likes and comments, and the accounts posting content all had thousands of followers. However, none of these numbers were significantly different between positively and negatively framed climate change posts. This finding suggests that climate change posts have a broad reach and receive engagement regardless of whether their message is positive or negative. Previous research shows that positive climate change messages may inspire action, whereas negative messages can result in passivity or helplessness [94,95]. Instagram should continue to allow both positively and negatively framed climate change posts on their platforms, as long as they are credible news statements, but should censor videos of murder, self-harm, violence, and other triggering content. As there was an equal engagement in positive and negative posts in this study, climate change advocates may wish to focus on sharing positively framed climate change posts.

Second, out of 100 comments, we found that 17 referenced sentiments consistent with depression, and 5 were related to anxiety. There was a total of 18 references to depression and anxiety under negatively framed posts and a total of 4 references under positively framed posts. This finding is consistent with previous research that noted a negative association between climate change and mental health [83,84]. However, only 22 sentiments were consistent with depression and anxiety in this study. We hypothesize that viewers may have been hesitant to share their true feelings on the internet, possibly because Instagram is not anonymous, and people may be nervous about expressing what seems like political views.

Finally, we found that 32% (32/100) of the comments referenced sentiments consistent with positive affect. This is a promising finding, as it suggests that climate change posts may inspire positive affect in some viewers. It is also possible that individuals are more likely to express positive opinions on social media, perhaps to seem more likable.

Limitations

We were limited by the small sample size of only 20 posts and 100 comments. In a larger sample, using a greater number of posts, it is likely that our numbers would be more generalizable. Furthermore, although we looked at the most recent comments on negatively and positively framed posts, responses to comments were not investigated. Another interesting challenge we encountered was the use of emojis in comments. It was surprising to see the number of comments that strictly used emojis, and interpretation may have been more subjective than the interpretation of words. Finally, we focused only on #climatechange. Searching for a larger variety of hashtags may have yielded different results.

Conclusions

This study has implications for the display of mental health sentiments in comment sections. Many comments showed sentiments of positive affect. Future research should aim to understand whether exposure to positively framed climate change posts positively affects mood and activism. Although this study focused on climate change advocacy on Instagram, future studies should examine climate change advocacy on other social media platforms. The high engagement in climate change advocacy Instagram pages in this study and the many positive messages may show the eagerness of the adolescent generation to approach climate change issues. Instagram should therefore be used as a platform to raise awareness on climate change issues as adolescents commonly use it, and this population is imperative for addressing climate change.

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Conflicts of Interest

None declared.

References

1. O'Neil S, Van Broeckhoven K. No Research About Us Without Us: Participatory Policy-oriented Research With Children and Youth Affected by Conflict. UNU-CPR Research Papers. New York: United Nations University; 2019 Nov 25. URL: http://collections.unu.edu/view/UNU:7508 [accessed 2021-07-29]
2. Kennedy H, DeChants J, Bender K, Anyon Y. More than Data Collectors: A Systematic Review of the Environmental Outcomes of Youth Inquiry Approaches in the United States. Am J Community Psychol 2019 Mar 06;63(1-2):208-226. [doi: 10.1002/ajcp.12321]
3. Anyon Y, Bender K, Kennedy H, Dechants J. A Systematic Review of Youth Participatory Action Research (YPAR) in the United States: Methodologies, Youth Outcomes, and Future Directions. Health Educ Behav 2018 May 11;45(6):865-878. [doi: 10.1177/1090198118769357]
4. Shamrova DP, Cummings CE. Participatory action research (PAR) with children and youth: An integrative review of methodology and PAR outcomes for participants, organizations, and communities. Children and Youth Services Review 2017 Oct;81:400-412. [doi: 10.1016/j.childyouth.2017.08.022]
5. Efuribe C, Barre-Hemingway M, Vaghefi E, Suleiman AB. Coping With the COVID-19 Crisis: A Call for Youth Engagement and the Inclusion of Young People in Matters That Affect Their Lives. Journal of Adolescent Health 2020 Jul;67(1):16-17. [doi: 10.1016/j.jadohealth.2020.04.009]
6. Cash SJ, Thelwall M, Peck SN, Ferrell JZ, Bridge JA. Adolescent Suicide Statements on MySpace. Cyberpsychology, Behavior, and Social Networking 2013 Mar;16(3):166-174. [doi: 10.1089/cyber.2012.0098]
7. Moreno MA, Parks M, Richardson LP. What are adolescents showing the world about their health risk behaviors on MySpace? MedGenMed 2007 Oct 11;9(4):9. [Medline: 18311359]
8. Summer Research Scholars. Social Media and Adolescent Health Research Team. Madison, Wisconsin URL: http://smahrtresearch.com/summer-research-scholars-srs/ [accessed 2021-07-28]
9. Tausczik YR, Pennebaker JW. The Psychological Meaning of Words: LIWC and Computerized Text Analysis Methods. Journal of Language and Social Psychology 2009 Dec 08;29(1):24-54. [doi: 10.1177/0261927x09351676]
10. Berry DS, Pennebaker JW. Nonverbal and Verbal Emotional Expression and Health. Psychother Psychosom 1993;59(1):11-19. [doi: 10.1159/000288640]
11. Francis ME, Pennebaker JW. Putting Stress into Words: The Impact of Writing on Physiological, Absentee, and Self-Reported Emotional Well-Being Measures. Am J Health Promot 2016 Aug 26;6(4):280-287. [doi: 10.4278/0890-1171-6.4.280]
12. Pennebaker JW. Putting stress into words: Health, linguistic, and therapeutic implications. Behaviour Research and Therapy 1993 Jul;31(6):539-548. [doi: 10.1016/0005-7967(93)90105-4]
13. Pennebaker JW, King LA. Linguistic styles: Language use as an individual difference. Journal of Personality and Social Psychology 1999;77(6):1296-1312. [doi: 10.1037/0022-3514.77.6.1296]
14. Pennebaker JW, Mayne TJ, Francis ME. Linguistic predictors of adaptive bereavement. Journal of Personality and Social Psychology 1997;72(4):863-871. [doi: 10.1037/0022-3514.72.4.863]
15. Rosenberg HJ, Rosenberg SD, Ernstoff MS, Wolford GL, Amdur RJ, Elshamy MR, et al. Expressive Disclosure and Health Outcomes in a Prostate Cancer Population. Int J Psychiatry Med 2016 Jun 24;32(1):37-53. [doi: 10.2190/agpf-vb1g-u82e-ae8c]
16. LIWC. Comparing LIWC2015 and LIWC2007. LIWC. 2016 Feb 8. URL: http://liwc.wpengine.com/compare-dictionaries/ [accessed 2021-07-28]
17. Wiltsey Stirman S, Pennebaker JW. Word Use in the Poetry of Suicidal and Nonsuicidal Poets. Psychosomatic Medicine 2001;63(4):517-522. [doi: 10.1097/00006842-200107000-00001]
18. Stemler S. An overview of content analysis. Practical Assessment, Research, and Evaluation 2000;7(1):1-6.
19. Moreno MA, Briner LR, Williams A, Brockman L, Walker L, Christakis DA. A Content Analysis of Displayed Alcohol References on a Social Networking Web Site. Journal of Adolescent Health 2010 Aug;47(2):168-175. [doi: 10.1016/j.jadohealth.2010.01.001]
20. Krauss MJ, Sowles SJ, Moreno M, Zewdie K, Grucza RA, Bierut LJ, et al. Hookah-Related Twitter Chatter: A Content Analysis. Prev. Chronic Dis 2015 Jul 30;12:1-9. [doi: 10.5888/pcd12.150140]
21. Cumulative Cases by Days Since 50th Confirmed Case. Johns Hopkins University. URL: https://coronavirus.jhu.edu/data/cumulative-cases [accessed 2021-07-28]
22. Cowling BJ, Ali ST, Ng TWY, Tsang TK, Li JCM, Fong MW, et al. Impact assessment of non-pharmaceutical interventions against coronavirus disease 2019 and influenza in Hong Kong: an observational study. The Lancet Public Health 2020 May;5(5):e279-e288. [doi: 10.1016/s2468-2667(20)30090-6]
23. Gao J, Zheng P, Jia Y, Chen H, Mao Y, Chen S, et al. Mental health problems and social media exposure during COVID-19 outbreak. PLoS ONE 2020 Apr 16;15(4):e0231924. [doi: 10.1371/journal.pone.0231924]
24. Mental Health by the Numbers. National Alliance on Mental Illness. URL: https://www.nami.org/mhstats [accessed 2021-07-28]
25. Oosterhoff B, Palmer C, Wilson J, Shook N. Adolescents' Motivations to Engage in Social Distancing During the COVID-19 Pandemic: Associations With Mental and Social Health. J Adolesc Health 2020 Aug;67(2):179-185. [doi: 10.31234/osf.io/jd2kq]
26. Rolling updates on coronavirus disease (COVID-19). World Health Organization. 2020. URL: https://www.who.int/emergencies/diseases/novel-coronavirus-2019/events-as-they-happen [accessed 2021-07-28]

27. Chen J. How to improve your social media engagement. Sprout Blog 2020 May 14:NA [FREE Full text]
28. Pennebaker J, Boyd R, Jordan K, Blackburn K. The Development and Psychometric Properties of LIWC2015. Texas ScholarWorks 2015 Sep 15:1-25.
29. Moreno MA, Gower AD, Brittain H, Vaillancourt T. Applying Natural Language Processing to Evaluate News Media Coverage of Bullying and Cyberbullying. Prev Sci 2019 Aug 14;20(8):1274-1283. [doi: 10.1007/s11121-019-01029-x]
30. Babal JC, Gower AD, Frohna JG, Moreno MA. Linguistic analysis of pediatric residency personal statements: gender differences. BMC Med Educ 2019 Oct 26;19:1-9 [FREE Full text] [doi: 10.1186/s12909-019-1838-x]
31. Kovacs B, Kleinbaum AM. Language-Style Similarity and Social Networks. Psychol Sci 2019 Dec 26;31(2):202-213. [doi: 10.1177/0956797619894557]
32. Orben A, Tomova L, Blakemore S. The effects of social deprivation on adolescent development and mental health. The Lancet Child & Adolescent Health 2020 Aug;4(8):634-640. [doi: 10.1016/s2352-4642(20)30186-3]
33. Ariapooran S. Individualism-collectivism, social support, resilience and suicidal ideation among women with the experience of the death of a young person. International journal of community based nursing and midwifery 2018;6(3):250.
34. Parmer J, Baur C, Eroglu D, Lubell K, Prue C, Reynolds B, et al. Crisis and Emergency Risk Messaging in Mass Media News Stories: Is the Public Getting the Information They Need to Protect Their Health? Health Communication 2016 Mar 03;31(10):1215-1222. [doi: 10.1080/10410236.2015.1049728]
35. Overview of the drug overdose epidemic: Behind the numbers. Centers for Disease Control and Prevention. 2018. URL: https://www.cdc.gov/opioids/data/index.html [accessed 2021-07-28]
36. Uchitel J, Hadland S, Raman S, McClellan M, Wong C. The Opioid Epidemic: A Needed Focus On Adolescents And Young Adults. Health Affairs Blog.: Health Affairs; 2019 Nov 29. URL: https://www.healthaffairs.org/do/10.1377/hblog20191115.977344/full/ [accessed 2021-07-28]
37. Griesler PC, Hu M, Wall MM, Kandel DB. Assessment of Prescription Opioid Medical Use and Misuse Among Parents and Their Adolescent Offspring in the US. JAMA Netw Open 2021 Jan 07;4(1):e2031073. [doi: 10.1001/jamanetworkopen.2020.31073]
38. Kim SJ, Marsch LA, Hancock JT, Das AK. Scaling Up Research on Drug Abuse and Addiction Through Social Media Big Data. J Med Internet Res 2017 Oct 31;19(10):e353. [doi: 10.2196/jmir.6426]
39. Anwar M, Khoury D, Aldridge AP, Parker SJ, Conway KP. Using Twitter to Surveil the Opioid Epidemic in North Carolina: An Exploratory Study. JMIR Public Health Surveill 2020 Jun 24;6(2):e17574. [doi: 10.2196/17574]
40. Moreno MA, Christakis DA, Egan KG, Brockman LN, Becker TB. Associations Between Displayed Alcohol References on Facebook and Problem Drinking Among College Students. Arch Pediatr Adolesc Med 2012 Feb 06;166(2):157-163. [doi: 10.1001/archpediatrics.2011.180]
41. Pokhrel P, Fagan P, Herzog TA, Laestadius L, Buente W, Kawamoto CT, et al. Social media e-cigarette exposure and e-cigarette expectancies and use among young adults. Addict Behav 2018;78:51-58. [doi: 10.1016/j.addbeh.2017.10.017]
42. Reddit. Reddit. URL: https://www.redditinc.com [accessed 2021-07-28]
43. Shearer E, Matsa KE. News Use Across Social Media Platforms 2018. Pew Research Center. 2018. URL: https://www.journalism.org/2018/09/10/news-use-across-social-media-platforms-2018/ [accessed 2021-07-28]
44. Pandrekar S, Chen X, Gopalkrishna G, Srivastava A, Saltz M, Saltz J, et al. Social media based analysis of opioid epidemic using Reddit. In: AMIA Annu Symp Proc. 2018 Presented at: AMIA Annual Symposium Proceedings. . American Medical Informatics Association; 2018; Unknown p. 867-876.
45. Jenkins MC, Moreno MA. Vaccination Discussion among Parents on Social Media: A Content Analysis of Comments on Parenting Blogs. Journal of Health Communication 2020 Mar 10;25(3):232-242. [doi: 10.1080/10810730.2020.1737761]
46. Signs of Opioid Abuse. Johns Hopkins Medicine. URL: https://www.hopkinsmedicine.org/opioids/signs-of-opioid-abuse.html [accessed 2021-07-28]
47. Lander L, Howsare J, Byrne M. The Impact of Substance Use Disorders on Families and Children: From Theory to Practice. Social Work in Public Health 2013 May;28(3-4):194-205. [doi: 10.1080/19371918.2013.759005]
48. Brett EI, Stevens EM, Wagener TL, Leavens EL, Morgan TL, Cotton WD, et al. A content analysis of JUUL discussions on social media: Using Reddit to understand patterns and perceptions of JUUL use. Drug and Alcohol Dependence 2019 Jan;194:358-362. [doi: 10.1016/j.drugalcdep.2018.10.014]
49. Stages of Adolescent Development. American Academy of Pediatrics. URL: https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/adolescent-sexual-health/Pages/Stages-of-Adolescent-Development.aspx [accessed 2021-07-28]
50. Manna G, Falgares G, Ingoglia S, Rosaria Como M, De Santis S. The Relationship between Self-Esteem, Depression and Anxiety: Comparing Vulnerability and Scar Model in the Italian Context. Mediterranean Journal of Clinical Psychology 2016;4(3):1-17.
51. Bhar S, Ghahramanlou-Holloway M, Brown G, Beck AT. Self-Esteem and Suicide Ideation in Psychiatric Outpatients. Suicide and Life-Threatening Behavior 2008 Oct;38(5):511-516. [doi: 10.1521/suli.2008.38.5.511]
52. Overholser JC, Adams DM, Lehnert KL, Brinkman DC. Self-Esteem Deficits and Suicidal Tendencies among Adolescents. Journal of the American Academy of Child & Adolescent Psychiatry 1995 Jul;34(7):919-928. [doi: 10.1097/00004583-199507000-00016]
53. Smith ER, Mackie DM, Claypool H. Social Psychology. In: Social Psychology. NA: Psychology Press; 2014.

54. Midgley C, Thai S, Lockwood P, Kovacheff C, Page-Gould E. When every day is a high school reunion: Social media comparisons and self-esteem. Journal of Personality and Social Psychology 2020 Aug 13:NA. [doi: 10.1037/pspi0000336]
55. Woods HC, Scott H. #Sleepyteens: Social media use in adolescence is associated with poor sleep quality, anxiety, depression and low self-esteem. Journal of Adolescence 2016 Aug;51:41-49. [doi: 10.1016/j.adolescence.2016.05.008]
56. Andreassen CS, Pallesen S, Griffiths MD. The relationship between addictive use of social media, narcissism, and self-esteem: Findings from a large national survey. Addictive Behaviors 2017 Jan;64:287-293. [doi: 10.1016/j.addbeh.2016.03.006]
57. Androulaki-Ralli G. The Leading Role of Influencers in the YouTube Beauty Community. Digitala Vetenskapliga Arkivet 2015:NA.
58. Annual beauty-related content views on YouTube from 2009 to 2018. Statista. 2021 Jan 6. URL: https://www.statista.com/statistics/294655/youtube-monthly-beauty-content-views/ [accessed 2021-07-28]
59. Tankovska H. Percentage of internet users who use YouTube as of 3rd quarter 2020, by age group. Statista. 2021. URL: https://www.statista.com/statistics/296227/us-youtube-reach-age-gender/ [accessed 2021-07-28]
60. Hashmi S. 50+ Youtube Statistics That You Must Know in 2020. Connectiva Systems. 2020 Apr 16. URL: https://www.connectivasystems.com/50-youtube-statistics-2020/ [accessed 2020-12-03]
61. Tiggemann M, Barbato I. “You look great!”: The effect of viewing appearance-related Instagram comments on women’s body image. Body Image 2018 Dec;27:61-66. [doi: 10.1016/j.bodyim.2018.08.009]
62. Top 10 Beauty Influencers on YouTube (Updated). Neoreach. URL: https://neoreach.com/top-10-beauty-influencers-youtube/ [accessed 2021-07-28]
63. Rosenberg M. Society and the Adolescent Self-Image Morris Rosenberg. In: Society and the adolescent self-image. Princeton, NJ: Princeton University Press; 1965.
64. Diener E, Wirtz D, Tov W, Kim-Prieto C, Choi D, Oishi S, et al. New Well-being Measures: Short Scales to Assess Flourishing and Positive and Negative Feelings. Soc Indic Res 2009 May 28;97(2):143-156. [doi: 10.1007/s11205-009-9493-y]
65. Most popular types of beauty content videos on YouTube as of August 2018, by share of views. Statista. 2021 Jan 26. URL: https://www.statista.com/statistics/294967/youtube-beauty-vlogger-content-consumption/ [accessed 2021-07-28]
66. McCullough KM, Wong YJ, Deng K. Exploring the connections between watching Asian American YouTubers, racial identity, and self-esteem. Asian American Journal of Psychology 2021 Mar;12(1):41-51. [doi: 10.1037/aap0000218]
67. García-Rapp F, Roca-Cuberes C. Being an online celebrity: Norms and expectations of YouTube’s beauty community. First Monday 2017 Jul 03;22(7):NA. [doi: 10.5210/fm.v22i7.7788]
68. Frohlich DO, Zmyslinski-Seelig A. The Presence of Social Support Messages on YouTube Videos About Inflammatory Bowel Disease and Ostomies. Health Communication 2012 Jul;27(5):421-428. [doi: 10.1080/10410236.2011.606524]
69. Percentage of US internet users who use YouTube as of 3rd quarter 2020, by age group. Statista. URL: https://www.statista.com/statistics/378198/share-internet-users-accessing-social-network-by-age/ [accessed 2021-07-28]
70. Scott K, Lewis CC, Marti CN. Trajectories of Symptom Change in the Treatment for Adolescents With Depression Study. Journal of the American Academy of Child & Adolescent Psychiatry 2019 Mar;58(3):319-328. [doi: 10.1016/j.jaac.2018.07.908]
71. Teen Suicide is Preventable. American Psychological Association. 2008. URL: https://www.apa.org/research/action/suicide [accessed 2021-07-28]
72. Suicide and Teens. Boston Children's Hospital. URL: https://www.childrenshospital.org/conditions-and-treatments/conditions/s/suicide-and-teens [accessed 2021-07-28]
73. Rideout V, Fox S. Digital health practices, social media use, mental well-being among teens and young adults in the US. Providence St. Joseph Health Digital Commons 2018:NA [FREE Full text]
74. Moreno MA, Christakis DA, Egan KG, Jelenchick LA, Cox E, Young H, et al. A Pilot Evaluation of Associations Between Displayed Depression References on Facebook and Self-reported Depression Using a Clinical Scale. J Behav Health Serv Res 2011 Aug 24;39(3):295-304. [doi: 10.1007/s11414-011-9258-7]
75. Tadesse MM, Lin H, Xu B, Yang L. Detection of Depression-Related Posts in Reddit Social Media Forum. IEEE Access 2019;7:44883-44893. [doi: 10.1109/access.2019.2909180]
76. Brake D. Sharing our lives online: Risks and exposure in social media. In: University of Bedfordshire. London: Palgrave Macmillan; 2014.
77. De Choudhury M, De S. Mental health discourse on reddit: Self-disclosure, social support, and anonymity. Eighth international AAAI conference on weblogs and social media 2014:71-80.
78. New user FAQ. Twitter. URL: https://help.twitter.com/en/new-user-faq [accessed 2021-07-28]
79. Berry N, Lobban F, Belousov M, Emsley R, Nenadic G, Bucci S. #WhyWeTweetMH: Understanding Why People Use Twitter to Discuss Mental Health Problems. J Med Internet Res 2017 Apr 05;19(4):e107. [doi: 10.2196/jmir.6173]
80. Waterloo SF, Baumgartner SE, Peter J, Valkenburg PM. Norms of online expressions of emotion: Comparing Facebook, Twitter, Instagram, and WhatsApp. New Media & Society 2017 May 23;20(5):1813-1831. [doi: 10.1177/1461444817707349]
81. Percentage of US adults who use Reddit as of February 2019, by age group. Statista. URL: https://www.statista.com/statistics/261766/share-of-us-internet-users-who-use-reddit-by-age-group/ [accessed 2021-07-28]
82. Distribution of Twitter users worldwide as of January 2021, by age group. Statista. URL: https://www.statista.com/statistics/283119/age-distribution-of-global-twitter-users/ [accessed 2021-07-28]

83. Berry HL, Bowen K, Kjellstrom T. Climate change and mental health: a causal pathways framework. Int J Public Health 2009 Dec 22;55(2):123-132. [doi: 10.1007/s00038-009-0112-0]
84. Clayton S. Climate anxiety: Psychological responses to climate change. Journal of Anxiety Disorders 2020 Aug;74:102263. [doi: 10.1016/j.janxdis.2020.102263]
85. Burke SEL, Sanson AV, Van Hoorn J. The Psychological Effects of Climate Change on Children. Curr Psychiatry Rep 2018 Apr 11;20(5):35. [doi: 10.1007/s11920-018-0896-9]
86. Hestres LE. Preaching to the choir: Internet-mediated advocacy, issue public mobilization, and climate change. New Media & Society 2013 Apr 01;16(2):323-339. [doi: 10.1177/1461444813480361]
87. Askanius T, Uldam J. Online social media for radical politics: climate change activism on YouTube. IJEG 2011;4(1/2):69. [doi: 10.1504/ijeg.2011.041708]
88. Anderson A. Effects of social media use on climate change opinion, knowledge, and behavior. Oxford Research Encyclopedia of Climate Science 2017:NA. [doi: 10.1093/acrefore/9780190228620.013.369]
89. Pearce W, Niederer S, Özkula SM, Sánchez Querubín N. The social media life of climate change: Platforms, publics, and future imaginaries. WIREs Clim Change 2018 Dec 27;10(2):NA. [doi: 10.1002/wcc.569]
90. Anderson M, Jiang J. Teens, Social Media and Technology 2018. Pew Research Center. 2018. URL: https://www.pewresearch.org/internet/2018/05/31/teens-social-media-technology-2018/ [accessed 2021-07-28]
91. Tankovska H. Instagram: distribution of global audiences 2021, by age group. Statista. 2021. URL: https://www.statista.com/statistics/325587/instagram-global-age-group/ [accessed 2021-07-28]
92. Diagnostic and statistical manual of mental disorders (DSM-5®). In: American Psychiatric Association. Arlington, VA: American Psychiatric Association; 2013.
93. Watson D, Clark LA. The PANAS-X: Manual for the positive and negative affect schedule-expanded form. Iowa Research Online 1999:NA. [doi: 10.17077/48vt-m4t2]
94. Taylor S. Anxiety disorders, climate change, and the challenges ahead: Introduction to the special issue. Journal of Anxiety Disorders 2020 Dec;76:102313. [doi: 10.1016/j.janxdis.2020.102313]
95. Nabi RL, Gustafson A, Jensen R. Framing Climate Change: Exploring the Role of Emotion in Generating Advocacy Behavior. Science Communication 2018 May 29;40(4):442-468. [doi: 10.1177/1075547018776019]

Abbreviations

DSM: Diagnostic and Statistical Manual of Mental Disorders
LIWC: Linguistic Inquiry and Word Count
SRS: Summer Research Scholars
WHO: World Health Organization

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Original Paper

The Roles of Social Comparison Orientation and Regulatory Focus in College Students' Responses to Fitspiration Posts on Social Media: Cross-sectional Study

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Abstract

Background: Information shared via social media influences college students' self-perceptions and behavior, particularly, "fitspiration" posts (ie, images of healthy food, people exercising, or fitness quotations). There are mixed findings regarding the mental health implications of fitspiration and its potential to motivate healthy behavior. Individual differences such as social comparison orientation and regulatory focus could aid in determining for whom fitspiration may be helpful versus harmful, though these characteristics have received limited attention in terms of students' fitspiration perceptions.

Objective: This cross-sectional study examined associations between students' fitspiration use (ie, intentional versus unintentional exposure while using social media), response tendencies (ie, feelings about the self and motivation to be physically active), social comparison orientation, and regulatory focus.

Methods: College students (N=344; 239/344, 69.5% women) completed an electronic survey in which they self-reported demographic information, the frequency of their social media use, exposure to fitspiration posts, typical feelings in response to fitspiration posts, and typical motivation for physical activity after viewing fitspiration posts. They also completed validated self-report measures of social comparison orientation and regulatory focus.

Results: College students reported frequent exposure to fitspiration posts on social media and that they experienced negative feelings in response to these posts more often than positive feelings. Average motivation for physical activity was rated as feeling motivated "some of the time." However, students who reported more negative feelings after viewing fitspiration also reported greater motivation to be physically active after exposure. Associations between the frequency of intentional fitspiration use and motivation for physical activity after viewing fitspiration posts were moderated by social comparison orientation (b=−0.01, *P*=.03) but not by regulatory focus (b=−0.002, *P*=.67).

Conclusions: Negative feelings about the self may be motivating for students with weak social comparison orientation, as fitspiration may highlight a discrepancy between one's real and ideal self that does not prompt dejection or disengagement. However, negative feelings for prevention-focused students might not be as motivating because there are no salient negative models to avoid. Further research into these associations is warranted and could inform future efforts to promote student health and well-being during college.

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KEYWORDS

social media; college; fitspiration; subjective well-being; social comparison; regulatory focus; perception; well-being; young adult; college student; cross-sectional; motivation

Introduction

College is identified as a critical time for health promotion, as health decisions at this time often have implications for long-term wellness [1,2]. Social media has emerged as a promising tool for mental and physical health promotion among college students; social media is rated as a top source for information about mental and physical health during college [3], and students trust health information on social media platforms [4-6].

For example, engagement in physical activity is a critical aspect of college students' wellness that can affect their overall physical and mental health [7]. Existing evidence indicates that social media can be both a barrier and a motivator to engaging in physical activity [8,9]. The popular "fitspiration" trend is prominent on platforms such as Instagram, which typically features images of fit individuals engaging in physical activity. These images are posted with the hashtag "#fitspiration" and are easily viewed by searching this hashtag. Posts with this hashtag are meant to inspire users to engage in physical activity and practice healthy living. For instance, these posts might include an individual in exercise clothing posing near weights or in a challenging fitness pose. Furthermore, they often include quotations such as "Be stronger than your best excuses" or "Make yourself a priority."

Although some findings show that fitspiration does contribute to increased physical activity [10], exposure to fitspiration also has been associated with body dissatisfaction, low self-esteem, and disordered eating behaviors [11-13]. Content analyses also suggest that fitspiration posts emphasize extrinsic reasons for physical activity (ie, attractiveness and unrealistic body ideals), which are associated with negative body image and may be especially harmful for individuals at risk for disordered eating and other associated mental health concerns (eg, body dissatisfaction) [10,14]. In a sample of young adults who self-reported frequent interaction with fitspiration content, 17.4% of individuals endorsed very high levels of psychological distress and 17.7% were considered at high risk for an eating disorder [15]. Thus, viewing fitspiration images on social media can have positive or negative consequences for self-image and healthy behavior. At present, however, it is not yet clear whether certain college students are more likely to show negative (versus positive) responses to fitspiration posts. Understanding individual differences in typical responses to fitspiration among college students could inform targeted wellness promotion on social media.

The social comparison theory provides one explanation for mixed findings on the association between fitspiration and wellness [16]. It suggests that individuals evaluate themselves in a valued area or domain (eg, health or appearance) in relation to other people, which provides information about one's current status and future standing in that domain. Individuals might view themselves as doing worse than, better than, or about the same as another individual in the comparison domain. If a discrepancy is realized between the self and others who are perceived as "doing better" in the valued domain, there may be motivation to reduce this gap by changing behavior [16]. A discrepancy between the actual and the ideal body (represented in images of fit individuals [17]) might be made salient by fitspiration posts, thus motivating healthy behaviors through a positive emotional response (eg, inspiration). However, a salient discrepancy can also prompt negative emotions and demotivation for actions toward desired fitness outcomes, as achievements similar to those of the comparison target (ie, the individual used for comparison) can seem out of reach. Fitspiration images (versus travel images) have been demonstrated to have an indirect effect on the state of body satisfaction through appearance-based social comparisons. Specifically, exposure to fitspiration was associated with more appearance comparison and this predicted lower body satisfaction [12].

Social comparison orientation reflects the degree to which individuals attend to and value social comparison information [18]. Strong comparison orientation has been reported as a potential vulnerability factor for subjective well-being, such that, for individuals who tend to highly value comparisons, subjective well-being often declines with social media use. In contrast, individuals who tend to value comparisons less often have no significant decrease in subjective well-being and sometimes experience increases in positive mental health outcomes (ie, increased self-esteem) [19]. Social comparison orientation also has been shown to moderate relations between social media use and subjective well-being, such that individuals who have a stronger (versus weaker) comparison orientation show future decreases in self-esteem and increases in loneliness and depressive feelings [20-22]. Consequently, social comparison orientation may moderate relations between these experiences and health behaviors. Yet, fitspiration literature has more often focused on the frequency of social comparisons (versus one's tendency to compare or place greater emphasis on comparisons).

Regulatory focus, or an individual's tendency to move toward idealized goals (ie, promotion focus) or move away from feared outcomes (ie, prevention focus), may play a similar role. Similar to work on social comparison, existing regulatory focus literature also suggests that other individuals act as a potential representation of one's future goals or outcomes [23]. To some people (those with promotion focus), other individuals who are doing well might represent idealized goals and motivate activity, while to other people (those with prevention focus), other individuals who are doing poorly might represent feared outcomes and motivate activity.

Thus, regulatory focus represents another way to understand which individuals will be motivated or not motivated to reduce the gap between one's perceived status and the perceived status of another individual. Tailoring weight maintenance intervention to individuals' regulatory focus has previously outperformed self-directed weight loss efforts [24]. Furthermore, a promotion focus has been associated with better psychological outcomes than a prevention focus [25]. Individuals who scored high on promotion-focused subscales of regulatory focus measures also reported higher self-esteem and life satisfaction and lower loneliness (compared with their prevention-focused counterparts) [25]. To our knowledge, however, regulatory focus has not been examined in relation to college students' social media use, particularly, their responses to fitspiration posts. Thus, it might be useful to apply both regulatory focus and social comparison orientation as potential influences on associations between fitspiration perceptions and subjective well-being outcomes among college students (eg, positive versus negative feelings in response to fitspiration posts or motivation for physical activity after viewing fitspiration posts).

Of note, the majority of fitspiration studies have focused almost exclusively on the health outcomes of women [14]. This aligns with body dissatisfaction research, which also tends to examine this experience in samples of women [26]. A content analysis of fitspiration images showed that women were featured more than men (68% and 31%, respectively) [27]. Furthermore, women in fitspiration posts were more likely to be showing skin or to be portrayed in sexualized ways, while men were more likely to be shown as muscular [27]. Mental health outcomes for men related to fitspiration are just now beginning to receive attention. Some early research has suggested a potential increase in negative mood and a decrease in body satisfaction among men due to exposure to fitspiration or thinspiration (ie, images emphasizing thinness in models), in addition to an increase in the urge to improve their own muscularity [28]. Overall, there is a need to further examine fitspiration use and response among both college women and men.

Toward these ends, the first aim of this cross-sectional study was to describe college students' overall social media use, their reported frequency of exposure to fitspiration posts, and their reported "typical" responses to these posts (ie, positive versus negative feelings and motivation for physical activity). The second, and ultimate, aim was to understand whether social comparison orientation or regulatory focus moderates associations between fitspiration exposure and responses. We thus aimed to identify the type(s) of students who might be most vulnerable to negative effects of fitspiration exposure while controlling for gender.

We hypothesized the following:

1. Social comparison orientation will moderate associations between feelings about the self after fitspiration exposure and self-reported physical activity motivation after fitspiration, such that those with stronger (versus weaker) social comparison orientation will show a stronger positive association.
2. Regulatory focus will moderate associations between feelings about the self and self-reported physical activity motivation after fitspiration, such that those with a greater promotion focus will show a stronger positive association than those with a greater prevention focus.
3. Social comparison orientation will moderate associations between both intentional and unintentional fitspiration exposure and self-reported physical activity motivation after fitspiration, such that those with stronger (versus weaker) social comparison orientation will show a stronger positive association.
4. Regulatory focus will moderate associations between both intentional and unintentional fitspiration exposure and self-reported physical activity motivation after fitspiration, such that those with a greater promotion focus will show a stronger positive association than those with a greater prevention focus.

Methods

Participants and Procedures

As part of a larger study of college students' experiences, students enrolled at the supporting institution (who were ages 18-23 years) were recruited to participate in an electronic survey about students' social habits and social media use. Data were collected between 2017 and 2019. In exchange, they received psychology course credit at a small university in the northeastern United States. Students used an online scheduling website to access available research opportunities; those interested in the study were directed to an online survey and instructed to complete it at their convenience. Data were deidentified after participants were assigned course credit. Procedures were approved by the respective institutional review board, and informed consent was documented electronically. The sample consisted of 336 students (235/336, 69.9% women; mean age 19 years; mean body mass index [BMI] 24.0 kg/m^2). Additional demographic information can be found in Table 1; these characteristics are reflective of the population at the supporting institution [29].

Table 1. Demographic characteristics of participants.

Characteristic	Frequency (N=344)[a], n (%)
Age	235
18	115 (48.9)
19	80 (34)
20	26 (11)
21	11 (4.7)
≥22	3 (1.3)
Gender	344
Men	105 (30.5)
Women	239 (69.5)
BMI[b] (kg/m^2)	338
<18.5	9 (2.7)
18.5-24.9	225 (66.6)
25-29.9	73 (21.6)
≥30	31 (9.2)
Race/ethnicity	344
Black/African American	11 (3.2)
White/Caucasian	275 (80)
Latino/Hispanic	23 (6.7)
East Asian	0 (0)
South Asian	16 (4.7)
Native American	7 (2)
Multiracial	12 (3.5)
Year in school	344
Freshman	232 (67.4)
Sophomore	76 (22.1)
Junior	23 (6.7)
Senior	7 (2)
>4 years	6 (1.7)

[a] Some participants did not answer all questions. Therefore, the total for each variable category differs.

[b] BMI: body mass index.

Measures

Demographic Information

Participants were asked to indicate their age, gender, racial/ethnic identification, living situation, height, and weight. Reported height and weight were used to calculate BMI (kg/m^2).

Social Media Use

To describe students' general social media use, participants were asked to self-report their frequency of using social media platforms with options of "less than one day per week," "1-2 days per week," "3-4 days per week," "5-6 days per week," "once per day," and "more than once per day." Platforms included Facebook, Snapchat, Instagram, Pinterest, YouTube, Twitter, blog sites, and LinkedIn.

Fitspiration Exposure

To better understand students' exposure to the fitspiration trend on social media, questions were included to assess days per week intentionally and unintentionally viewing posts, with intentional and unintentional viewing as separate items. Response options included "less than one day per week," "1-2 days per week," "3-4 days per week," "5-6 days per week," "once per day," and "more than once per day." We asked participants for feelings about the self after viewing posts with a 5-point Likert scale from 1 ("much better than before viewing") to 5 ("much worse than before viewing"). Motivation to engage in physical activity after viewing posts was measured with a 5-point Likert scale from 1 ("never") to 5 ("all of the time"). These items were used in a previous study of fitspiration perceptions among posters and followers [30].

Social Comparison Orientation

The Iowa-Netherlands Social Comparison Measure [18] comprises 11 items that assess general social comparison. It includes questions such as “I always pay a lot of attention to how I do things compared with how others do things.” Responses are rated on a 5-point Likert scale from 1 (“I strongly disagree”) to 5 (“I strongly agree”) and are summed to create subscale scores; higher scores indicate a stronger tendency to compare socially. This measure has shown strong psychometric properties among college students, and internal consistency has previously been cited as α=.83 [18]; in this study, α=.82.

Regulatory Focus

The General Regulatory Focus Measure [31] uses 18 items to assess respondents’ tendencies to approach positive outcomes versus avoid negative outcomes (9 promotion items and 9 prevention items). The promotion-focused portion includes statements such as “I frequently imagine how I will achieve my hopes and aspirations,” while the prevention-focused portion includes items such as “In general, I am focused on preventing negative events in my life.” Responses are provided on a 9-point Likert scale ranging from 1 (“not at all true of me”) to 9 (“very true of me”). Items are summed, and the prevention score is subtracted from the promotion score, with higher scores indicating greater promotion focus. This measure also has shown strong psychometric properties, including internal consistency for promotion items (α=.81) and prevention items (α=.75) [31]. In this study, internal consistency was α=.89 for promotion items and α=.77 for prevention items.

Statistical Analysis

To address the first study aim, descriptive statistics were obtained for the reported frequency of social media use across platforms, social comparison orientation, regulatory focus, and the 4 variables related to fitspiration: (1) frequency of intentional and (2) unintentional exposure to fitspiration, (3) typical feelings about the self after viewing fitspiration posts, and (4) typical level of motivation to engage in physical activity after viewing fitspiration posts. Descriptive differences between genders in the variables of interest were obtained with two-tailed independent samples *t* tests corrected for unequal group sizes. Pearson correlation coefficients were used to examine bivariate relations between these experiences. To address the second study aim, separate general linear models were used to test for the potential moderating effects of social comparison orientation and regulatory focus on associations between (1) average feelings after viewing fitspiration and average motivation for physical activity after viewing fitspiration, (2) intentional fitspiration use and average motivation to engage in physical activity after viewing fitspiration, and (3) unintentional fitspiration use and average motivation to engage in physical activity after viewing fitspiration. Sensitivity analyses were used to determine the potential impact of gender on interpretation of moderation models. Statistical significance was set at $P<.05$, and effect sizes were expressed as change in R^2. Our sample size of 336 students afforded power >.80, allowing us to detect small effects with these tests.

Results

Social Media Use, Fitspiration Exposure and Response, and Individual Differences in Social Comparison Orientation and Regulatory Focus

Snapchat was the most frequently used platform among students, with the majority of participants (309/344, 89.8%) reporting use at least once per day. Following in popularity was Instagram (277/344, 80.5%), Facebook (190/344, 55.2%), Twitter (122/344, 35.5%), and YouTube (120/344, 34.9%). Participants reported spending a mean of 2.95 hours per day (SD 2.23) on these platforms.

On average, intentional searches for fitspiration appeared to be less common (at least 5-6 days per week), compared with unintentional exposure (at least once every day). On average, students’ typical motivation for engaging in physical activity after viewing fitspiration posts was reported as “occasional” (mean 3.09, SD 1.01; Table 2). Feelings about the self after viewing fitspiration posts were predominately “about the same” or “somewhat worse” than prior to viewing (mean 3.40, SD 0.85).

Overall, significant gender differences were seen in the majority of the variables of interest. Compared with men, women reported greater frequency of unintentionally viewing fitspiration posts ($t_{318}=-2.87$, $P=.01$). Women indicated more negative feelings about the self ($t_{224}=-6.71$, $P<.001$) and higher motivation, on average, after viewing fitspiration ($t_{158}=-2.57$, $P=.01$). Lastly, women endorsed a stronger social comparison orientation, ($t_{335}=-2.10$, $P=.04$). No significant gender differences were found in intentional fitspiration use ($P=.39$) or regulatory focus ($P=.97$). Age was not associated with any variables of interest (intentional fitspiration use, $P=.12$; unintentional fitspiration use, $P=.15$; feelings about the self after fitspiration, $P=.06$; physical activity motivation after fitspiration, $P=.32$; regulatory focus, $P=.55$; social comparison orientation, $P=.67$). Race/ethnicity was not associated with the variables of interest (intentional fitspiration use, $P=.05$; feelings about the self after fitspiration, $P=.99$; physical activity motivation after fitspiration, $P=.14$; regulatory focus, $P=.18$; social comparison orientation, $P=.06$), with the exception of unintentional fitspiration use ($P=.02$). However, no pairwise comparisons were significant in a Tukey post hoc test ($P=.08$-.99). As controlling for gender did not meaningfully affect our results or conclusions, we presented the results of reduced models, without gender, for parsimony.

Table 2. Correlations between fitspiration use and response variables.

Variable	Intentional fitspiration	Unintentional fitspiration	Feelings after fitspiration	Physical activity motivation after fitspiration	Social comparison orientation	Regulatory focus
Intentional fitspiration						
r	1	0.544	–0.168	0.384	–0.013	0.073
P value	—[a]	<.001	.003	<.001	.814	.199
Unintentional fitspiration						
r	0.544	1	0.042	0.247	0.005	0.128
P value	<.001	—	.452	<.001	.924	.023
Feelings after fitspiration						
r	–0.168	0.042	1	–0.046	0.144	–0.130
P value	.003	.452	—	.401	.008	.018
Physical activity motivation after fitspiration						
r	0.384	0.247	–0.046	1	0.038	0.045
P value	<.001	<.001	.401	—	.486	.414
Social comparison orientation						
r	–0.013	0.005	0.144	0.038	1	–0.165
P value	.814	.924	.008	.486	—	.003
Regulatory focus						
r	0.073	0.128	–0.130	0.045	–0.165	1
P value	.199	.023	.018	.414	.003	—

[a] Not applicable.

As shown in Table 2, social comparison orientation was positively associated with feelings about the self after viewing fitspiration (*r*=0.14, *P*=.008), such that students with a stronger (versus weaker) comparison orientation experienced more frequent negative feelings. In contrast, regulatory focus was inversely associated with feelings about the self after viewing fitspiration, such that students with a stronger promotion focus experienced more frequent positive feelings (*r*=−0.13, *P*=.02). In addition, regulatory focus was positively associated with unintentional fitspiration use, such that students with a stronger promotion focus more frequently encountered fitspiration posts without searching for them (*r*=0.13, *P*=.02). No significant associations were found between motivation to engage in physical activity after fitspiration and either social comparison orientation (*P*=.49) or regulatory focus (*P*=.41).

Intentional fitspiration use was negatively associated with feelings about the self (*r*=−0.17, *P*=.003), and positively associated with motivation to engage in physical activity after viewing fitspiration (*r*=0.38, *P*<.001). However, unintentional fitspiration use was only associated with motivation (*r*=0.25, *P*=.001). Feelings and motivation after fitspiration were not correlated with one another (*r*=−0.05, *P*=.40).

Moderating Roles of Social Comparison Orientation and Regulatory Focus

As indicated, our ultimate aim was to examine potential individual differences in associations between fitspiration exposure and responses based on social comparison orientation and regulatory focus. Social comparison orientation did not moderate associations between feelings about the self and motivation for physical activity after viewing fitspiration (b=−0.001, *P*=.88; Table 3). At all levels of social comparison orientation, there were insignificant negative associations between average feelings and average motivation after viewing fitspiration (Figure 1). However, social comparison orientation did moderate the association between intentional fitspiration use and motivation after viewing fitspiration (b=−0.01, *P*=.03; Table 4). Adding this interaction resulted in a significant change in R^2 (ΔR^2 =.016, *P*=.03). There were positive linear associations across all levels of comparison orientation, with the strongest association in those with the highest level of comparison orientation (Figure 2). This association was not significant when fitspiration use was unintentional, however (b=0.003, *P*=.41; Figure 3).

Table 3. Moderation of associations between feelings about self and motivation for physical activity after fitspiration by social comparison orientation.

Variable	Motivation for physical activity after fitspiration				
	b	SE	95% CI	*t* test (df)	*P* value
Feelings after fitspiration	−0.0012	0.38	−0.74 to 0.74	−0.003 (329)	.10
Social comparison orientation	0.008	0.03	−0.05 to 0.07	0.25 (329)	.80
Feelings after fitspiration × social comparison orientation	−0.001	0.009	−0.02 to 0.02	−0.15 (329)	.88

Figure 1. Moderation of feelings about self and motivation for exercise after fitspiration by social comparison orientation.

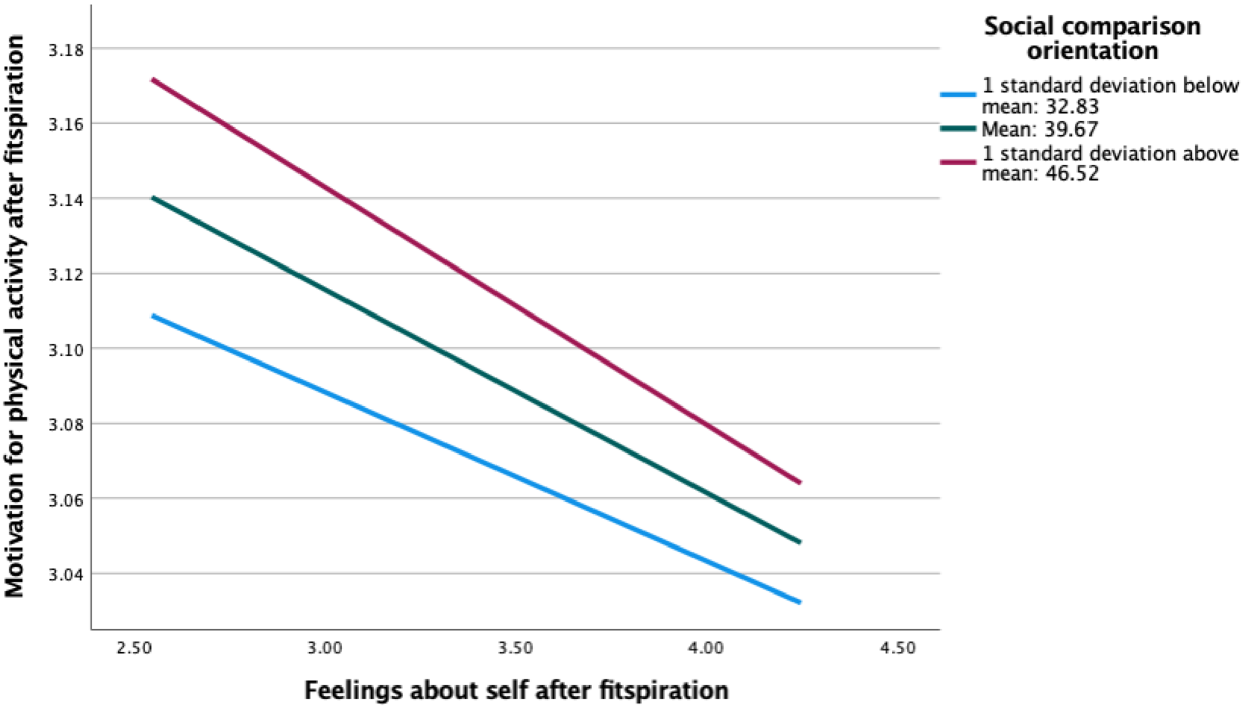


Table 4. Moderation of associations between fitspiration use and motivation for physical activity after fitspiration by social comparison orientation.

Variable	Analysis 1: motivation for physical activity after intentional fitspiration					Analysis 2: motivation for physical activity after unintentional fitspiration				
	b	SE	95% CI	*t* test (df)	*P* value	b	SE	95% CI	*t* test (df)	*P* value
Fitspiration use	0.67	0.19	0.30 to 1.1	3.5 (310)	<.001	0.004	0.18	−0.36 to 0.37	0.02 (309)	.98
Social comparison orientation	0.03	0.01	0.001 to .06	2.1 (310)	.04	−0.01	0.02	−0.05 to 0.03	−0.55 (309)	.58
Fitspiration × social comparison orientation	−0.01	0.005	−0.02 to 0.001	−2.2 (310)	.03	0.004	0.005	−0.01 to 0.01	0.82 (309)	.41

Figure 2. Moderation of intentional fitspiration use and motivation for exercise after fitspiration by social comparison orientation.

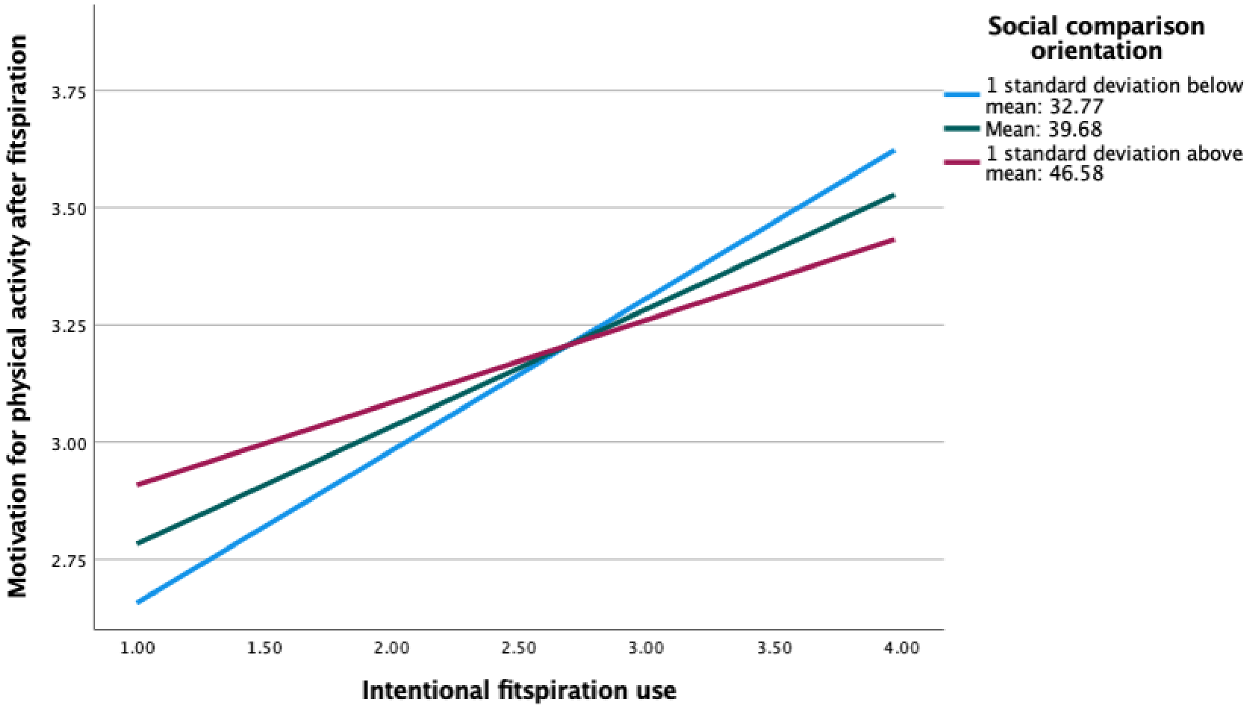
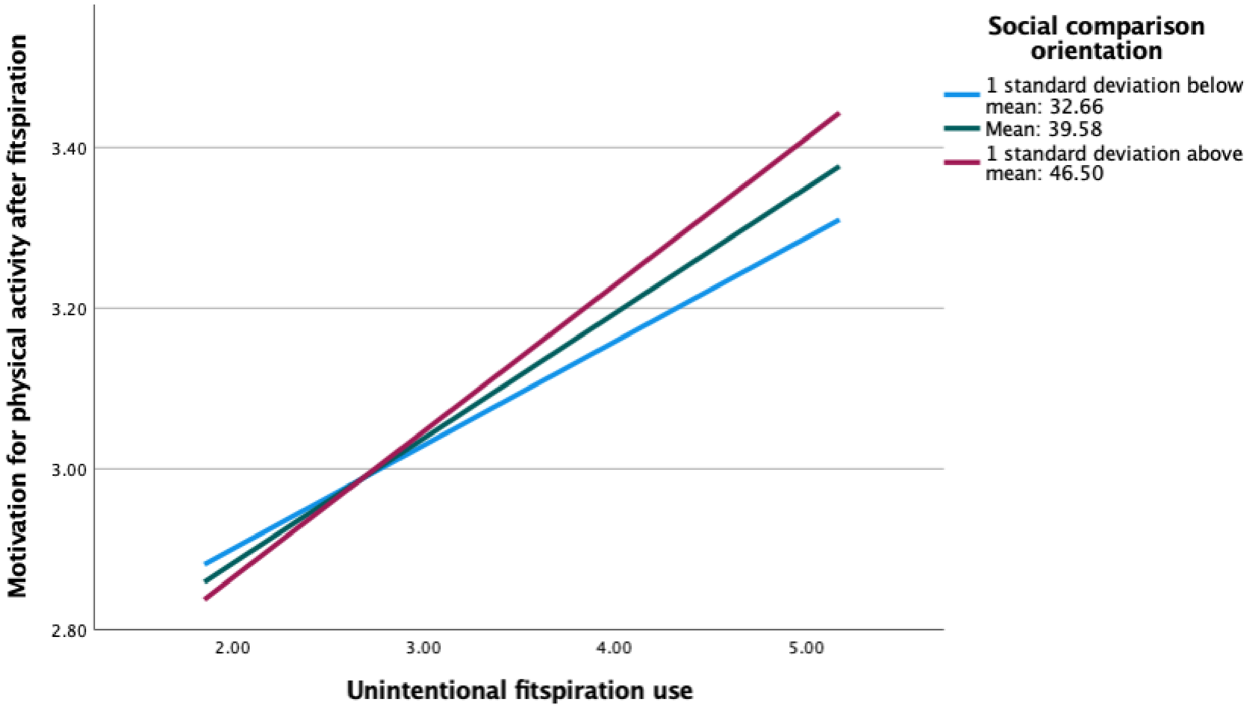


Figure 3. Moderation of unintentional fitspiration use and motivation for exercise after fitspiration by social comparison orientation.



Regulatory focus also did not moderate the association between feelings about the self and motivation for physical activity after viewing fitspiration (b=−0.002, *P*=.67; Table 5). Simple slopes were similar, overall, for models with social comparison orientation and regulatory focus (Figure 4). However, there were larger differences between levels of regulatory focus compared with social comparison orientation. Almost no association was present at low levels of regulatory focus, compared with low levels of social comparison orientation, which showed stronger negative associations. In moderation analyses between fitspiration use (intentional and unintentional) and motivation for physical activity after fitspiration, simple slope patterns in regulatory focus were once again similar to that of social comparison orientation (ie, strong positive associations across all levels), although there were no significant differences (*P*=.33-.83; Table 6 and Figures 5-6).

Table 5. Moderation of associations between feelings about self and motivation for physical activity after fitspiration by regulatory focus.

Variable	Motivation for physical activity after fitspiration				
	b	SE	95% CI	*t* test (df)	*P* value
Feelings after fitspiration	−0.03	0.08	−0.19 to 0.14	−0.31(328)	.76
Regulatory focus	0.01	0.02	−0.02 to 0.04	0.53 (328)	.59
Feelings after fitspiration × regulatory focus	−0.002	0.05	−0.01 to 0.01	−0.42 (328)	.01

Figure 4. Moderation of feelings about self and motivation for exercise after fitspiration by regulatory focus.

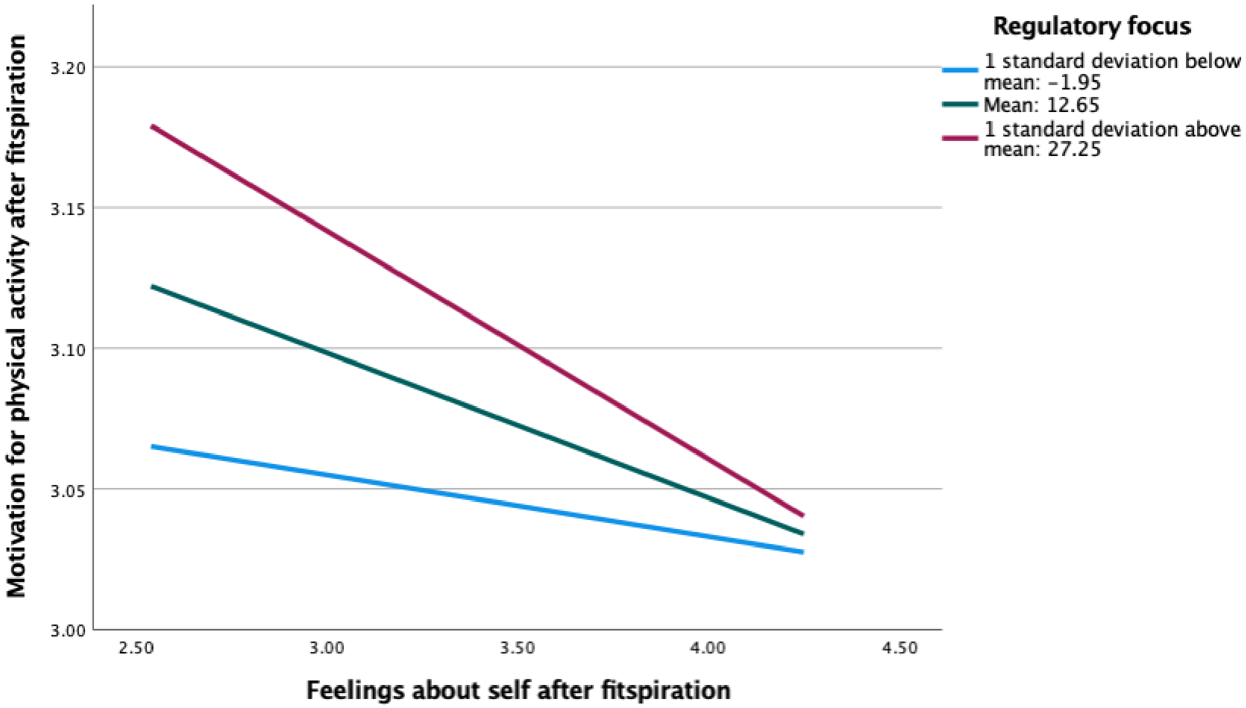


Table 6. Moderation of associations between fitspiration use and motivation for physical activity after fitspiration by regulatory focus.

Variable	Analysis 1: motivation for physical activity after intentional fitspiration					Analysis 2: motivation for physical activity after unintentional fitspiration				
	b	SE	95% CI	*t* test (df)	*P* value	b	SE	95% CI	*t* test (df)	*P* value
Fitspiration use	0.22	0.05	0.13 to 0.31	4.7 (309)	<.001	0.15	0.04	0.07 to 0.24	3.5 (311)	.001
Regulatory focus	0.006	0.01	−0.02 to 0.01	−0.94 (309)	.35	0.001	0.01	−0.01 to 0.02	0.022 (311)	.83
Fitspiration × regulatory focus	0.002	0.002	−0.002 to 0.01	0.98 (309)	.33	−0.001	0.002	−0.05 to 0.003	−0.26 (311)	.79

Figure 5. Moderation of intentional fitspiration use and motivation for exercise after fitspiration by regulatory focus.

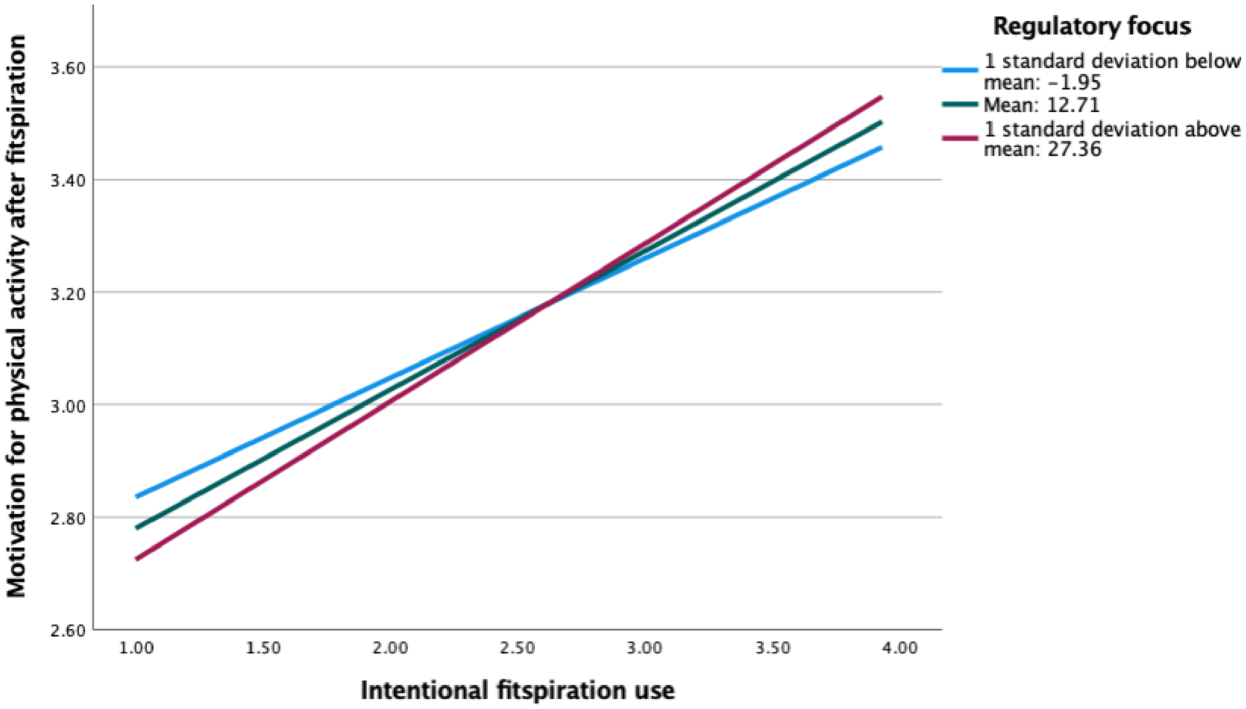
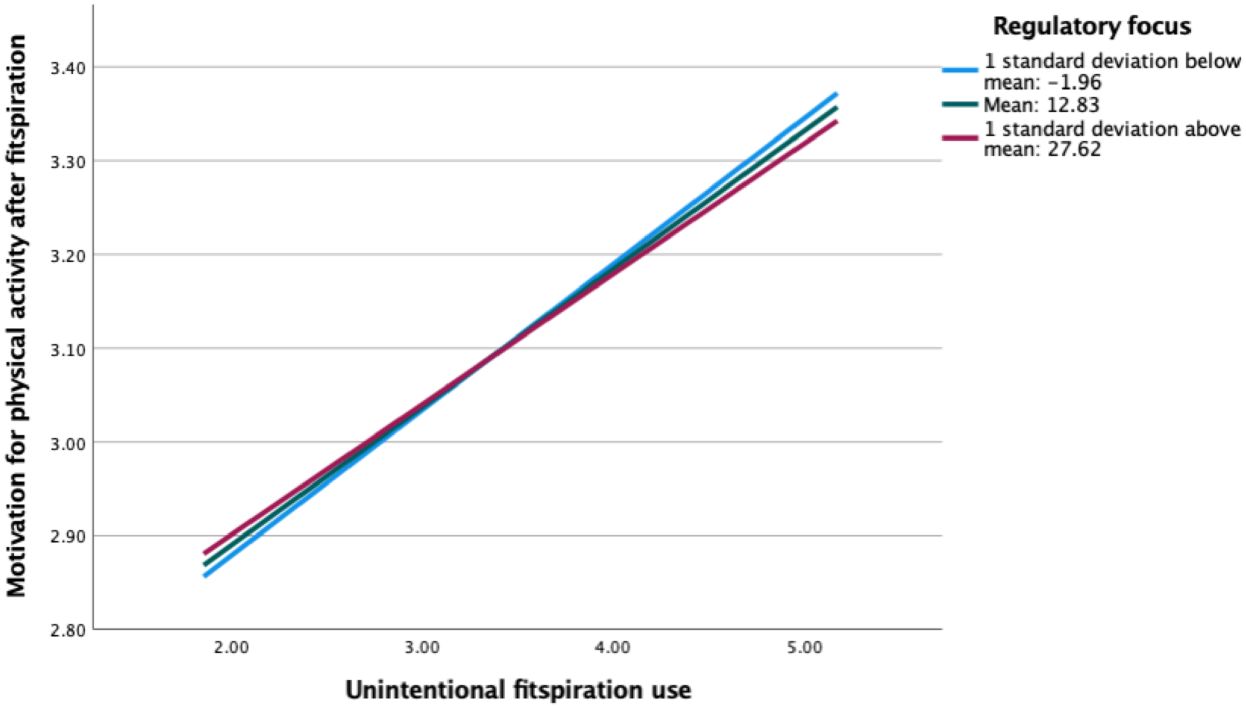


Figure 6. Moderation of unintentional fitspiration use and motivation for exercise after fitspiration by regulatory focus.



Discussion

Principal Findings

The overall purpose of this study was to examine college students' self-reported exposure and response to fitspiration posts (with respect to their cognitive and emotional responses) and examine individual differences in psychological tendencies that could distinguish between helpful versus harmful fitspiration use.

Intentional searches for fitspiration posts appeared to be less common than unintentional exposure to these posts (ie, while scrolling through a newsfeed). This finding seems intuitive, given that individuals might more commonly be exposed to fitspiration posts randomly while scrolling through their newsfeed, rather than possessing previous knowledge of the fitspiration trend and purposefully searching for these posts. Average feelings about the self after viewing fitspiration posts were predominately "about the same" and "somewhat worse" than feelings about the self prior to viewing. Motivation for physical activity after viewing these posts was low to moderate. These findings are important due to their direct contrast with the stated intentions of the fitspiration trend, which is to inspire positive self-image and behaviors [30,32].

Overall, women self-reported significantly more unintentional viewing of fitspiration posts, more negative feelings about the self, greater motivation for physical activity after viewing posts, and greater social comparison orientation, compared with men. The observed gender difference in mood after viewing fitspiration posts could be due to factors such as (1) greater focus on women in fitspiration posts; (2) less social acceptance in identifying negative moods among men; or (3) a tendency among men to only report negative moods after viewing muscular or bare-chested images, while women appear to have negative reactions regardless of image detail [33]. However, controlling for gender did not affect any of our conclusions.

Social comparison orientation was positively associated with feelings about the self after viewing fitspiration, while regulatory focus was negatively associated with feelings about the self after viewing fitspiration and positively associated with unintentional fitspiration use. Both results are consistent with previous literature, which shows that a stronger (versus weaker) social comparison orientation is associated with worse self-reported mood after viewing others' social media posts [34]. Previous research also suggests that individuals with a promotion focus (ie, a focus on meeting goals versus avoiding failures) tend to be motivated when seeing others who represent a higher achievement of a goal, relative to the individual's current state (ie, positive role models) [31]. Interestingly, the present findings show that these individuals are also more likely to view fitspiration unintentionally. It is possible that highly promotion-focused individuals naturally have a cognitive bias toward focusing on and remembering these positive role models from their social media experiences. Existing work demonstrates that even when social media posts have a positive tone, individuals with a stronger social comparison orientation still report more negative mood (compared with when they view neutral posts or no posts) [35]. As the target may be different across social comparison orientation and regulatory focus, this raises a question about potential cognitive biases within both of these processes.

Of note, students who reported more negative feelings about the self after viewing fitspiration also reported more motivation to engage in physical activity. Consistent with social comparison theory, the increased salience of a discrepancy between an individual's body, appearance, or activity level and that of another individual may promote body dissatisfaction and motivation for physical activity, to reduce a perceived gap between the self and other [36]. In this study, individuals with stronger (versus weaker) comparison orientations did show trends toward stronger associations between negative feelings and motivation for physical activity after viewing fitspiration posts, though the moderating effect of comparison orientation was not significant.

This is somewhat inconsistent with previous literature that suggests it might be more harmful to the mental well-being of individuals with high social comparison orientation to view comparison-inducing stimuli (ie, stimuli regarding self-esteem or self-evaluation) on Facebook as well as on Instagram [20]. Social comparison orientation has also been cited as mediating associations between Instagram use and a variety of mental health outcomes (eg, physical appearance anxiety, depressive symptoms, body dissatisfaction) [37]. It is possible that social comparison orientation does not differentiate individuals with whom fitspiration may be more harmful versus helpful. However, there are some important considerations. Previous studies examined social media use broadly, rather than use specific to the fitspiration trend, and the few studies that were in this area focused on differentiating between comparisons made toward "better-off" and "worse-off" others. Consequently, the discrepancy between findings could be a function of measurements used. Specifically, previous work may not have captured individuals' stable perceptions of how important social comparison information is to them. It also might be that what truly differentiates harmfulness versus helpfulness of fitspiration is how important *certain kinds* of social comparison information are to an individual (ie, those who you perceive are doing better than you) rather than social comparison information more generally. It is also possible that inconsistencies in these findings are due to the methods used in this study. For example, since there are no validated measures of fitspiration exposure and response, we used items generated for our work in this area. It is possible that these measures were not sensitive to the differences of interest and that the use of different measures would have led to different outcomes.

In addition, students who had more negative feelings about the self after viewing fitspiration also reported more motivation to engage in physical activity after viewing fitspiration, regardless of the level of social comparison orientation. These associations held for those with greater regulatory focus (ie, strong promotion focus or equal promotion and prevention focus), but the associations did not hold for lower regulatory focus (ie, strong prevention focus). Thus, (negative) feelings about the self after viewing fitspiration may play a role in motivating physical activity across all levels of social comparison orientation. When individuals are higher in regulatory focus (ie, focus that is predominately or partly concentrated on promotion—an outlook of "I want to meet my goals"), negative feelings about the self might be motivating in a similar way. However, this is not the case with people low in regulatory focus (ie, focus that is predominately concentrated on prevention— an outlook of "I want to prevent my failures"). Although there is minimal literature examining the role of regulatory focus in fitspiration use, previous literature has suggested that "positive" role models (similar to an upward social comparison) might be motivating for individuals with a high regulatory focus (ie, promotion-focused individuals) but not motivating for physical activity for individuals low in regulatory focus (ie, prevention-focused individuals); instead, “negative” role models might be more motivating for these individuals [31,38].

Neither social comparison orientation nor regulatory focus were associated with intentional fitspiration use. Social comparison orientation did significantly moderate associations between intentional fitspiration use and motivation after viewing fitspiration, though the effect size was weak. This was not the case for the same model with unintentional fitspiration use. Regulatory focus was not a significant moderator of either type of fitspiration use. Although not significant, patterns for the moderation analyses of social comparison orientation and regulatory focus were nearly identical for the associations between average motivation to engage in physical activity after viewing fitspiration and (1) intentional fitspiration use and (2) unintentional fitspiration use. Simple slopes across all models suggested strong positive linear associations between variables, at all levels of each moderator. It might be useful to further examine the common and distinct contributions of social comparison orientation and regulatory focus within fitspiration to clarify potential individual differences.

Finally, despite significant gender differences in the majority of variables of interest, sensitivity analyses for all moderation models suggested that the inclusion of gender as a covariate did not meaningfully change interaction effects. It is possible that this was due to a smaller sample size for men than women. However, although some differences may exist in fitspiration use, general patterns in response may persist across gender. This would be consistent with emergent research suggesting some overlap in how men and women interact with fitspiration posts [33,35]. Specifically, it has been posited that, similar to women, men experience some negative effects of fitspiration images. However, images that were most harmful for men, specifically, included heavily muscular and bare-chested males. Furthermore, men have been suggested to have less of a poor response to appearance-based social comparisons, potentially due to (1) a lower frequency of comparisons, (2) a fear of making comparisons and seeming less “manly,” (3) a decreased frequency of making upward-comparisons, or (4) a tendency to feel less negatively than women do after making comparisons [33].

Overall, this cross-sectional study provides additional support for the observations that (1) individuals who tend to have negative feelings about the self after fitspiration also report greater motivation for physical activity, (2) social comparison orientation moderates associations between intentional fitspiration use and motivation for physical activity after fitspiration, and (3) considerable overlap appears to be present across levels of social comparison orientation and regulatory focus in moderating associations between feelings about the self and motivation for physical activity after fitspiration use. However, these findings should be interpreted with caution until replicated.

Implications of This Study

Recently, safety concerns have been raised in response to the increasingly prevalent nature of mental and physical health symptoms on social media, such as depression and disordered eating behaviors [39]. Some argue that social media provides a supportive space to share health experiences (eg, weight loss efforts) or receive a response to a plea for help [40]. Others argue that these platforms allow for perpetuation of negative health behaviors. Before #fitspiration, #thinspiration led to controversy about the glamorization of images that suggested eating disorders. The thinspiration hashtag has since been banned to prevent further harm [41], and individuals attempting to use it are redirected to mental health resources. This study’s findings demonstrate the power of fitspiration in promoting negative feelings, which may be an unintended consequence of the trend. Although negative feelings might ultimately lead to positive health behaviors (eg, physical activity motivation), more nuanced examination of fitspiration and similar trends is needed to determine for whom and under what circumstances these trends are beneficial (versus harmful).

Strengths, Limitations, and Future Directions

Strengths of this study were its considerable sample size for detecting the hypothesized effects and its novel examination of social comparison orientation and regulatory focus as potential individual differences in fitspiration outcomes. However, as an initial investigation, this study was limited by the self-report methods used to assess fitspiration exposure and response; although these fitspiration assessments have been used in previous work, they have not been validated using traditional psychometric evaluation. Recruitment for this study occurred between 2017 and 2019; some fitspiration trends in exposure and response might have changed since collection, given the rapidly changing nature of social media and the introduction of platforms such as TikTok. Other limitations include a cross-sectional design that does not allow for determining the direction of observed effects. Using temporally sophisticated methods to clarify the sequence of platform use and behaviors (eg, longitudinal or within-person designs) would be informative, as would experimental methods to determine cause-and-effect relations between fitspiration exposure and response. Given the sample’s heavy inclusion of individuals that identify as Caucasian, female, and of healthy BMI, results should be interpreted with caution and should be replicated across more diverse samples. Different racial and ethnic groups promote different body ideals (eg, there are larger body ideals among Black women versus White women [42]). Therefore, these results should be interpreted with caution, as they may not generalize for people of color. Meta-analyses have also suggested that research in areas such as body satisfaction has been biased toward the experiences of Caucasian women and their body ideals (ie, the thin ideal) [43]. Thus, future fitspiration and body image research should take care to avoid generalizing from homogenous samples. Additional work is needed to determine whether social comparison tendencies may help to identify students most vulnerable to the negative effects of fitspiration, particularly, with a more heterogenous sample.

Conclusions

Findings from this study show associations between college students’ fitspiration exposure and subjective well-being (ie, feelings about the self and motivation for physical activity), with potential moderators to identify individuals who might have helpful versus harmful mental health effects of fitspiration. Students who reported more negative feelings, on average, after viewing fitspiration also reported greater motivation for physical activity after exposure. Social comparison orientation did not significantly moderate associations between feelings about the self and motivation for physical activity; this requires further exploration. Social comparison orientation and regulatory focus appeared to function similarly within fitspiration use. This is with the exception of negative feelings about the self potentially acting as a motivator for individuals with a low social comparison orientation, as fitspiration may produce a discrepancy between one's real and ideal self, while negative feelings for individuals with a low regulatory focus (ie, prevention-focused individuals) might not be as motivated because there are no negative outcomes to avoid. A greater understanding of these associations within the context of fitspiration could allow for a maximization of health benefits and a minimization of harm from social media use among college students.

Conflicts of Interest

None declared.

References

1. Blondin K, Giles C, Cradock A, Gortmaker S, Long M. US States' Childhood Obesity Surveillance Practices and Recommendations for Improving Them, 2014-2015. Prev Chronic Dis 2016 Jul 28;13:E97 [FREE Full text] [doi: 10.5888/pcd13.160060] [Medline: 27468156]
2. Jacobs M. Adolescent health behaviors predict adult success. Journal of Obesity and Nutritional Disorders 2019;1(134):2577-2244.
3. Vaterlaus J, Patten E, Roche C, Young J. #Gettinghealthy: The perceived influence of social media on young adult health behaviors. Computers in Human Behavior 2015 Apr;45:151-157. [doi: 10.1016/j.chb.2014.12.013]
4. Boyle SC, LaBrie JW, Froidevaux NM, Witkovic YD. Different digital paths to the keg? How exposure to peers' alcohol-related social media content influences drinking among male and female first-year college students. Addict Behav 2016 Jun;57:21-29 [FREE Full text] [doi: 10.1016/j.addbeh.2016.01.011] [Medline: 26835604]
5. Korda H, Itani Z. Harnessing social media for health promotion and behavior change. Health Promot Pract 2013 Jan;14(1):15-23. [doi: 10.1177/1524839911405850] [Medline: 21558472]
6. Steers MN, Moreno MA, Neighbors C. The Influence of Social Media on Addictive Behaviors in College Students. Curr Addict Rep 2016 Dec;3(4):343-348 [FREE Full text] [doi: 10.1007/s40429-016-0123-x] [Medline: 28458990]
7. Murphy M, Carlin A, Woods C, Nevill A, MacDonncha C, Ferguson K, et al. Active Students Are Healthier and Happier Than Their Inactive Peers: The Results of a Large Representative Cross-Sectional Study of University Students in Ireland. J Phys Act Health 2018 Oct 01;15(10):737-746. [doi: 10.1123/jpah.2017-0432] [Medline: 30119614]
8. Viner RM, Gireesh A, Stiglic N, Hudson LD, Goddings A, Ward JL, et al. Roles of cyberbullying, sleep, and physical activity in mediating the effects of social media use on mental health and wellbeing among young people in England: a secondary analysis of longitudinal data. Lancet Child Adolesc Health 2019 Oct;3(10):685-696. [doi: 10.1016/S2352-4642(19)30186-5] [Medline: 31420213]
9. Zhang J, Brackbill D, Yang S, Centola D. Efficacy and causal mechanism of an online social media intervention to increase physical activity: Results of a randomized controlled trial. Prev Med Rep 2015;2:651-657 [FREE Full text] [doi: 10.1016/j.pmedr.2015.08.005] [Medline: 26844132]
10. Fardouly J, Willburger B, Vartanian L. Instagram use and young women's body image concerns and self-objectification: Testing mediational pathways. New Media and Society 2018;20(4):1380-1395.
11. Tiggemann M, Zaccardo M. "Exercise to be fit, not skinny": The effect of fitspiration imagery on women's body image. Body Image 2015 Sep;15:61-67. [doi: 10.1016/j.bodyim.2015.06.003] [Medline: 26176993]
12. Dignard N, Jarry J. The "Little Red Riding Hood effect:" Fitspiration is just as bad as thinspiration for women's body satisfaction. Body Image 2021 Mar;36:201-213. [doi: 10.1016/j.bodyim.2020.11.012] [Medline: 33360477]
13. Rounds E, Stutts L. The impact of fitspiration content on body satisfaction and negative mood: An experimental study. Psychology of Popular Media 2021 Apr;10(2):267-274. [doi: 10.1037/ppm0000288]
14. Carrotte E, Prichard I, Lim M. "Fitspiration" on Social Media: A Content Analysis of Gendered Images. J Med Internet Res 2017 Mar 29;19(3):e95 [FREE Full text] [doi: 10.2196/jmir.6368] [Medline: 28356239]
15. Raggatt M, Wright CJC, Carrotte E, Jenkinson R, Mulgrew K, Prichard I, et al. "I aspire to look and feel healthy like the posts convey": engagement with fitness inspiration on social media and perceptions of its influence on health and wellbeing. BMC Public Health 2018 Aug 10;18(1):1002 [FREE Full text] [doi: 10.1186/s12889-018-5930-7] [Medline: 30097034]
16. Festinger L. A Theory of Social Comparison Processes. Human Relations 2016 Apr 22;7(2):117-140. [doi: 10.1177/001872675400700202]
17. Dignard N. The Effects of Thinspiration and Fitspiration on Body Satisfaction and Appearance Self-Esteem Are Equivalent and Mediated by Appearance Comparisons. Electronic Theses and Dissertations 2017;7249:7249.

18. Gibbons FX, Buunk BP. Individual differences in social comparison: development of a scale of social comparison orientation. J Pers Soc Psychol 1999 Jan;76(1):129-142. [doi: 10.1037//0022-3514.76.1.129] [Medline: 9972558]
19. Verduyn P, Gugushvili N, Massar K, Täht K, Kross E. Social comparison on social networking sites. Curr Opin Psychol 2020 Dec;36:32-37 [FREE Full text] [doi: 10.1016/j.copsyc.2020.04.002] [Medline: 32387840]
20. Vogel E, Rose J, Okdie B, Eckles K, Franz B. Who compares and despairs? The effect of social comparison orientation on social media use and its outcomes. Personality and Individual Differences 2015 Nov;86:249-256. [doi: 10.1016/j.paid.2015.06.026]
21. Alfasi Y. The grass is always greener on my Friends' profiles: The effect of Facebook social comparison on state self-esteem and depression. Personality and Individual Differences 2019 Sep;147:111-117. [doi: 10.1016/j.paid.2019.04.032]
22. Yang C. Instagram Use, Loneliness, and Social Comparison Orientation: Interact and Browse on Social Media, But Don't Compare. Cyberpsychol Behav Soc Netw 2016 Dec;19(12):703-708. [doi: 10.1089/cyber.2016.0201] [Medline: 27855266]
23. Higgins E. Beyond pleasure and pain. American Psychologist 1997;52(12):1280-1300. [doi: 10.1037/0003-066X.52.12.1280]
24. Fuglestad P, Rothman AJ, Jeffery RW, Sherwood NE. Regulatory Focus, Proximity to Goal Weight, and Weight Loss Maintenance. Am J Health Behav 2015 Sep;39(5):709-720 [FREE Full text] [doi: 10.5993/AJHB.39.5.12] [Medline: 26248180]
25. Liu H, Yao M. Regulatory Focus Profiles Among Chinese Pre-adolescents and Adolescents and Their Relationship to Personality and Psychological Outcomes. J Happiness Stud 2018 Aug 30;20(6):1807-1824. [doi: 10.1007/s10902-018-0025-9]
26. Barlett C, Vowels C, Saucier D. Meta-Analyses of the Effects of Media Images on Men's Body-image Concerns. Journal of Social and Clinical Psychology 2008 Mar;27(3):279-310. [doi: 10.1521/jscp.2008.27.3.279]
27. Deighton-Smith N, Bell B. Objectifying fitness: A content and thematic analysis of #fitspiration images on social media. Psychology of Popular Media Culture 2018 Oct;7(4):467-483. [doi: 10.1037/ppm0000143]
28. Yee Z, Griffiths S, Fuller-Tyszkiewicz M, Blake K, Richardson B, Krug I. The differential impact of viewing fitspiration and thinspiration images on men's body image concerns: An experimental ecological momentary assessment study. Body Image 2020 Dec;35:96-107. [doi: 10.1016/j.bodyim.2020.08.008] [Medline: 32977202]
29. University of Scranton. Fact Book 2017-2018 Review of Fact Book 2017-2018. Scranton.edu. 2018. URL: https://www.scranton.edu/pir/institutional-research/factbook/Fact_Book_2017-2018.pdf [accessed 2021-04-25]
30. DiBisceglie S, Arigo D. Perceptions of #fitspiration activity on Instagram: Patterns of use, response, and preferences among fitstagrammers and followers. J Health Psychol 2021 Jul;26(8):1233-1242 [FREE Full text] [doi: 10.1177/1359105319871656] [Medline: 31455118]
31. Lockwood P, Jordan C, Kunda Z. Motivation by positive or negative role models: Regulatory focus determines who will best inspire us. Journal of Personality and Social Psychology 2002;83(4):854-864. [doi: 10.1037/0022-3514.83.4.854] [Medline: 12374440]
32. Boepple L, Thompson JK. A content analytic comparison of fitspiration and thinspiration websites. Int J Eat Disord 2016 Jan;49(1):98-101. [doi: 10.1002/eat.22403] [Medline: 25778714]
33. Tiggemann M, Anderberg I. Muscles and bare chests on Instagram: The effect of Influencers' fashion and fitspiration images on men's body image. Body Image 2020 Dec;35:237-244. [doi: 10.1016/j.bodyim.2020.10.001] [Medline: 33157398]
34. Robinson L, Prichard I, Nikolaidis A, Drummond C, Drummond M, Tiggemann M. Idealised media images: The effect of fitspiration imagery on body satisfaction and exercise behaviour. Body Image 2017 Sep;22:65-71. [doi: 10.1016/j.bodyim.2017.06.001] [Medline: 28654826]
35. de Vries D, Möller A, Wieringa M, Eigenraam A, Hamelink K. Social Comparison as the Thief of Joy: Emotional Consequences of Viewing Strangers' Instagram Posts. Media Psychology 2017 Jan 06;21(2):222-245. [doi: 10.1080/15213269.2016.1267647]
36. Robinson L, Prichard I, Nikolaidis A, Drummond C, Drummond M, Tiggemann M. Idealised media images: The effect of fitspiration imagery on body satisfaction and exercise behaviour. Body Image 2017 Sep;22:65-71. [doi: 10.1016/j.bodyim.2017.06.001] [Medline: 28654826]
37. Sherlock M, Wagstaff D. Exploring the relationship between frequency of Instagram use, exposure to idealized images, and psychological well-being in women. Psychology of Popular Media Culture 2019 Oct;8(4):482-490. [doi: 10.1037/ppm0000182]
38. Bui M, Krishen A. So Close Yet So Far Away: The Moderating Effect of Regulatory Focus Orientation on Health Behavioral Intentions. Psychol. Mark 2015 Apr 20;32(5):522-531. [doi: 10.1002/mar.20797]
39. Holland G, Tiggemann M. "Strong beats skinny every time": Disordered eating and compulsive exercise in women who post fitspiration on Instagram. Int J Eat Disord 2017 Jan;50(1):76-79. [doi: 10.1002/eat.22559] [Medline: 27302867]
40. Whitehead K. Hunger Hurts but Starving Works: A case study of gendered practices in the online pro-eating-disorder community. Can. J. Soc 2010 Aug 22;35(4):595-626. [doi: 10.29173/cjs7976]
41. Hasan H. Instagram Bans Thinspo Content. Time Magazine. 2012 Apr 26. URL: https://tinyurl.com/bpwmdjn3 [accessed 2019-12-21]
42. Hebl M, King E, Perkins A. Ethnic differences in the stigma of obesity: Identification and engagement with a thin ideal. Journal of Experimental Social Psychology 2009 Nov;45(6):1165-1172. [doi: 10.1016/j.jesp.2009.04.017]

43. Betz DE, Ramsey LR. Should women be "All About That Bass?": Diverse body-ideal messages and women's body image. Body Image 2017 Sep;22:18-31. [doi: 10.1016/j.bodyim.2017.04.004] [Medline: 28554090]

Abbreviations

BMI: body mass index.

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Original Paper

Associations Between Social Media, Bedtime Technology Use Rules, and Daytime Sleepiness Among Adolescents: Cross-sectional Findings From a Nationally Representative Sample

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Abstract

Background: Social media use is associated with poor sleep among adolescents, including daytime sleepiness, which affects adolescents' mental health. Few studies have examined the associations among specific aspects of social media, such as frequency of checking and posting, perceived importance of social media for social belonging, and daytime sleepiness. Identifying whether certain adolescents are more at risk or protected from the effects of social media on sleepiness may inform future interventions for social media, sleep, and mental health.

Objective: This study aims to examine the association between social media use frequency and importance, daytime sleepiness, and whether the perceived importance of social media for social interactions and parental rules around bedtime technology moderated these relationships.

Methods: This cross-sectional survey study was conducted with a sample of 4153 adolescents from across the United States. Qualtrics was used to collect data via panel recruitment from a national sample representing the US demographics of teens aged 12 to 17 years. Participants completed measures of daytime sleepiness, frequency of social media checking and posting, and the importance of social media for social interactions. Parents reported whether they had a household rule around bedtime media and screen use. Hierarchical regressions and moderation analyses were conducted, covarying for age, gender, and age at first smartphone use.

Results: Participants had a mean age of 14.64 (SD 1.66) years in grades 6 to 12, 46.45% (1929/4153) identified as female, and 67.93% (2821/4153) identified as White. The results indicated that adolescents who posted (B=0.70, SE 0.04; *P*<.001) or checked (B=0.76, SE 0.04; *P*<.001) social media more frequently or who perceived social media to be more important for social belonging (B=0.36, SE 0.02; *P*<.001) had higher levels of daytime sleepiness. Moderation analyses indicated that the relationship between social media use frequency and daytime sleepiness was exacerbated by higher levels of perceived social media importance (B=0.04, SE 0.01; *P*<.001). Adolescents without household rules around bedtime technology use were more likely to be affected by social media checking (B=−0.34, SE 0.09; *P*<.001) and importance (B=−0.16, SE 0.04; *P*<.001) on daytime sleepiness.

Conclusions: The findings suggest that social media use frequency and perceived importance of social interactions are associated with daytime sleepiness among adolescents. It is important to consider youth's perceptions of social media when assessing the potential effects of social media use frequency on youth well-being. Furthermore, youth who did not have parental rules around bedtime technology use were most likely to be affected by social media use and perceived importance. The findings may extend to other mental health outcomes and may guide future prevention and intervention programs designed to improve social media use, sleep, and mental health.

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KEYWORDS

adolescents; social media; daytime sleepiness; parenting; bedtime; mental health; mobile phone

Introduction

Background

Sleep health is critical for the promotion of adolescent mental health. One major consequence of poor sleep and insufficient sleep is daytime sleepiness [1]. Daytime sleepiness is common among adolescents [2-5] and has significant consequences for daytime functioning and mood. Adolescents who report excessive daytime sleepiness (ie, tendency to doze off or fall asleep during the day) are at risk for poorer academic performance, accidents and injuries, substance use, and mental health problems [6]. In particular, daytime sleepiness is linked with depression and suicidal thoughts and behaviors [7,8]. A recent longitudinal study found that excessive daytime sleepiness predicted future suicidal thoughts and attempts among adolescents [9]. Given the increase in the rates of adolescent depression and suicide [10], it is critical to move toward prevention. Thus, identifying modifiable behavioral factors that contribute to poor sleep health, and specifically, daytime sleepiness, may have upstream effects on promoting mental well-being and preventing adolescent depression and suicide.

Adolescents undergo normative developmental shifts in sleep-wake processes, including delayed circadian rhythms and decreasing homeostatic sleep drive (ie, *the need to sleep*), which shifts the natural propensity toward sleepiness to later in the evening [1,11,12]. Psychosocial factors, such as academic demands and heightened importance of engaging and socializing with peers [13], also shift sleep times later [12]. Portable electronic devices have further complicated this issue by providing adolescents with continuous, round-the-clock access to engaging and stimulating activities. Indeed, electronic device use among adolescents is associated in both cross-sectional and longitudinal studies with a range of sleep outcomes, including later, shorter, and poorer sleep [14-17], as well as daytime sleepiness [18-22]. Portable devices now offer teens access to communicate directly and indirectly with peers at any time of the day or night via social media. In the context of adolescent development, it is not surprising that social media is uniquely engaging for adolescents. Adolescence is a developmental stage in which there is an increasing importance of peer relationships and focus on social standing within ones' peer groups [23]. Furthermore, neurobiological changes that occur in the adolescent brain heighten sensitivity to information and experiences with peers, including those that are socially rewarding and socially threatening [24,25]. Thus, adolescents can now engage with peers and access social information through social media's unique and readily available platforms. Consequently, emerging research has sought to better understand the effects of social media on youth mental health [26].

With more than 90% of adolescents using social media, predominantly accessed through portable devices, adolescents are able to access social media at night, which is linked to later sleep onset, shorter sleep duration, and poorer sleep quality [27-30]. Several studies have also indicated a cross-sectional relationship between social media use and daytime sleepiness among adolescents [31,32]. However, few studies have examined whether specific aspects of social media use affect sleep outcomes, such as how adolescents use social media (eg, checking and posting behaviors) and individuals' perceived importance of using social media for social connection. social media can provide adolescents with a range of social affordances, including a sense of belonging and a network of peers [33]. Although social media can have benefits for youth development and mental health [26,34], it may affect adolescent sleep behaviors and daytime sleepiness, especially for those who place heightened importance of using social media for social belonging may spend more time using social media. Thus, youth with both higher levels of social media use and greater perceived importance of social media for social connection may be doubly at risk for poor sleep outcomes, including daytime sleepiness. Identifying whether social media behaviors and perceived importance of social media affect daytime sleepiness and whether youth with both higher levels of social media use and perceived importance of social media are at greater risk may shed light on which aspects of social media are associated with sleepiness and guide future interventions around social media use and mental health.

To date, most studies have examined the relationship between social media and mental health in isolation without considering contextual factors that may influence the effects of social media use. Despite developmental shifts toward peers during adolescence, parents continue to play an important role in adolescents' lives [35]. In particular, parental rules around bedtime affect youth sleep behaviors and sleep duration [36-38]. Specific behaviors or rules around digital media, particularly around bedtime, may buffer the potential negative effects of social media on daytime sleepiness among adolescents. Indeed, one study found that parents' rules about technology use at bedtime were associated with an earlier bedtime for adolescents [39]. However, this study only reported the effect of technology rules on adolescents' sleep without considering the extent to which youth use social media or their perceived importance of social media. It is critical to better understand whether parents' technology rules, particularly around bedtime, affect the effect of social media on daytime sleepiness, which may provide valuable information for improving youth well-being and mental health.

Objectives

The primary aim of this study is to examine the association between social media, including frequency of social media behaviors (posting and checking), perceived importance of social media for social interactions, and daytime sleepiness. It was hypothesized that adolescents with more frequent social media behaviors and greater importance of social media for social connection would have higher levels of daytime sleepiness. However, it is critical to identify *which youth* are most vulnerable to the effects of social media on sleepiness, which is a risk factor for poor mental health outcomes [1]. Thus, the second and third aims of this study are to evaluate whether (1) social media importance moderated the effect of social media frequency and daytime sleepiness and (2) whether parental bedtime technology rules moderated the effects of social media (frequency and importance) on daytime sleepiness. It was hypothesized that youth with greater perceived social media importance and more frequent social media behaviors would have greater daytime sleepiness. Furthermore, it was expected that the effect of social media on daytime sleepiness would be exacerbated among youth with no parental rules around bedtime media use.

Methods

Recruitment and Procedures

A cross-sectional web-based survey was conducted using the Qualtrics platform, which was used for both participant recruitment and survey administration. Potential participants were recruited by Qualtrics through web-based advertisements on social media and in-app games. Adolescents and their parents or legal guardians were recruited using the following criteria: adolescents aged 12 to 17 years and English speakers. Adolescents were recruited to be a representative sample of the race and ethnicity of the 2010 US census population for 12- to 17-year-olds. Qualtrics' recruitment procedures took place between February and April 2019 and included a background check to confirm participants' eligibility. In this study, only adolescents who reported being in grades 6 to 12 were included, as school environments may affect sleep opportunities and daytime sleepiness. Adolescents' legally authorized representatives provided informed consent, and adolescents provided informed assent before being instructed to complete the web-based survey in a location that was private or where they felt comfortable. Adolescents were compensated if they completed at least 50% of the survey, and those who did not complete the survey were automatically replaced by Qualtrics recruitment. Participants were compensated by earning credit toward rewards (eg, gift cards and in-app purchases). This survey was approved by a local institutional review board.

Survey Measures

Daytime Sleepiness

The eight-item Pediatric Daytime Sleepiness Scale was used to assess daytime sleepiness [40]. Participants answered items on a 5-point Likert scale, ranging from 0 (never) to 4 (always). Item examples include, *How often do you fall asleep or get drowsy during class periods?*, *How often do you need someone to awaken you in the morning?*, and *How often do you think that you need more sleep?* The internal consistency in this study was 0.85.

Social Media Behavior Frequency and Importance

Social media behavior frequency was assessed using two items: checking and posting behaviors. Items included *How often do you check social media?* and *How often do you post on social media?*, with response options ranging from *Never* to *Almost Constantly*. Items were examined separately, and scores were reverse coded so that higher values reflect more frequent social media behaviors. For these items, social media was not defined for participants. Examples of checking might include opening the social media to browse others' updates or checking likes or comments on a post. Examples of posting might include posting photos or updates on social media. To understand the quality of social media use, adolescents completed the Adolescents' Digital Technology Interactions and Importance Scale [41]. The Adolescents' Digital Technology Interactions and Importance Scale is an 18-item measure that assesses the importance of activities on social media to bridge online and offline preferences and experience, go outside one's identity in the offline environment, and social connection (eg, see what people are up to without asking them, direct message, and video chat). Given the unique importance of social connection during adolescence and the use of social media for social affordances [33], the importance of *technology for social connection* was the focus of this study (5 items). Adolescents responded to questions regarding the importance of their engagement in these activities on a 5-point Likert scale, ranging from *Not at all important* to *Extremely important*. Scores were summed for each category, with higher scores reflecting greater perceived importance. The internal consistency of the technology for the social subscale was 0.92.

Household Technology Rules

Parents reported household rules around media and technology by endorsing whether they have certain rules. For this study, the primary focus was whether a bedtime technology rule was endorsed (yes or no): "My house has rules about viewing screens around bedtime." Parents also reported whether they had rules around *screen-free* zones and *screen-free times* (yes or no). To compare specificity to bedtime rules (vs total media rules), a total score was created to reflect the total number of rules involving media access, with scores ranging from 0 to 3. Age at first smartphone use also was assessed via both parent and teen report (ie, "How old were you or your child when you received your first smart phone [a phone that is able to connect to the internet]?"), which was used as a covariate in this study.

Statistical Analyses

Descriptive analyses were first conducted using two-tailed independent *t* tests and correlations to evaluate demographic differences by age and gender. Regression analyses were conducted using R software (version 3.6; R Core Team). The analyses examined the direct relationships between the frequency of social media behaviors (checking and posting, separately) and daytime sleepiness and the importance of social media for social connection and daytime sleepiness. Given the similar patterns of findings for direct effects and the high correlation between social media checking and posting behaviors, an average score of social media frequency (posting and checking) was used for all interaction analyses to be more parsimonious. Moderation analyses were conducted to examine the interaction between social media frequency and the importance of social media. The interactions between social media (average frequency and importance, separately) and endorsement of bedtime technology rules were also tested. To determine the specificity of bedtime technology rules compared with having more rules around access to media, an interaction was included between social media and the total number of media access rules. Continuous predictors were centered before the analyses. Significant interactions for continuous variables were probed at one SD above or below the mean to reflect high and low levels of social media importance or at each level for household rules. Covariates included age, gender, and parent-reported age at first smartphone use. A total of eight regressions were conducted, and Bonferroni corrections were used to control for multiple comparisons (*P*=.006). The effect sizes (changes in r^2) were calculated for all analyses.

Results

Participants

The final sample included 4153 adolescents, with a mean age of 14.64 (SD 1.66) years. Adolescents were evenly distributed across ages of 12 to 17 and grades 6 to 12, with the majority (2177/4153, 52.42%) in grades 8 to 10. Per the study design, the sample was evenly divided by gender and reflected the demographic characteristics of the United States for ages 12 to 17 years (Table 1). The legally authorized guardians of adolescent participants included 86.01% (3572/4153) biological parents and 13.99% (581/4153) were the adolescents' foster or adoptive parents, grandparents, or other relatives or guardians. A total of 58.01% (2409/4153) of parents (inclusive of all guardians) were female, and 92.01% (3821/4153) obtained at least a high school education.

Table 1. Demographic information for the sample (N=4153)[a].

Variables	Full sample statistics
Gender, n (%)	
Female	1929 (46.45)
Male	2184 (52.59)
Nonbinary or transgender	35 (0.84)
Race, n (%)	
White	2821 (67.93)
Black or African American	608 (14.64)
Asian	210 (5.06)
American Indian, Alaska Native, Native Hawaiian, or Other Pacific Islander	130 (3.13)
Multiracial	205 (4.94)
Ethnicity, n (%)	
Hispanic or Latino	733 (17.65)
Age (years), mean (SD)	14.64 (1.66)
Grade, mean (SD)	8.58 (1.78)
Parent education, n (%)	
High school or less	249 (6)
High school or General Educational Development	782 (18.83)
Some college or associate's	1321 (31.81)
Four-year college or bachelor's	967 (23.28)
Professional degree	810 (19.5)
Sleepiness and social media behaviors, mean (SD)	
Daytime sleepiness	13.08 (6.62)
Social media checking frequency	5.00 (2.64)
Social media posting frequency	5.79 (2.38)
Technology for social importance	16.26 (5.57)
Technology access and rules	
Bedtime technology rules (yes), n (%)	1417 (34.12)
Total media access rules, mean (SD)	1.03 (1.06)
Smartphone age (parent), mean (SD)	12.36 (2.19)
Smartphone age (teen), mean (SD)	11.98 (2.01)

[a]Participant responses that were not provided or stated prefer not to say are not included in the above table.

Descriptive Results

Nearly all (3987/4153, 96%) adolescents and their parents reported that they own a smartphone. Parents and teens reported that their first smartphone use was at the age of approximately 12 years. Parents and teen reports correlated at 0.81. Of teens who owned smartphones, parents reported that 8.83% (352/3987) owned their first phone before the age of 10, 21.77% (868/3987) owned their first phone at ages 10 or 11, 41.03% (1636/3987) owned their first phone at ages 12 or 13, and 28.37% (1131/3987) owned their first phone at age ≥14 years. A total of 34.12% (1417/4153) of parents reported having rules around bedtime media or screen time, 41.15% (1709/4153) of parents reported having no media access rules, and 13.85% (575/4153) of parents reported having all three rules around media access. In addition, 23.24% (965/4153) of teens reported checking social media constantly, and approximately 12.62% (524/4153) of teens reported posting constantly. Teens' posting and checking behavior was significantly correlated (r=0.80), as were reports of interest and importance of social media use (r=0.55-0.57). Teens with parental bedtime rules had lower social media frequency of posting and checking (t_{4151}=8.94 and t_{4151}=7.33, respectively; *P*<.001) and perceived importance of social media for social connection (t_{4151}=6.85; *P*<.001). In terms of gender differences, males reported more daytime sleepiness (t_{4111}=4.10; *P*<.001) and social media behaviors (checking: t_{4111}=4.60, *P*<.001 and posting: t_{4111}=4.15, *P*<.001) than females, whereas females reported greater interest and importance of using social media for these activities than males (t_{4111}=3.58; *P*<.001). There were no differences in parents' rules around bedtime screen or media use; however, those with parental rules tended to be younger. Table 1 presents the demographic characteristics and means for the primary study variables across the sample.

Main Results

Our first study aim examined the direct effects of the frequency of social media checking and posting on daytime sleepiness. Consistent with the hypotheses, hierarchical linear regressions indicated that adolescents who checked and posted on social media more frequently had higher levels of daytime sleepiness (Table 2), covarying for age, gender, and age at first smartphone use. Social media posting and checking accounted for 7% and 8% more variance in daytime sleepiness, respectively.

For our analyses examining perceived social media importance and daytime sleepiness, we found that adolescents with greater perceived importance of social media for social interactions also reported higher levels of daytime sleepiness (Table 3), which accounted for 9% of the variance in daytime sleepiness. Among the covariates, younger adolescents and boys were also more likely to have higher levels of daytime sleepiness. Age at first smartphone use was not associated with daytime sleepiness.

For the moderation analyses, there was a significant interaction between social media frequency (average of checking and posting) and importance of social media for social interactions on daytime sleepiness (B=0.04, SE 0.007; *P*<.001), such that adolescents with more frequent social media use had higher levels of daytime sleepiness when they also had higher levels of social media importance for social interactions (B=0.76, SE 0.07; *P*<.001) than those with lower levels (B=0.29, SE 0.06; *P*<.001; Figure 1). Higher and lower levels reflect values one SD above and below the mean, respectively. The model with the interaction accounted for nearly 13% of the variance in daytime sleepiness, which is an additional 4% to 6% from prior models.

Table 2. Social media posting and checking frequency and daytime sleepiness (N=4153).

Predictors	Pediatric Daytime Sleepiness Scale	
	Estimate, B (95% CI)	*P* value[a]
Intercept	12.49 (12.21 to 12.77)	<.001
Gender (1)[b]	1.07 (0.68 to 1.46)	<.001
Age	−0.26 (−0.39 to −0.13)	<.001
Phone age[c]	−0.01 (−0.10 to 0.07)	.76
Social media posting[d]	0.70 (0.63 to 0.78)	<.001
Social media checking[d]	0.76 (0.68 to 0.84)	<.001

[a] Statistically significant (*P*<.05).

[b] Gender: 0 (female) and 1 (male).

[c] Phone age: parent-reported age of adolescent first smartphone.

[d] Social media posting and checking reflect frequency on a daily basis. Models were conducted separately, with covariate estimates similar across models.

Table 3. Social media importance and daytime sleepiness (N=4153).

Predictors	Pediatric Daytime Sleepiness Scale	
	Estimate, B (95% CI)	*P* value[a]
Intercept	12.49 (12.21 to 12.77)	<.001
Gender (1)[b]	1.06 (0.67 to 1.44)	<.001
Age	−0.26 (−0.38 to −0.13)	<.001
Phone age[c]	−0.01 (−0.09 to 0.08)	.92
Social media importance[d]	0.36 (0.33 to 0.40)	<.001

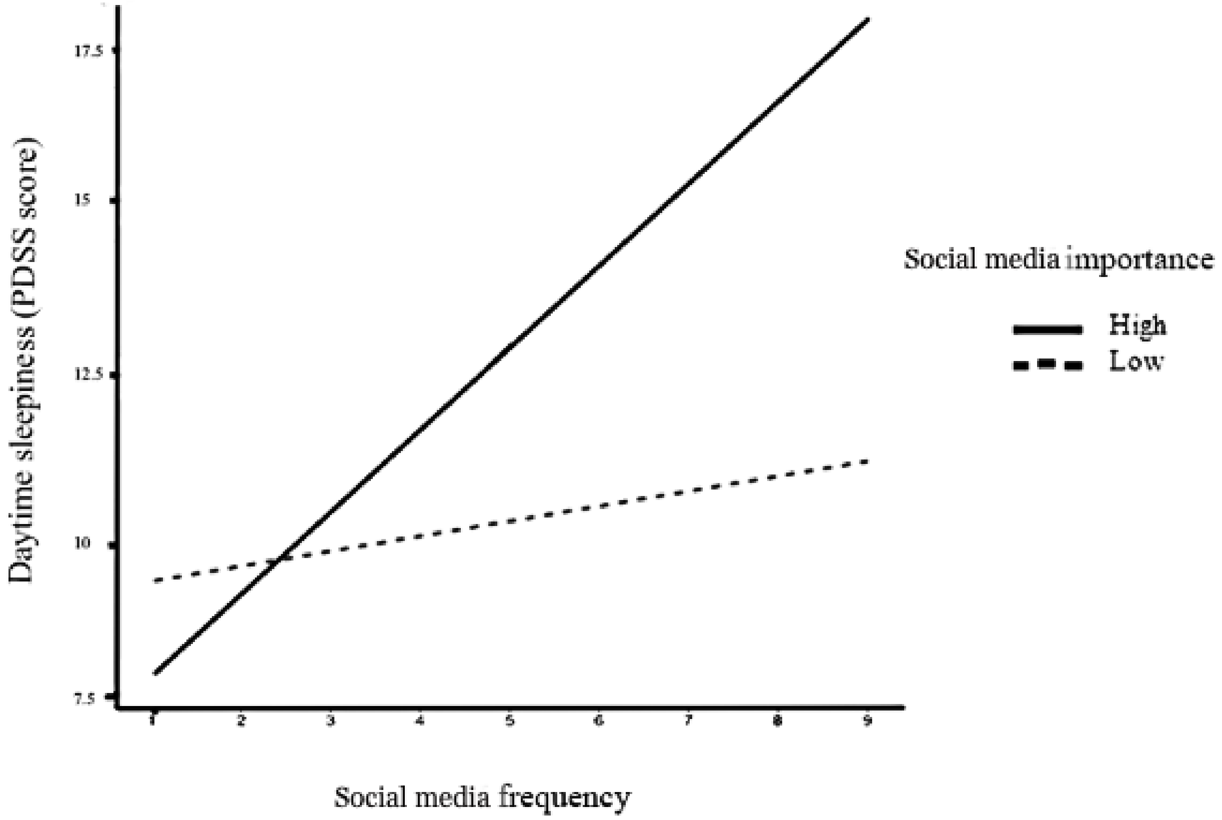
[a] Statistically significant (*P*<.05).

[b] Gender: 0 (female) and 1 (male).

[c] Parent-reported age of adolescent’s first smartphone.

[d] Social media importance is the subscale (technology for social interaction) on Adolescents’ Digital Technology Interactions and Importance Scale.

Figure 1. Effect of social media frequency on daytime sleepiness by levels of perceived social media importance. Daytime sleepiness scores were derived from the 8-item PDSS (Pediatric Daytime Sleepiness Scale).



The second moderation analysis indicated that there was a significant interaction between social media frequency and endorsement of parents’ technology rules around bedtime (B=−0.34, SE 0.09; *P*<.001). The relationship between social media frequency and daytime sleepiness was stronger for adolescents who did not have parental rules around bedtime (B=0.60, SE 0.07; *P*<.001) than for those who did have rules around bedtime (B=0.95, SE 0.05; *P*<.001; Figure 2). Similarly, there was a significant interaction between social media importance and bedtime technology rules (B=−0.16, SE 0.04; *P*<.001; Figure 3) on daytime sleepiness in the same direction.

For the moderation analyses examining specificity to bedtime technology rules, the results indicated that the interactions were not significant (with Bonferroni corrections) for social media frequency or social media importance and number of media access rules predicting daytime sleepiness.

Figure 2. Social media frequency and daytime sleepiness by bedtime technology rules. Daytime sleepiness scores were derived from the 8-item PDSS (Pediatric Daytime Sleepiness Scale).

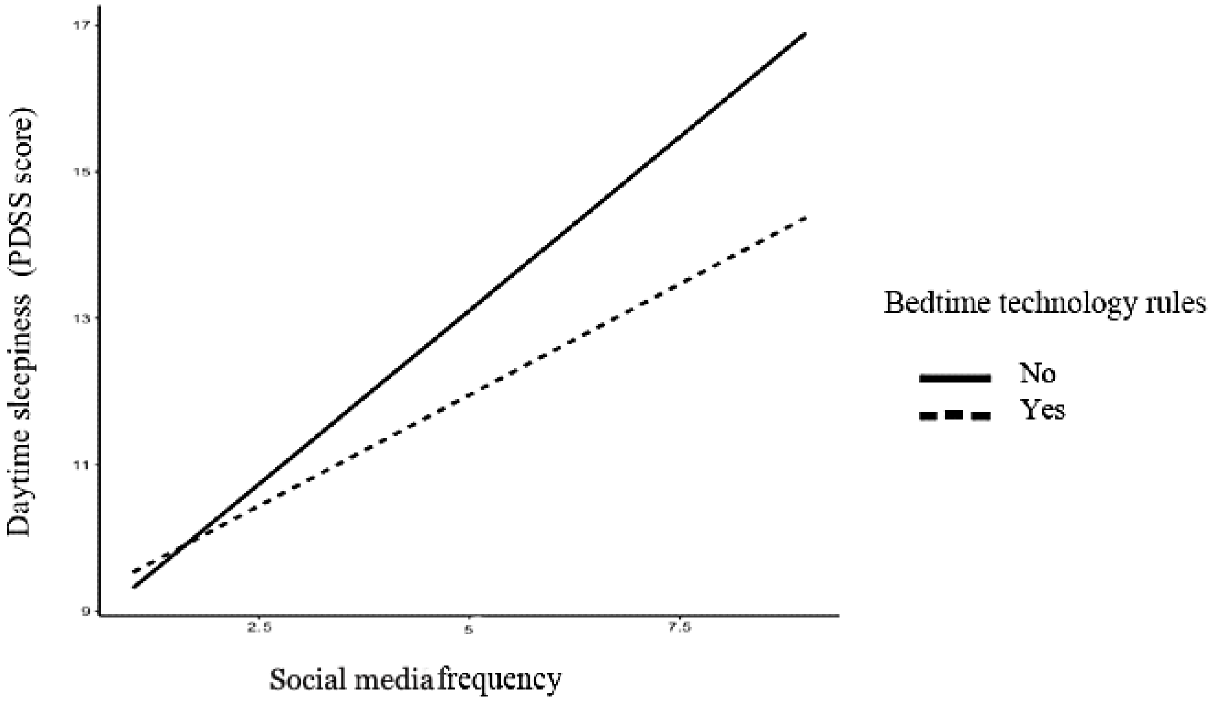
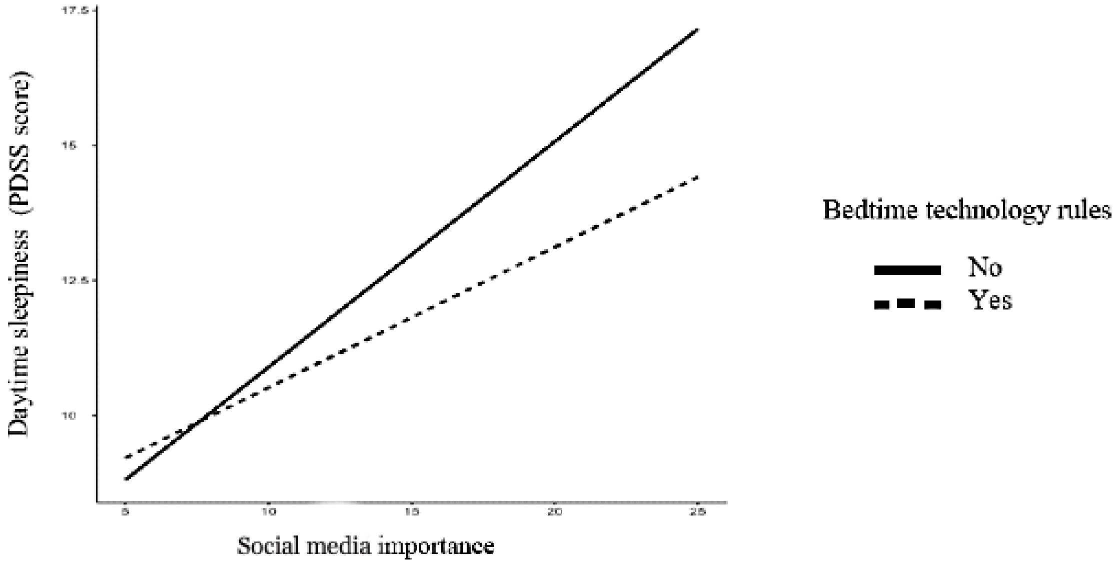


Figure 3. Social media importance and daytime sleepiness by bedtime technology rules. Daytime sleepiness scores were derived from the 8-item PDSS (Pediatric Daytime Sleepiness Scale).



Discussion

Principal Findings

Daytime sleepiness has significant consequences for adolescents' mental health [6], including depression and suicide [9]. This study examined several potentially modifiable risk factors for daytime sleepiness: youth social media behaviors and perceptions and parental bedtime media rules. The results indicate that adolescents with more frequent social media checking and posting behaviors and those who value social media for social connection had higher levels of daytime sleepiness and those with both higher levels of social media use and importance were most likely to report daytime sleepiness. Furthermore, the absence of bedtime *screentime* rules exacerbated the effects of both social media frequency and importance on daytime sleepiness. Overall, our findings identify several modifiable behaviors among youth and their parents that affect youth sleepiness, with potential implications for adolescent mental health outcomes.

It is important to first describe behaviors around social media and technology in our sample, which provides a context for our findings and future research. In a large sample of adolescents aged 12-17 years representing the demographics of adolescents in the United States, 96% (3987/4153) of adolescents had their own smartphone, which was generally obtained by the of age 12. In general, nearly 1 in 5 adolescents reported checking their phones constantly, whereas more than 1 in 10 teens reported constantly posting on social media. Adolescents with more frequent social media behaviors also tended to have a greater perceived importance of social media for social belonging. Only 34.12% (1417/4153) of parents reported having rules in their household around bedtime screen use, and a total of 41.15% (1709/4153) of parents did not endorse having any rules around screen access (eg, certain rooms or times). Importantly, youth with no parental *screentime* rules around bedtime had more frequent social media behaviors and greater importance of social media for social connection than youth with parental rules.

Our findings suggest that more frequent social media behaviors and greater importance of social media are associated with higher levels of daytime sleepiness. Importantly, youth with both more social media use and who place more emphasis on social media for social purposes have higher levels of daytime sleepiness. Thus, even among those with more frequent social media use, social media importance further exacerbates this relationship, highlighting the importance of assessing youth perceptions of social media. It is possible that these adolescents (ie, those with more frequent social media use and perceived social media importance for social affordances) are more psychosocially affected by their experiences on social media, which may lead them to use even more social media and at times that may further delay or disrupt sleep [30]. Specifically, these adolescents may fear missing out on social experiences [29] when not using social media, and social media may displace other activities that promote wakefulness, such as exercise or in-person socializing. Furthermore, these youth may use social media more at night [31] to stay connected to peers, which increases exposure to blue light and psychophysiological arousal closer to bedtime [42]. Given that adolescents with higher levels of perceived social media importance also engage in more social media checking and posting activities, these youth may be in a vicious cycle. As youth use more social media and are more affected by it, they may have more sleep problems and daytime sleepiness, which, in turn, impairs youth mood and social interactions [43,44]. Less rewarding in-person peer interactions may then heighten youth's perceptions that social media is important for social belonging, thereby contributing to a vicious cycle of acute and chronic sleepiness. Given that directionality cannot be determined from this cross-sectional study, further research is needed to examine these potential mechanisms and explore whether targeting youth social media behaviors and daytime sleepiness improves youth mental health.

Importantly, our study also examined whether parents' media rules at bedtime affected the relationship between daytime sleepiness and social media frequency and importance. Consistent with prior research on parental bedtime monitoring [36] and rules around bedtime technology use [39], the absence of *screentime* rules around bedtime exacerbated the effects of both social media frequency and importance on daytime sleepiness. Specifically, adolescents with more social media use and perceived importance had higher levels of daytime sleepiness if their parents did not have rules for bedtime technology use. These findings suggest that parents' rules at night may protect against the effects of social media on sleepiness. However, it is important to note that parents who have technology rules at bedtime may have additional bedtime rules or more parental monitoring of social media behaviors that affect sleepiness. There might also be a *third variable* of parenting or parent-child relationships influencing these associations, such as how parents themselves use and relate to social media, which may affect both enforcement of rules and teens' social media use [45]. Of note, we did not find a moderating effect of total *screentime*, suggesting specificity of bedtime media rules on social media and sleep outcomes. Future research should not only examine a greater scope of parental mediation to better understand which parenting behaviors have the greatest buffering effect on social media and specific youth outcomes but also explore other factors that moderate the association between parental rules and social media use and ultimately daytime sleepiness. For instance, it is possible that media rules at bedtime not only affect youth sleep but also protect youth from using social media in a way that exacerbates their mood and anxiety, which should be examined in future studies. However, individual differences among adolescents may affect their need for specific technology use rules; youth with poorer self-regulation may benefit more from parental rules around bedtime technology use than others [46].

Limitations

Although our study provides preliminary data suggesting the importance of examining individual and environmental factors involving social media, it is not without limitations. First, our study is cross-sectional, which limits our ability to determine causality. It is possible that adolescents with sleepiness and poor mental health may be more likely to use social media [47], and this is likely a bidirectional relationship that fuels a vicious cycle for certain youth. Second, this study did not examine sleep and circadian characteristics that likely mediate and further explain the observed associations between social media and daytime sleepiness. Future research is needed to examine these relationships using both objective and subjective methods as well as multi-informant approaches to daytime sleepiness and other sleep characteristics. Our study did not evaluate other aspects of social media, such as actual stressors or positive and negative peer interactions or adolescents' quality of peer relationships and perceived importance of social feedback more generally, which may provide more information about the specificity of the observed associations. Our study also did not define social media for youth, which might affect how teens responded to social media checking and posting questions. However, given individual differences and rapid changes in social media, capturing youth-defined posting and checking behaviors on social media may better capture youth's individual experiences. Furthermore, we did not examine youth pubertal development, which may affect youth perception and engagement in social media [48] and daytime sleepiness [5]. Thus, it is important to consider puberty and explore potential gender differences in these associations. Although our study examined whether parents had bedtime rules around technology use, we did not test the enforcement or effectiveness of these rules, which is an important extension of this study. Finally, our study did not assess whether sleepiness was associated with poor mental health outcomes, which is critical in further highlighting the importance of this study in mental health prevention efforts.

Conclusions

The findings from this study provide initial support for the associations between daytime sleepiness and both social media use and perceived importance of social interactions in a large, nationally representative sample of adolescents. Although specific to daytime sleepiness, our results have important implications for adolescent mental health more broadly. First, daytime sleepiness is significantly associated with and prospectively predicts youth mental health problems [1], including depression and suicide [9], which are major public health crises. Second, this study highlights the importance and potential clinical relevance of targeting social media use and advances our understanding of which youth may be most at risk for negative effects of social media (eg, those who highly value social media use for social belonging), which may also extend to other mental health outcomes. Finally, our study indicates the importance of parental rules around media use on youth behaviors and outcomes, which suggests that parenting behaviors may affect how and in what ways youth use social media and its potential effects on their mental health. Thus, parents and youth providers (eg, clinicians, school counselors, and educators) should consider discussing parental rules around technology use with families, particularly around bedtime. Given that parenting rules are modifiable, these results may have important implications for interventions aimed at improving social media use and protecting adolescents from its negative effects on mental health. Although preliminary, these findings may be beneficial for researchers and clinicians in the development and implementation of prevention and intervention programs for social media, sleep, and mental health.

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Authors' Contributions

JLH conceived the current aims of this study, conducted the data analysis, and drafted the manuscript. WL helped draft and review the manuscript.

Conflicts of Interest

None declared.

References

1. Owens JA, Weiss MR. Insufficient sleep in adolescents: causes and consequences. Minerva Pediatr 2017 Aug;69(4):326-336. [doi: 10.23736/S0026-4946.17.04914-3] [Medline: 28211649]
2. Chung K, Cheung M. Sleep-wake patterns and sleep disturbance among Hong Kong Chinese adolescents. Sleep 2008 Feb;31(2):185-194 [FREE Full text] [doi: 10.1093/sleep/31.2.185] [Medline: 18274265]
3. Gibson ES, Powles ACP, Thabane L, O'Brien S, Molnar DS, Trajanovic N, et al. "Sleepiness" is serious in adolescence: two surveys of 3235 Canadian students. BMC Public Health 2006 May 02;6:116 [FREE Full text] [doi: 10.1186/1471-2458-6-116] [Medline: 16670019]
4. Gradisar M, Gardner G, Dohnt H. Recent worldwide sleep patterns and problems during adolescence: a review and meta-analysis of age, region, and sleep. Sleep Med 2011 Feb;12(2):110-118. [doi: 10.1016/j.sleep.2010.11.008] [Medline: 21257344]
5. Liu Y, Zhang J, Li SX, Chan NY, Yu MW, Lam SP, et al. Excessive daytime sleepiness among children and adolescents: prevalence, correlates, and pubertal effects. Sleep Med 2019 Jan;53:1-8. [doi: 10.1016/j.sleep.2018.08.028] [Medline: 30384136]
6. Millman RP, Working Group on Sleepiness in Adolescents/Young Adults, AAP Committee on Adolescence. Excessive sleepiness in adolescents and young adults: causes, consequences, and treatment strategies. Pediatrics 2005 Jun;115(6):1774-1786. [doi: 10.1542/peds.2005-0772] [Medline: 15930245]
7. Yang B, Choe K, Park Y, Kang Y. Associations among daytime sleepiness, depression and suicidal ideation in Korean adolescents. Int J Adolesc Med Health 2017 Jun 09;31(2):0161. [doi: 10.1515/ijamh-2016-0161] [Medline: 28598800]
8. Moore M, Kirchner HL, Drotar D, Johnson N, Rosen C, Ancoli-Israel S, et al. Relationships among sleepiness, sleep time, and psychological functioning in adolescents. J Pediatr Psychol 2009;34(10):1175-1183 [FREE Full text] [doi: 10.1093/jpepsy/jsp039] [Medline: 19494088]

9. Liu X, Liu Z, Wang Z, Yang Y, Liu B, Jia C. Daytime sleepiness predicts future suicidal behavior: a longitudinal study of adolescents. Sleep 2019 Feb 01;42(2):225. [doi: 10.1093/sleep/zsy225] [Medline: 30445534]
10. WISQARS™ — Web-based Injury Statistics Query and Reporting System. Centers for Disease Control and Prevention: Injury Prevention & Control. URL: https://www.cdc.gov/injury/wisqars/index.html [accessed 2021-06-21]
11. Hagenauer MH, Perryman JI, Lee TM, Carskadon MA. Adolescent changes in the homeostatic and circadian regulation of sleep. Dev Neurosci 2009;31(4):276-284 [FREE Full text] [doi: 10.1159/000216538] [Medline: 19546564]
12. Carskadon MA. Sleep in adolescents: the perfect storm. Pediatr Clin North Am 2011 Jun;58(3):637-647 [FREE Full text] [doi: 10.1016/j.pcl.2011.03.003] [Medline: 21600346]
13. Colrain IM, Baker FC. Changes in sleep as a function of adolescent development. Neuropsychol Rev 2011 Mar;21(1):5-21 [FREE Full text] [doi: 10.1007/s11065-010-9155-5] [Medline: 21225346]
14. Cain N, Gradisar M. Electronic media use and sleep in school-aged children and adolescents: a review. Sleep Med 2010 Sep;11(8):735-742. [doi: 10.1016/j.sleep.2010.02.006] [Medline: 20673649]
15. Hale L, Guan S. Screen time and sleep among school-aged children and adolescents: a systematic literature review. Sleep Med Rev 2015 Jun;21:50-58. [doi: 10.1016/j.smrv.2014.07.007] [Medline: 25193149]
16. Twenge JM, Hisler GC, Krizan Z. Associations between screen time and sleep duration are primarily driven by portable electronic devices: evidence from a population-based study of U.S. children ages 0-17. Sleep Med 2019 Apr;56:211-218. [doi: 10.1016/j.sleep.2018.11.009] [Medline: 30639033]
17. Varghese NE, Santoro E, Lugo A, Madrid-Valero JJ, Ghislandi S, Torbica A, et al. The role of technology and social media use in sleep-onset difficulties among Italian adolescents: cross-sectional study. J Med Internet Res 2021 Jan 21;23(1):e20319 [FREE Full text] [doi: 10.2196/20319] [Medline: 33475517]
18. Choi K, Son H, Park M, Han J, Kim K, Lee B, et al. Internet overuse and excessive daytime sleepiness in adolescents. Psychiatry Clin Neurosci 2009 Aug;63(4):455-462 [FREE Full text] [doi: 10.1111/j.1440-1819.2009.01925.x] [Medline: 19490510]
19. Mak YW, Wu CS, Hui DW, Lam SP, Tse HY, Yu WY, et al. Association between screen viewing duration and sleep duration, sleep quality, and excessive daytime sleepiness among adolescents in Hong Kong. Int J Environ Res Public Health 2014 Oct 28;11(11):11201-11219 [FREE Full text] [doi: 10.3390/ijerph111111201] [Medline: 25353062]
20. Munezawa T, Kaneita Y, Osaki Y, Kanda H, Minowa M, Suzuki K, et al. The association between use of mobile phones after lights out and sleep disturbances among Japanese adolescents: a nationwide cross-sectional survey. Sleep 2011 Aug 01;34(8):1013-1020 [FREE Full text] [doi: 10.5665/SLEEP.1152] [Medline: 21804663]
21. Nathan N, Zeitzer J. A survey study of the association between mobile phone use and daytime sleepiness in California high school students. BMC Public Health 2013 Sep 12;13:840 [FREE Full text] [doi: 10.1186/1471-2458-13-840] [Medline: 24028604]
22. Polos PG, Bhat S, Gupta D, O'Malley RJ, DeBari VA, Upadhyay H, et al. The impact of Sleep Time-Related Information and Communication Technology (STRICT) on sleep patterns and daytime functioning in American adolescents. J Adolesc 2015 Oct;44:232-244. [doi: 10.1016/j.adolescence.2015.08.002] [Medline: 26302334]
23. Choukas-Bradley S, Prinstein MJ. Peer Relationships and the Development of Psychopathology. In: Lewis M, Rudolph KD, editors. Handbook of Developmental Psychopathology. Boston, MA: Springer; 2014:185-204.
24. Guyer AE, Choate VR, Pine DS, Nelson EE. Neural circuitry underlying affective response to peer feedback in adolescence. Soc Cogn Affect Neurosci 2012 Jan;7(1):81-92 [FREE Full text] [doi: 10.1093/scan/nsr043] [Medline: 21828112]
25. Silk JS, Stroud LR, Siegle GJ, Dahl RE, Lee KH, Nelson EE. Peer acceptance and rejection through the eyes of youth: pupillary, eyetracking and ecological data from the Chatroom Interact task. Soc Cogn Affect Neurosci 2012 Jan;7(1):93-105 [FREE Full text] [doi: 10.1093/scan/nsr044] [Medline: 21775386]
26. de la Torre JA, Puigdomenech E, García X, Valderas JM, Eiroa-Orosa FJ, Fernández-Villa T, et al. Relationship between depression and the use of mobile technologies and social media among adolescents: umbrella review. J Med Internet Res 2020 Aug 26;22(8):e16388 [FREE Full text] [doi: 10.2196/16388] [Medline: 32663157]
27. Harbard E, Allen NB, Trinder J, Bei B. What's keeping teenagers up? Prebedtime behaviors and actigraphy-assessed sleep over school and vacation. J Adolesc Health 2016 Apr;58(4):426-432. [doi: 10.1016/j.jadohealth.2015.12.011] [Medline: 26874590]
28. Scott H, Biello SM, Woods HC. Identifying drivers for bedtime social media use despite sleep costs: the adolescent perspective. Sleep Health 2019 Dec;5(6):539-545 [FREE Full text] [doi: 10.1016/j.sleh.2019.07.006] [Medline: 31523005]
29. Scott H, Woods HC. Fear of missing out and sleep: cognitive behavioural factors in adolescents' nighttime social media use. J Adolesc 2018 Oct;68:61-65. [doi: 10.1016/j.adolescence.2018.07.009] [Medline: 30031979]
30. Scott H, Woods HC. Understanding links between social media use, sleep and mental health: recent progress and current challenges. Curr Sleep Medicine Rep 2019 Jul 13;5(3):141-149. [doi: 10.1007/s40675-019-00148-9]
31. Nasirudeen AM, Adeline LL, Josephine KW, Seng LL, Wenjie L. Impact of social media usage on daytime sleepiness: a study in a sample of tertiary students in Singapore. Digit Health 2017;3:2055207617699766 [FREE Full text] [doi: 10.1177/2055207617699766] [Medline: 29942584]

32. van der Schuur WA, Baumgartner SE, Sumter SR. Social media use, social media stress, and sleep: examining cross-sectional and longitudinal relationships in adolescents. Health Commun 2019 May;34(5):552-559. [doi: 10.1080/10410236.2017.1422101] [Medline: 29313723]
33. Moreno MA, Uhls YT. Applying an affordances approach and a developmental lens to approach adolescent social media use. Digit Health 2019;5:2055207619826678 [FREE Full text] [doi: 10.1177/2055207619826678] [Medline: 30746154]
34. Hamilton JL, Coulter R, Radovic A. Mental health benefits and opportunities. In: Moreno MA, Hoopes AJ, editors. Technology and Adolescent Health. Amsterdam: ScienceDirect; 2020:305-345.
35. Laursen B, Coy KC, Collins WA. Reconsidering changes in parent-child conflict across adolescence: a meta-analysis. Child Dev 1998 Jun;69(3):817-832 [FREE Full text] [Medline: 9680687]
36. Short MA, Gradisar M, Wright H, Lack LC, Dohnt H, Carskadon MA. Time for bed: parent-set bedtimes associated with improved sleep and daytime functioning in adolescents. Sleep 2011 Jun 01;34(6):797-800 [FREE Full text] [doi: 10.5665/SLEEP.1052] [Medline: 21629368]
37. Meijer AM, Reitz E, Deković M. Parenting matters: a longitudinal study into parenting and adolescent sleep. J Sleep Res 2016 Oct;25(5):556-564 [FREE Full text] [doi: 10.1111/jsr.12406] [Medline: 27178659]
38. Pyper E, Harrington D, Manson H. Do parents' support behaviours predict whether or not their children get sufficient sleep? A cross-sectional study. BMC Public Health 2017 May 24;17(1):432 [FREE Full text] [doi: 10.1186/s12889-017-4334-4] [Medline: 28535759]
39. Bowers JM, Moyer A. Adolescent sleep and technology-use rules: results from the California Health Interview Survey. Sleep Health 2020 Feb;6(1):19-22 [FREE Full text] [doi: 10.1016/j.sleh.2019.08.011] [Medline: 31732441]
40. Drake C, Nickel C, Burduvali E, Roth T, Jefferson C, Pietro B. The pediatric daytime sleepiness scale (PDSS): sleep habits and school outcomes in middle-school children. Sleep 2003 Jun 15;26(4):455-458. [Medline: 12841372]
41. Moreno MA, Binger K, Zhao Q, Eickhoff J. Measuring interests not minutes: development and validation of the adolescents' digital technology interactions and importance scale (ADTI). J Med Internet Res 2020 Feb 12;22(2):e16736 [FREE Full text] [doi: 10.2196/16736] [Medline: 32049068]
42. LeBourgeois MK, Hale L, Chang A, Akacem LD, Montgomery-Downs HE, Buxton OM. Digital media and sleep in childhood and adolescence. Pediatrics 2017 Nov;140(Suppl 2):92-96 [FREE Full text] [doi: 10.1542/peds.2016-1758J] [Medline: 29093040]
43. Beattie L, Kyle SD, Espie CA, Biello SM. Social interactions, emotion and sleep: a systematic review and research agenda. Sleep Med Rev 2015 Dec;24:83-100 [FREE Full text] [doi: 10.1016/j.smrv.2014.12.005] [Medline: 25697832]
44. Gordon AM, Mendes WB, Prather AA. The social side of sleep: elucidating the links between sleep and social processes. Curr Dir Psychol Sci 2017 Oct;26(5):470-475 [FREE Full text] [doi: 10.1177/0963721417712269] [Medline: 29398789]
45. Lauricella AR, Wartella E, Rideout VJ. Young children's screen time: the complex role of parent and child factors. J Appl Dev Psychol 2015 Jan;36:11-17. [doi: 10.1016/j.appdev.2014.12.001]
46. Clifford S, Doane LD, Breitenstein R, Grimm KJ, Lemery-Chalfant K. Effortful control moderates the relation between electronic-media use and objective sleep indicators in childhood. Psychol Sci 2020 Jul 19;31(7):822-834. [doi: 10.1177/0956797620919432] [Medline: 32558622]
47. Mazzer K, Bauducco S, Linton SJ, Boersma K. Longitudinal associations between time spent using technology and sleep duration among adolescents. J Adolesc 2018 Jul;66:112-119. [doi: 10.1016/j.adolescence.2018.05.004] [Medline: 29842997]
48. Crone EA, Konijn EA. Media use and brain development during adolescence. Nat Commun 2018 Feb 21;9(1):588 [FREE Full text] [doi: 10.1038/s41467-018-03126-x] [Medline: 29467362]

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Original Paper

Investigating Mental Health Service User Opinions on Clinical Data Sharing: Qualitative Focus Group Study

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Abstract

Background: Sharing patient data can help drive scientific advances and improve patient care, but service users are concerned about how their data are used. When the National Health Service proposes to *scrape* general practitioner records, it is very important that we understand these concerns in some depth.

Objective: This study aims to investigate views of mental health service users on acceptable data sharing to provide clear recommendations for future data sharing systems.

Methods: A total of 4 focus groups with 4 member-checking groups were conducted via the internet between October 2020 and March 2021, with a total of 22 service users in the United Kingdom. Thematic analysis was used to identify the themes.

Results: Six main themes, with several subthemes were identified, such as the *purpose* of data sharing—for profit, public good, and continuation of care; *discrimination* through the misattribution of physical symptoms to mental health conditions (ie, diagnostic overshadowing) alongside the discrimination of individuals or groups within society (ie, institutional discrimination); *safeguarding* data by preserving anonymity and confidentiality, strengthening security measures, and holding organizations accountable; data *accuracy* and *informed consent*—increasing transparency about data use and choice; and incorporating *service user involvement* in system governance to provide insight and increase security.

Conclusions: This study extends the limited research on the views and concerns of mental health service users regarding acceptable data sharing. If adopted, the recommendations should improve the confidence of service users in sharing their data. The five recommendations include screening to ensure that data sharing benefits the public, providing service users with information about how their data are shared and what for, highlighting the existing safeguarding procedures, incorporating service user involvement, and developing tailored training for health care professionals to address issues of diagnostic overshadowing and inaccurate health records. Adopting such systems would aid in data sharing for legitimate interests that will benefit patients and the National Health Service.

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KEYWORDS

clinical data; data sharing; mental health data; service users; focus groups; mental health; digital health; health records

Introduction

Background

Patient-level clinical data are increasingly recognized as a valuable resource that can help drive scientific advances and innovations to improve patient care [1]. Global initiatives actively promote and enable data sharing, and in research, most funders mandate researchers to plan for sharing their data [2-4]. However, to facilitate responsible data sharing, we need to develop systems that work for all stakeholders, and mental health service users need to be central to these developments. We already know that people with depression, epilepsy, and multiple sclerosis all have concerns about how their data would and should be used in health services [5-9]; however, these have not been explored in depth, and we do not know what service users consider to be acceptable limits for sharing their data. As the National Health Service (NHS) currently plans to scrape data from general practitioner practices [10], any concerns are likely to affect the legitimacy of such actions and potentially undermine the trust of mental health service users.

The Academy of Medical Sciences published a report on harnessing NHS data for future health benefits together with a dialogue report of conversations with NHS patients and the public on data use [11,12]. One challenge that surfaced is the continued protection of privacy, a particular concern for mental health service users [13]. The report also highlighted the balance between maintaining confidence in safeguarding data and enabling appropriate access to data-driven technologies. Many principles of data sharing are important for patients and the public, but there is considerable sensitivity among those with mental health problems because of stigma and discrimination [14]. There were few such individuals in the data dialogue study [11], but even when these individuals were asked or when others commented on mental health case studies, more skepticism was exhibited.

A previous qualitative study that investigated the views of service users about sharing administrative data [15] found that participants were largely comfortable sharing health records, including sensitive mental health data, with organizations that they trust. Trust was contingent on high transparency (ie, clarity on how this information would be shared and used), service user autonomy (ie, the ability of service users to have a say in the sharing of their data), and adequate security (ie, guarantees that the data shared would be adequately protected). However, this was a very small study (N=8); therefore, the themes reported are not generally applicable to the mental health population because of the geographic, age, and size limitations of their sample [15].

Objectives

There are various accepted data sharing and use models that exist domestically and internationally, but the technological landscape for data to be shared, integrated, and analyzed is constantly evolving. Therefore, there is a clear need for the views of service users to be represented in the development and governance of future data storage and use systems. This study investigates service user views to demarcate the boundaries of acceptable data use and sharing and provide clear recommendations for future systems.

Methods

Design

This is a qualitative study with focus groups conducted virtually between October 15, 2020, and March 15,2021, using a videoconferencing software (Microsoft Teams) because of COVID-19. Focus groups followed a topic guide that contained open questions on sharing clinical data and their views on how systems should be developed to ensure that future data sharing initiatives are ethical and efficient. Each focus group was also followed with a member-checking focus group [16], to view the initial data analysis.

Recruitment

Participants were eligible if they were aged at least 18 years and had experience using mental health services. Participants needed internet or phone access and were excluded if they were unable to provide informed consent. They were recruited through purposive sampling via existing patient involvement groups and a research register (Consent for Contact) held by the South London and Maudsley NHS Foundation Trust (SLaM).

Focus Groups

The *topic guide* was based on previous data sharing research [15] and was expanded to include other issues that became apparent with changes in technology. The guide explored what participants thought about different data sharing models; how participants felt about their clinical data being shared with other hospitals, universities, government organizations, and companies; specific concerns about data sharing; how data can be shared (eg, raw data or aggregated summary data); their boundaries for what information can be shared; and how their trust can be earned about how their data are shared.

Participants were provided with a summary paper outlining current data sharing systems to provide background to the topic (Multimedia Appendix 1). This was referred to and summarized at the start of each focus group to ensure that participants had the same baseline prerequisite knowledge. In brief, the summary sheet includes the following information:

1. *NHS Digital's Hospital Episode Statistics* data, which contain more than 1 billion records of patient service attendances across hospitals commissioned by England's NHS Clinical Commissioning Groups [17].
2. The *Clinical Record Interactive Search* (CRIS) system, which provides authorized researchers with regulated access to anonymized patient-level data that are extracted from the SLaM electronic clinical records system. CRIS was developed with service user input on data protection issues, and applications were reviewed by a CRIS oversight committee, chaired by a service user. All data remained within the NHS firewall [18,19].

We also discussed the following potential adaptations to the CRIS data sharing system:

1. Extending CRIS by amalgamating data with other NHS trusts to provide a larger database so we can ask more questions. The data would be anonymous, and access will be governed by a committee as in the SLaM CRIS system. In this model, the data are outside the NHS firewall.
2. Developing separate CRIS databases within each individual NHS trust. These data would also be anonymous and follow similar rules as that of the SLaM CRIS system; however, the data would still be accessible within the NHS firewall of each NHS trust.

Each focus group lasted up to 2 hours, and each member-checking group lasted up to 1 hour; they were all digitally recorded using Microsoft Teams, and the recordings were transcribed manually.

Procedure

The study was approved by the East of the Scotland Research Ethics Committee (ref. 20/ES/0004). Participants provided written informed consent and their self-reported clinical and demographic characteristics before each of the 2 focus groups. The first focus group discussed acceptable data sharing, which was then analyzed to identify relevant themes and construct an initial thematic map. The second *member-checking* group considered the thematic map and provided feedback as a check that service users agreed with the emerging themes. Participants were reimbursed for their participation, and researchers supported the participants' well-being and welfare throughout the study.

Data Analysis

Data collection continued until we reached data saturation, which was established by a review of the summary findings from each focus group (Multimedia Appendix 2) [20]. We used thematic analysis, following the six stages prescribed by Braun and Clarke [21]:

- Stage 1: The focus group recordings were manually transcribed to facilitate data immersion, and the recordings were listened to multiple times to ensure accurate transcription.
- Stage 2: Two service user researchers independently coded the data using an inductive coding approach.
- Stage 3: Once the initial codes were developed, potential themes were identified by combining codes to produce thematic maps.
- Stage 4: These themes were reviewed to establish relevance to the research question and ensure that they were coherent and distinctive. Any themes that were not supported with sufficient data or deemed too discrete were discarded.
- Stage 5: Relevant themes were clearly defined and named and then combined into a final thematic map.
- Stage 6: Relevant extracts from the transcripts were chosen to illustrate each theme. NVivo 12 software (QSR International) was used to manage and code the data.

Results

Sample Characteristics

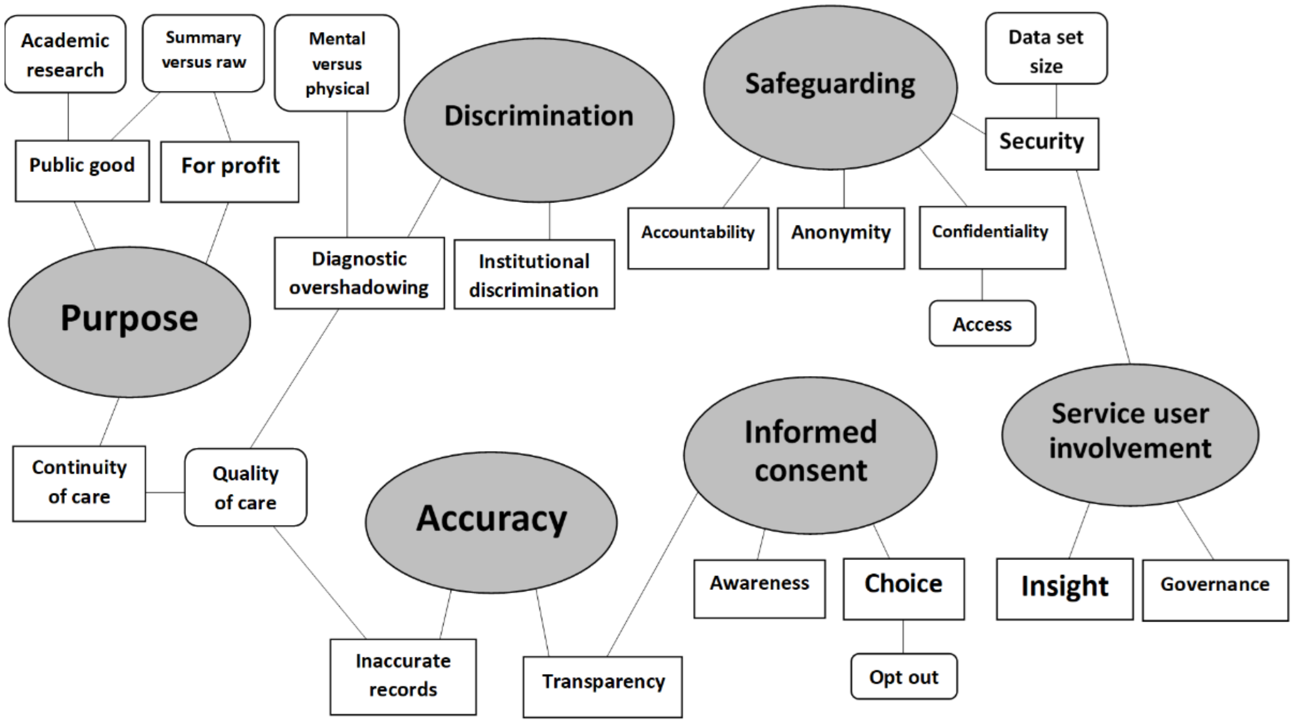
A total of 22 people aged between 21 and 74 years (mean 45.04, SD 16.29 years) participated. The majority were women (15/22, 68%), and we had a diverse sample with only 55% (12/22) White British. The remaining samples were White European, Asian or Asian British, Black or Black British, or mixed White and Black Caribbean. Of the total participants, 91% (20/22) were diagnosed with a mental health condition (eg, depression or anxiety) and 64% (14/22) were educated to the degree level. Approximately 68% (15/22) of the participants resided in London (Southeast England), and the remaining participants lived in different regions of England (eg, West Midlands, East Midlands, and Southwest England).

Themes

Overview

Each theme and subtheme included in the final thematic map was discussed in at least two of the 4 focus groups (Multimedia Appendix 2). Figure 1 illustrates a summary of the six main themes and 22 subthemes. Service users found some existing models acceptable (eg, SLaM's CRIS system) [18] because service users were involved in their development. Despite accepting this model, there were conflicting opinions about pooling data across different NHS trusts versus each NHS trust establishing their own CRIS-style data sharing system. Service users were concerned about the impact on security and diagnostic overshadowing (ie, where health care professionals appeared to dismiss their physical illnesses when made aware of their mental health diagnosis [22]), if CRIS was extended across NHS trusts, but they recognized the benefit of continuity of care. We subsequently describe each theme in detail.

Figure 1. Thematic map showing six main themes and 22 subthemes.



Purpose

Service users expressed that they felt uncomfortable with their data being shared with commercial companies that used this information for their own financial gain, that is, *for profit*:

> *The concept of selling people's data to a company for profit is completely unacceptable.* [Participant 21]

However, service users were comfortable sharing data that contributed to *the public good*, such as *academic research*:

> *I feel quite comfortable about researchers and letting universities access it because I feel like the intention is to see health trends and to do good.* [Participant 3]

Although service users generally found data sharing within the NHS acceptable and in line with the *public good* narrative, they did acknowledge that there was some skepticism because of the increasing privatization. However, it could be argued that the skepticism was because of NHS privatization in general, rather than solely in the context of data sharing:

> *Because of all this privatization of the NHS, which is very concerning for most of us, I signed a petition last week, because 49 GP surgeries have been sold to an American health insurance company. So that to me is very concerning.* [Participant 21]

The extent to which service users were comfortable with organizations having access to *summary versus raw data* (or aggregated vs patient-level data) was also dependent on the purpose. Generally, service users felt it was more appropriate for summary data only to be provided when data were shared for profit, but when data were shared to benefit the public, service users voiced that organizations should have access to raw data to maximize use:

> *I would prefer summary [data] because companies like Google - the more information they have, they exploit it. So, I would say a summary can still help them to do research if they need to.* [Participant 4]

It was also felt that sharing data to facilitate *continuity of care* for patients in health care settings was acceptable and could improve the *quality of care* service users received:

> *I couldn't agree more with what you just said for continuity purposes. For example, ...you end up in another city, then you would hope they have access to the medical information - know what drugs you are on and so on so they can treat you quickly and correctly.* [Participant 2]
>
> *...data sharing is quite important in terms of improving services or reducing the amount of time you have to keep explaining to different people about who you are, what you are, what you're doing.* [Participant 9]

Service users suggested that extending CRIS and having data from different NHS trusts collated in one place could be beneficial for continuity of care in health care settings:

> *...if you're accessing different hospitals and then there's not an exchange of information, sometimes you can think there's no continuity.* [Participant 3]

Discrimination

Within health care settings, service users recounted experiencing *diagnostic overshadowing*:

> *I have been basically stigmatized and dismissed when attending A&E for physical health concerns because they saw my mental health diagnosis. So, often in that situation, I wish it worked separately.* [Participant 2]

Service users believed that data sharing within health care settings could also be detrimental to the *quality of care* when discriminatory beliefs or actions were present. As a result, service users were more comfortable with their *physical health data being shared than their mental health data*:

> *People with mental health conditions generally get poorer physical health care as they are often not believed...so many of us with mental health histories would prefer clinicians who are treating our physical ailments not to know about our mental health.* [Participant 13]
>
> *...there's a discrepancy between physical health and mental health for me personally...I don't really mind if somebody knew that I'd broken my leg, for example, but actually I would mind if somebody knew that I went to see a doctor about my mental health.* [Participant 3]

Service users also voiced concerns that were centered on discrimination toward individuals or groups in society, that is, *institutional discrimination*. It was felt that data sharing could lead to people being scapegoated or restricted from doing or receiving certain things, given the historical discrimination (eg, with Romani and gay communities):

> *Well it [the data] could be used, I suppose to stigmatise people or to prevent people from having, for example, the benefits that they are entitled to...* [Participant 1]
>
> *Research was done into lots of communities, not just the Jewish community; Romani communities and lots of other communities in which the purpose wasn't for the benefit of science. It was to discriminate...so lots of Romani people today feel very reluctant about giving information because they're scared about where it may go.* [Participant 7]

Accuracy

Service users reported having *inaccurate clinical records* and the negative impact that this had on their *quality of care*:

> *I do worry of false information that is there, that might have been entered years ago and nobody ever bothered to check...because it's simply inaccurate.* [Participant 2]

To address this, service users wanted more *transparency* from health care professionals regarding the content of their clinical notes. They wanted the opportunity to view their records to check that the information was accurate and if it was found to be inaccurate, to either have this amended or their disagreement noted in their records:

> *I mean for me it's even more important that I had chance to regularly look at that information and check that it's the correct information.* [Participant 1]

Informed Consent

It was felt that there needed to be more *transparency* from organizations about what the data were being used for:

> *I think that people need to feel that their data is being used correctly. So, I think that they have to be more open and say we will use your data for this...* [Participant 19]

They also discussed the need to increase *awareness* among service users about the data sharing process, as not all service users were aware that their data could be shared this way:

> *I think it's really important that everybody, like every member of the public, knows that their data can be accessed because I didn't personally know that a researcher could access it in that way until I was doing this.* [Participant 3]

Furthermore, service users wanted to have a *choice* in the sharing of their data after being appropriately informed, including the option to *opt out* of data sharing if they were not comfortable:

> *Just give the choice to the patient to decide which information to give out.* [Participant 10]

Safeguarding

This theme considers the importance of storing and sharing data securely. Service users discussed the need to maintain *confidentiality*, with more consideration of who has *access* to sensitive data and preserving service user *anonymity* when sharing data:

> *...there might be a few things that you really need to share with the GP or a professional to see why you're feeling the way you're feeling or what's causing you the mental health issues or physical health issues, but you don't really want anyone else to read certain parts.* [Participant 9]
>
> *I think as long as it's anonymized, that's fine.* [Participant 19]

Service users were concerned about the *security* of data systems and the increased risk to security with a *larger data set*. For this reason, there was some hesitancy about expanding the CRIS system to pool all the data from different NHS trusts into one place:

> *I think in general it's best not to put all your eggs in one basket [with the third CRIS model] and there is more of a security risk from pulling everything together. It also makes it much more likely to be the target of an attack.* [Participant 13]
>
> *...the bigger it gets, the more I trust that the data wouldn't be secure.* [Participant 17]

It was felt that organizations needed to be held *accountable* for adhering to *safeguarding* protocols; if these protocols were breached, organizations should be penalized, and service users should be appropriately compensated:

> *...very much falls on the organisations to be accountable for making sure that they are adhering to data protection, GDPR, data storage, data sensitivity.* [Participant 9]
>
> *...it would have to be a significant compensation measure for a person who potentially could have their*

> *lives ruined by a data leak and if that was in place, I'd probably feel a lot more trusting of it [data sharing], and more free with the idea of that going ahead.* [Participant 18]

Service User Involvement

There was a particular emphasis on service users being involved in the *governance* of data sharing systems, as is currently the case within the CRIS data sharing model. Service users felt that there was a need for a service user perspective to provide invaluable *insight* and make people feel more *secure* in sharing their data:

> *I would want service users to be involved in some of that governance.* [Participant 1]
>
> *When you talk about CRIS and how the data are protected, I think it's wonderful that you're using it chaired by a service user and service user input is very valid throughout the protection system.* [Participant 14]
>
> *...in terms of an additional security measure, you've got a group of trusted people [service users] who decide on what to do with the request...* [Participant 18]

Discussion

Principal Findings

Trust has again been identified as a key component to effective engagement in research and health care settings [23]. Service users were hesitant about sharing data with commercial companies as they were mistrustful of their intentions, which were largely believed to be unethical and purely for profit. Currently, there is a limited sharing of data to commercial companies directly [24], although some commercial companies do register potential customers as pharmaceutical companies and medical device services.

Service users felt more comfortable sharing sensitive data within the NHS and with academic institutions as they had more confidence that the information would be used for public benefit, which mirrors the existing literature [11,15]. However, they also mentioned that increasing NHS privatization was beginning to affect their trust [25,26].

Service user trust is contingent on high transparency and service user autonomy [15], which was mirrored in our data, especially choice in the sharing of their data after learning how it is to be used. The current plan for data scraping and sharing by the NHS is being rolled out quietly and with little publicity. Although this is not suspicious, the lack of transparency is likely to undermine the confidence and reduce the overall worth of the data if many people decide to opt out. We recommend that future systems incorporate comprehensive screening processes to ensure that data sharing between organizations benefits the public and provides service users with adequate information about how their data are shared, and what for, to enable them to make an informed choice.

This concept of transparency can also be applied to health care settings. Service users wanted health care professionals to be more transparent with them about the content of their clinical notes, to resolve concerns about inaccurate health care records. Solutions proposed by service users in our study included ensuring that information is double-checked with patients before entering it and allowing service users to frequently view their health care records and dispute inaccuracies. Transparent medical records enhance trust, improve relationships with professionals, and increase understanding of health information [27,28]; however, there are concerns about service users reacting negatively to their content because of misinterpretation or misunderstanding, which could result in mistrust of health care professionals [28]. For transparency to be effective, the information within health care records must be communicated effectively and understood by the service user. We recommend increasing the transparency of clinical records and developing bespoke training for health care professionals in clinical data input and the communication of clinical information.

Discrimination within health care settings can have a negative effect on people's trust in the health care system [29]. Existing studies indicate heightened skepticism about data sharing among individuals with mental health problems [11]. This is because of the stigma and discrimination experienced by service users within health care settings, resulting in poorer quality health care for people with mental health difficulties [14,30]. The issue of diagnostic overshadowing is not a new problem for service users, and we found that our service users' experiences were not dissimilar to the findings in existing literature [31-34]. Improving clinical health care skills and knowledge can increase competence, reduce symptom misattribution, and encourage staff to reflect on their attitudes to prevent diagnostic overshadowing [30]. As a result, we recommend tailored training for nonmental health professionals to develop these skills.

Our results support the existing literature that highlights security and protection of privacy as prominent service user concerns, with trust contingent on adequate security [11-13,15]. Service users expressed the need to establish effective safeguarding measures and hold organizations accountable for any breach. Perceptions of security and privacy are positively correlated with trust, and greater perceptions of trust increase the likelihood of information sharing [35]. We recommend providing service users with clear information on existing General Data Protection Regulation procedures that are in place to protect patient data and hold organizations accountable for any data breach. Using trusted research environments may also be another solution to address security concerns related to sharing patient-level data [36].

Service user involvement was identified as an important factor to consider when developing future data sharing systems because it made them feel more confident. Service users have reported more open attitudes and improved trust in research as a result of involvement [37]. We recommend involving service users in the governance of future data systems to ensure that they are prioritized.

In terms of future research, there is a need to understand the acceptable levels of pseudonymization of data, as it is not understood how much data would breach the high public expectations of privacy. As more data are likely to be collated, for example, in the general practitioner records data scraping [10], information from reduced post codes, criminal records, and other data will affect the chance of patient identification. Although this may be acceptable for high levels of patient benefit, this should not go unchallenged or agreed upon by the public, especially those who use mental health services.

Strengths and Limitations

The web-based nature of the study could have excluded some participants who did not have access to the required technology or who lacked digital competency [38,39]. Most of the participants were women. Although the current literature does not suggest differences in views, it is possible that the views of men and those from more diverse backgrounds might have weighted them differently. However, through our remote recruitment and data collection, it was more convenient and flexible for service users to participate and allowed participation from service users in geographically dispersed locations [40]. Our sample also fulfilled qualitative sample size criteria (N=22) [20,41,42] and provided views across a wider age range.

Implications and Conclusions

This study extends the limited research available on service user views and concerns regarding acceptable data sharing and provides a foundation for further research. We make five main recommendations to build service user trust in data sharing: (1) comprehensive screening processes, (2) developing tailored training for health care professionals to tackle diagnostic overshadowing and inaccurate health records, (3) providing service users with adequate information, (4) highlighting existing safeguarding procedures, and (5) incorporating service user involvement.

Although the qualitative nature of this study allowed us to obtain rich and detailed data, we found it challenging to clearly determine service user preferences for specific data sharing models. Future research should focus on conducting discrete choice experiments to quantify service user preferences and conclusively determine what models service users deem more acceptable for clinical data sharing in the United Kingdom.

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Authors' Contributions

SJ and TW designed the study. All authors carried out the literature search. SJ and AA collected data. AA, CM, and SJ analyzed the data. AA, SJ, and TW wrote the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Summary sheet.
[DOCX File , 1154 KB - mental_v8i9e30596_app1.docx]

Multimedia Appendix 2
Saturation grid of themes and subthemes represented in focus groups.
[DOCX File , 26 KB - mental_v8i9e30596_app2.docx]

References

1. Kochhar S, Knoppers B, Gamble C, Chant A, Koplan J, Humphreys GS. Clinical trial data sharing: here's the challenge. BMJ Open 2019 Aug 21;9(8):e032334 [FREE Full text] [doi: 10.1136/bmjopen-2019-032334] [Medline: 31439612]
2. Institute of Medicine (IOM). Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk. Washington, DC: The National Academies Press; 2015.
3. Kiley R, Peatfield T, Hansen J, Reddington F. Data sharing from clinical trials - a research funder's perspective. N Engl J Med 2017 Nov 16;377(20):1990-1992 [FREE Full text] [doi: 10.1056/NEJMsb1708278] [Medline: 29141170]
4. Taichman D, Backus J, Baethge C, Bauchner H, de Leeuw PW, Drazen JM, et al. Sharing clinical trial data: a proposal from the International Committee of Medical Journal Editors. Rev Med Chil 2016 Jan;144(1):11-13 [FREE Full text] [doi: 10.4067/S0034-98872016000100002] [Medline: 26998977]
5. Bruno E, Simblett S, Lang A, Biondi A, Odoi C, Schulze-Bonhage A, RADAR-CNS Consortium. Wearable technology in epilepsy: The views of patients, caregivers, and healthcare professionals. Epilepsy Behav 2018 Aug;85(10):141-149 [FREE Full text] [doi: 10.1016/j.yebeh.2018.05.044] [Medline: 29940377]

6. Simblett S, Greer B, Matcham F, Curtis H, Polhemus A, Ferrão J, et al. Barriers to and facilitators of engagement with remote measurement technology for managing health: systematic review and content analysis of findings. J Med Internet Res 2018 Jul 12;20(7):e10480 [FREE Full text] [doi: 10.2196/10480] [Medline: 30001997]
7. Simblett SK, Bruno E, Siddi S, Matcham F, Giuliano L, López JH, RADAR-CNS Consortium. Patient perspectives on the acceptability of mHealth technology for remote measurement and management of epilepsy: A qualitative analysis. Epilepsy Behav 2019 Aug;97:123-129 [FREE Full text] [doi: 10.1016/j.yebeh.2019.05.035] [Medline: 31247523]
8. Simblett SK, Evans J, Greer B, Curtis H, Matcham F, Radaelli M, RADAR-CNS consortium. Engaging across dimensions of diversity: A cross-national perspective on mHealth tools for managing relapsing remitting and progressive multiple sclerosis. Mult Scler Relat Disord 2019 Jul;32:123-132 [FREE Full text] [doi: 10.1016/j.msard.2019.04.020] [Medline: 31125754]
9. Simblett S, Matcham F, Siddi S, Bulgari V, di San Pietro CB, López JH, RADAR-CNS Consortium. Barriers to and facilitators of engagement with mhealth technology for remote measurement and management of depression: qualitative analysis. JMIR Mhealth Uhealth 2019 Jan 30;7(1):e11325 [FREE Full text] [doi: 10.2196/11325] [Medline: 30698535]
10. General Practice Data for Planning and Research (GPDPR). NHS Digital. 2021. URL: https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research#top [accessed 2021-06-10]
11. Our data-driven future in healthcare: People and partnerships at the heart of health related technologies. Academy of Medical Sciences. 2018. URL: https://acmedsci.ac.uk/file-download/74634438 [accessed 2021-06-10]
12. Castell S, Robinson L, Ashford H. Future data-driven technologies and the implications for use of patient data: Dialogue with public, patients and healthcare professionals. Academy of Medical Sciences. 2018. URL: https://acmedsci.ac.uk/file-download/6616969 [accessed 2021-06-10]
13. Robotham D, Satkunanathan S, Doughty L, Wykes T. Do we still have a digital divide in mental health? A five-year survey follow-up. J Med Internet Res 2016 Nov 22;18(11):e309 [FREE Full text] [doi: 10.2196/jmir.6511] [Medline: 27876684]
14. Knaak S, Mantler E, Szeto A. Mental illness-related stigma in healthcare: Barriers to access and care and evidence-based solutions. Healthc Manage Forum 2017 Mar;30(2):111-116 [FREE Full text] [doi: 10.1177/0840470416679413] [Medline: 28929889]
15. Satinsky EN, Driessens C, Crepaz-Keay D, Kousoulis A. Mental health service users' perceptions of data sharing and data protection: a qualitative report. J Innov Health Inform 2018 Dec 31;25(4):239-242 [FREE Full text] [doi: 10.14236/jhi.v25i4.1033] [Medline: 30672404]
16. Birt L, Scott S, Cavers D, Campbell C, Walter F. Member Checking: A tool to enhance trustworthiness or merely a nod to validation? Qual Health Res 2016 Nov 10;26(13):1802-1811. [doi: 10.1177/1049732316654870] [Medline: 27340178]
17. Hospital Episode Statistics. NHS Digital. 2016. URL: https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics [accessed 2021-06-10]
18. Perera G, Broadbent M, Callard F, Chang CK, Downs J, Dutta R, et al. Cohort profile of the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLaM BRC) Case Register: current status and recent enhancement of an Electronic Mental Health Record-derived data resource. BMJ Open 2016 Mar 01;6(3):e008721 [FREE Full text] [doi: 10.1136/bmjopen-2015-008721] [Medline: 26932138]
19. CRIS blog: Eight years on. NIHR Maudsley BRC. 2016. URL: https://www.maudsleybrc.nihr.ac.uk/posts/2016/april/cris-blog-eight-years-on/ [accessed 2021-06-10]
20. Guest G, Namey E, McKenna K. How many focus groups are enough? Building an evidence base for nonprobability sample sizes. Field Methods 2016 Jul 24;29(1):3-22. [doi: 10.1177/1525822X16639015]
21. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
22. Jones S, Howard L, Thornicroft G. 'Diagnostic overshadowing': worse physical health care for people with mental illness. Acta Psychiatr Scand 2008 Sep;118(3):169-171. [doi: 10.1111/j.1600-0447.2008.01211.x] [Medline: 18699951]
23. Wilkins C. Effective engagement requires trust and being trustworthy. Med Care 2018 Oct;56 Suppl 10 Suppl 1:6-8 [FREE Full text] [doi: 10.1097/MLR.0000000000000953] [Medline: 30015725]
24. Data Release Register. NHS Digital. 2021. URL: https://nhs-prod.global.ssl.fastly.net/binaries/content/assets/website-assets/services/dars/release-registers/releaseregister_20210301_20210331.xlsx [accessed 2021-06-10]
25. Triggle N. NHS privatisation: Why the fuss? BBC News. 2015. URL: https://www.bbc.co.uk/news/health-31435842 [accessed 2021-06-10]
26. Iacobucci G. Is the NHS being privatised? Br Med J 2019 Nov 05:l6376. [doi: 10.1136/bmj.l6376]
27. Esch T, Mejilla R, Anselmo M, Podtschaske B, Delbanco T, Walker J. Engaging patients through open notes: an evaluation using mixed methods. BMJ Open 2016 Jan 29;6(1):e010034 [FREE Full text] [doi: 10.1136/bmjopen-2015-010034] [Medline: 26826154]
28. Erlingsdóttir G, Petersson L, Jonnergård K. A theoretical twist on the transparency of open notes: qualitative analysis of health care professionals' free-text answers. J Med Internet Res 2019 Sep 25;21(9):e14347 [FREE Full text] [doi: 10.2196/14347] [Medline: 31573905]

29. Rivenbark JG, Ichou M. Discrimination in healthcare as a barrier to care: experiences of socially disadvantaged populations in France from a nationally representative survey. BMC Public Health 2020 Jan 09;20(1):31 [FREE Full text] [doi: 10.1186/s12889-019-8124-z] [Medline: 31918699]
30. Nash M. Diagnostic overshadowing: a potential barrier to physical health care for mental health service users. Mental Health Practice 2013 Dec;17(4):22-26. [doi: 10.7748/mhp2013.12.17.4.22.e862]
31. Nash M. Mental health service users' experiences of diabetes care by Mental Health Nurses: an exploratory study. J Psychiatr Ment Health Nurs 2014 Oct 18;21(8):715-723. [doi: 10.1111/jpm.12140] [Medline: 24548452]
32. van Nieuwenhuizen A, Henderson C, Kassam A, Graham T, Murray J, Howard LM, et al. Emergency department staff views and experiences on diagnostic overshadowing related to people with mental illness. Epidemiol Psychiatr Sci 2012 Oct 17;22(3):255-262. [doi: 10.1017/s2045796012000571]
33. Hamilton S, Pinfold V, Cotney J, Couperthwaite L, Matthews J, Barret K, et al. Qualitative analysis of mental health service users' reported experiences of discrimination. Acta Psychiatr Scand 2016 Aug;134 Suppl 446:14-22 [FREE Full text] [doi: 10.1111/acps.12611] [Medline: 27426642]
34. Shefer G, Henderson C, Howard LM, Murray J, Thornicroft G. Diagnostic overshadowing and other challenges involved in the diagnostic process of patients with mental illness who present in emergency departments with physical symptoms--a qualitative study. PLoS One 2014;9(11):e111682 [FREE Full text] [doi: 10.1371/journal.pone.0111682] [Medline: 25369130]
35. Gupta A, Dhami A. Measuring the impact of security, trust and privacy in information sharing: A study on social networking sites. J Direct Data Digit Mark Pract 2015 Sep 30;17(1):43-53. [doi: 10.1057/dddmp.2015.32]
36. Trusted Research Environments (TRE): A strategy to build public trust and meet changing health data science needs. Draft Green Paper v1.0 for consultation. UK Health Data Research Alliance. 2020. URL: https://ukhealthdata.org/wp-content/uploads/2020/04/200430-TRE-Green-Paper-v1.pdf [accessed 2021-06-10]
37. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. A systematic review of the impact of patient and public involvement on service users, researchers and communities. Patient 2014;7(4):387-395 [FREE Full text] [doi: 10.1007/s40271-014-0065-0] [Medline: 25034612]
38. Exploring the UK's digital divide. Office for National Statistics. 2019. URL: https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04 [accessed 2021-06-10]
39. Mannheim I, Schwartz E, Xi W, Buttigieg SC, McDonnell-Naughton M, Wouters EJ, et al. Inclusion of older adults in the research and design of digital technology. Int J Environ Res Public Health 2019 Oct 02;16(19):4-5 [FREE Full text] [doi: 10.3390/ijerph16193718] [Medline: 31581632]
40. Janghorban R, Roudsari R, Taghipour A. Skype interviewing: the new generation of online synchronous interview in qualitative research. Int J Qual Stud Health Well-being 2014;9:24152 [FREE Full text] [doi: 10.3402/qhw.v9.24152] [Medline: 24746247]
41. Mason M. Sample size and saturation in Phd studies using qualitative interviews. Forum Qualitative Social Research/Sozialforschung. 2010. URL: http://www.qualitative-research.net/index.php/fqs/article/view/1428/3027 [accessed 2021-06-10]
42. Guest G, Bunce A, Johnson L. How many interviews are enough? Field Methods 2016 Jul 21;18(1):59-82 [FREE Full text] [doi: 10.1177/1525822X05279903]

Abbreviations

CRIS: Clinical Record Interactive Search
NHS: National Health Service
SLaM: South London and Maudsley National Health Service Foundation Trust

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Original Paper

Characteristics of Dimensional Psychopathology in Suicidal Patients With Major Psychiatric Disorders and Its Association With the Length of Hospital Stay: Algorithm Validation Study

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Abstract

Background: Suicide has emerged as a serious concern for public health; however, only few studies have revealed the differences between major psychiatric disorders and suicide. Recent studies have attempted to quantify research domain criteria (RDoC) into numeric scores to systematically use them in computerized methods. The RDoC scores were used to reveal the characteristics of suicide and its association with major psychiatric disorders.

Objective: We intended to investigate the differences in the dimensional psychopathology among hospitalized suicidal patients and the association between the dimensional psychopathology of psychiatric disorders and length of hospital stay.

Methods: This retrospective study enrolled hospitalized suicidal patients diagnosed with major psychiatric disorders (depression, schizophrenia, and bipolar disorder) between January 2010 and December 2020 at a tertiary hospital in South Korea. The RDoC scores were calculated using the patients' admission notes. To measure the differences between psychiatric disorder cohorts, analysis of variance and the Cochran Q test were conducted and post hoc analysis for RDoC domains was performed with the independent two-sample *t* test. A linear regression model was used to analyze the association between the RDoC scores and sociodemographic features and comorbidity index. To estimate the association between the RDoC scores and length of hospital stay, multiple logistic regression models were applied to each psychiatric disorder group.

Results: We retrieved 732 admissions for 571 patients (465 with depression, 73 with schizophrenia, and 33 with bipolar disorder). We found significant differences in the dimensional psychopathology according to the psychiatric disorders. The patient group with depression showed the highest negative RDoC domain scores. In the cognitive and social RDoC domains, the groups with schizophrenia and bipolar disorder scored higher than the group with depression. In the arousal RDoC domain, the depression and bipolar disorder groups scored higher than the group with schizophrenia. We identified significant associations between the RDoC scores and length of stay for the depression and bipolar disorder groups. The odds ratios (ORs) of the length of stay were increased because of the higher negative RDoC domain scores in the group with depression (OR 1.058, 95% CI 1.006-1.114) and decreased by higher arousal RDoC domain scores in the group with bipolar disorder (OR 0.537, 95% CI 0.285-0.815).

Conclusions: This study showed the association between the dimensional psychopathology of major psychiatric disorders related to suicide and the length of hospital stay and identified differences in the dimensional psychopathology of major psychiatric disorders. This may provide new perspectives for understanding suicidal patients.

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KEYWORDS

suicide; computed phenotype; natural language processing; research domain criteria; electronic health record

Introduction

Background

The World Health Organization states that nearly 800,000 people die each year from suicide, one every 40 seconds [1]. Most patients who committed suicide had psychiatric disorders [2]. Among psychiatric disorders, schizophrenia and affective disorders demonstrate the highest risk for suicide [3], but few studies have examined the differences in the suicide-related features of psychiatric disorders [4].

Suicide attempts vary depending on the method, intent, and medical severity of the aftereffects [5]. The length of hospital stay is especially related to the outcome of a patient hospitalized for suicide attempts [3] with some studies stating that patients with longer admissions are at greater risk of postdischarge suicide [6]. Understanding the psychiatric features of patients who stay longer in the hospital might help reduce the length of stay and perhaps their postdischarge outcomes [7]. Several studies have explored the factors associated with the length of stay in suicidal patients, but the results have been inconsistent [8].

Meanwhile, the diagnosis of psychiatric patients so far has relied on categorical diagnostic systems. As the limitations of categorical diagnostic systems became increasingly apparent, the research domain criteria (RDoC) was introduced as an alternate nosology by the National Institute of Mental Health (NIMH) [9]. Natural language processing (NLP) was introduced as one of the ways to use RDoC, and hospital readmission could be predicted with RDoC domains extracted by NLP [10]. Thus, NLP can be used effectively to evaluate psychiatric notes as RDoC domains [11].

Objectives

In this study, we aimed to explore the differences in the RDoC domains extracted by NLP among patients with depression, schizophrenia, and bipolar disorder who were hospitalized for suicide attempts. We sought to determine whether narrative clinical notes could identify suicide-related features of each disorder. We also investigated how these domains were associated with the length of hospital stay and compared them for each disorder.

Methods

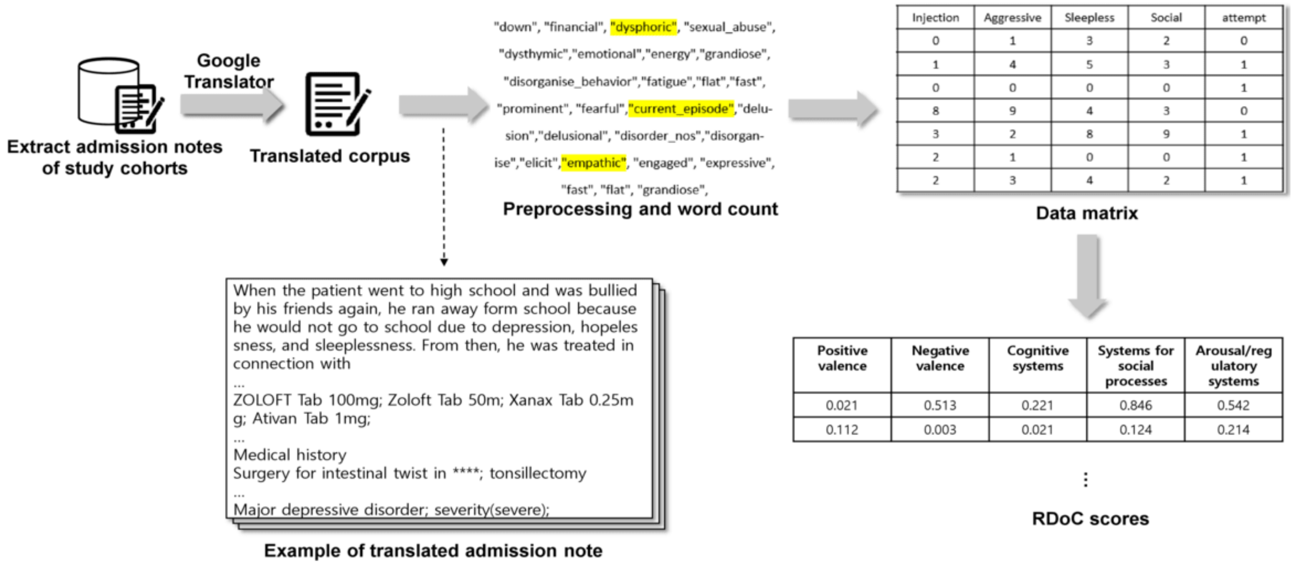
Data Collection

Clinical and sociodemographic data were extracted from the electronic health records of patients in the psychiatry inpatient unit at Ajou University Hospital in South Korea between 2010 and 2020. All patients received a Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV-TR or DSM-5 diagnosis from a trained psychiatrist [12,13]. Clinical data included diagnosis (ie, depression, schizophrenia, and bipolar disorder) at admission and chief complaints at admission such as suicide attempts, suicide planning, and suicidal ideations. Sociodemographic data included the age, sex, length of stay, past medical history, and Charlson Comorbidity Index (CCI) score. Admission notes on the patients were extracted for estimating the RDoC scores by NLP. The data were encoded using the Observational Medical Outcomes Partnership (OMOP) common data model (CDM) (version 5) of the [14] in combination with a deidentification procedure. The OMOP-CDM is maintained by the Observational Health Data Sciences and Informatics network, which provides tools to facilitate data analysis. This study was approved by the Ajou University Hospital Institutional Review Board (AJIRB-MED-MDB-21-151), and the requirement for informed consent was waived owing to the deidentification.

Calculation of RDoC Scores Using Narrative Clinical Text

McCoy et al [11] previously described a method for estimating RDoC scores from narrative text. In summary, the method evaluates a document using a predetermined set of terms belonging to a given research domain. This list of terms was developed through a group of clinical professionals, including the NIMH RDoC working group. The score can be calculated using a bag of words of the corpus and the count of predefined RDoC terms that appear in the document. For instance, if 10 terms comprise a predefined list and 2 appear in a document, the note would be assigned a score of 2/10 (20%). The list of terms predetermined by the NIMH RDoC working group is publicly available on the internet [11]. The patient admission notes in this study were written in English and Korean. The source texts were 33% in English and 67% in Korean, which were similar for each patient. However, important medical entities such as chief complaints, medical histories, medication prescriptions, and any other important descriptions that directly indicated the patients' status are represented in English. Moreover, to minimize data loss in the corpus, we systematically translated the corpus into English that was generated by the googleLanguageR package of the R programming language (version 3.6.2) [15]. As a result, we were able to derive RDoC scores from the documents, regardless of the language, as shown in Figure 1.

Figure 1. Overall workflow of extracting research domain criteria scores using a natural language processing pipeline. Admission notes were extracted from the electronic health records of the patients with diagnosis (ie, depression, schizophrenia, and bipolar disorder) and chief complaints such as suicide attempts, suicide planning, and suicidal ideation. Admission notes were translated into English by Google translator. After preprocessing, the score was calculated using the count of the predefined research domain critieria terms that appeared in the document. RDoC: research domain criteria.



Injection	Aggressive	Sleepless	Social	attempt
0	1	3	2	0
1	4	5	3	1
0	0	0	0	1
8	9	4	3	0
3	2	8	9	1
2	1	0	0	1
2	3	4	2	1

Positive valence	Negative valence	Cognitive systems	Systems for social processes	Arousal/regulatory systems
0.021	0.513	0.221	0.846	0.542
0.112	0.003	0.021	0.124	0.214

⋮

When the patient went to high school and was bullied by his friends again, he ran away form school because he would not go to school due to depression, hopeles sness, and sleeplessness. From then, he was treated in connection with

...

ZOLOFT Tab 100mg; Zoloft Tab 50m; Xanax Tab 0.25mg; Ativan Tab 1mg;

...

Medical history
Surgery for intestinal twist in ****; tonsillectomy

...

Major depressive disorder; severity(severe);

Study Design and Analysis

We conducted a retrospective cohort study to explore the differences in the RDoC domains extracted by NLP among patients with depression, schizophrenia, and bipolar disorder who were hospitalized for suicide attempts. We also investigated how these domains were associated with the length of hospital stay and compared them for each disorder. Baseline demographic and clinical data are expressed as numbers (%) for categorical variables and means (SDs) for continuous variables. Differences between psychiatric disorders were compared using analysis of variance (ANOVA) for continuous variables and Cochran Q tests for categorical variables. Post hoc analysis of the RDoC domains was conducted using independent two-sample *t* tests. Linear regression modeling with adjustments for the sex, age, and CCI was used to analyze five domains (positive valence, negative valence, cognitive systems, systems for social processes, and arousal/regulatory systems) of the RDoC in different sociodemographic profiles. For each psychiatric disorder, a multiple logistic regression model analyzing the sociodemographic variables and RDoC domains was used to identify the factors associated with the length of hospital stay. For a secondary analysis, a Cox regression model with adjustments for demographics and categorical diagnosis was used to identify each domain associated with the length of hospital stay without controlling the other four domains. As the Mental Health Promotion and Welfare Act in South Korea defines involuntary psychiatric admission within 3 days [16], hospitalization for more than 3 days indicates serious psychiatric problems. Owing to this policy, the distribution of the length of stay was also divided into less than 3 days and more than 3 days. For these reasons, we defined the length of stay as less than3 days or more than 3 days. All analyses were performed using the R programming language (version 3.6.2, R Foundation for Statistical Computing) and the open-source R packages.

Results

The demographic and clinical characteristics of 732 admissions for 571 participants are shown in Table 1. No significant differences were observed in the age, length of stay, CCI, sex, and medical history between the three psychiatric disorder groups. Table 2 shows that significant differences are observed in the negative valence, cognitive systems, systems for social processes, and arousal/regulatory systems domains in more than two of the three psychiatric disorder groups. In the post hoc analysis of the RDoC domains in the three psychiatric disorders, negative valence was the highest in the depression group ($P<.001$), whereas cognitive systems were significantly higher in the schizophrenia group than in the depression group ($P=.004$) and in the bipolar disorder group than in the depression group ($P<.001$). Like cognitive systems, systems for social processes were significantly higher in the schizophrenia group and the bipolar disorder group than in the depression group ($P<.001$). Arousal/regulatory systems were significantly higher in the depression ($P=.004$) and bipolar disorder ($P=.04$) groups than in the schizophrenia group. Furthermore, the RDoC domains differed in their associations with sociodemographic variables given in Multimedia Appendix 1. Age was significantly associated with the RDoC domains. Patients with increased levels of arousal/regulatory systems were older, whereas patients with more systems for social processes were younger. Being male was also associated with increased levels of positive valence. On the other hand, CCI was not associated with any RDoC domain.

Table 1. Baseline characteristics of the patient groups (N=571).[a]

Patient characteristic	Depression (n=465)	Schizophrenia (n=73)	Bipolar disorder (n=33)	*P* value
Age (years), mean (SD)	36.4 (18.3)	31.3 (15.3)	34.8 (14.7)	.11
Length of stay, mean (SD)	8.8 (9.5)	9.9 (13.2)	6.4 (5)	.89
Charlson Comorbidity Index, mean (SD)	0.3 (0.9)	0.1 (0.4)	0.1 (0.4)	.44
Sex: female, n (%)	293 (63)	39 (53.4)	22 (66.7)	.25
Medical history, n (%)				
Hypertensive disorder	62 (13.3)	5 (6.8)	4 (12.1)	.30
Diabetes mellitus	24 (5.2)	2 (2.7)	0 (0)	.28
Ischemic stroke	4 (1.5)	0 (0)	0 (0)	.45
Renal impairment	10 (2.2)	1 (1.4)	1 (3)	.85
Pneumonia	21 (4.5)	2 (2.7)	1 (3)	.74

[a] ANOVA for continuous variables and Cochran Q tests for categorical variables were performed.

Table 2. Comparisons of research domain criteria scores of patients in the three psychiatric disorders (N=571).[a]

Characteristic	Depression (n=465)	Schizophrenia (n=73)	Bipolar disorder (n=33)	*P* value	Post hoc (*P* value)
Research domain criteria score, mean (SD)					
Positive valence	0.112 (0.048)	0.108 (0.045)	0.098 (0.036)	.21	—[b]
Negative valence	0.146 (0.052)	0.099 (0.041)	0.100 (0.037)	<.001	Depression > schizophrenia (<.001) depression > bipolar disorder (<.001)
Cognitive systems	0.189 (0.096)	0.156 (0.092)	0.189 (0.096)	<.001	Schizophrenia > depression (.004) bipolar disorder > depression (<.001)
Systems for social processes	0.112 (0.081)	0.168 (0.091)	0.176 (0.099)	<.001	Schizophrenia > depression (<.001) bipolar disorder > depression (<.001)
Arousal/regulatory systems	0.101 (0.059)	0.080 (0.051)	0.102 (0.044)	.02	Depression > schizophrenia (.004) bipolar disorder > schizophrenia (.04)

[a] Data were analyzed by ANOVA followed by independent two-sample *t* tests during post hoc analysis.

[b] Not applicable.

Next, we examined the association between the RDoC domains extracted from the admission notes and length of hospital stay. Table 3 summarizes the results of each psychiatric disorder group. In the patient group with depression, patients who scored high in negative valence were at an increased risk of a longer length of stay (odds ratio [OR] 1.058, 95% CI 1.006-1.114). In the patient group with schizophrenia, the RDoC domains were not associated with the length of stay. In the patient group with bipolar disorder, patients who scored high in the arousal/regulatory systems were at a decreased risk of a longer length of stay (OR 0.537, 95% CI 0.285-0.815).

In the secondary analysis, compared to the primary analysis, which considered 3-day hiccups and other domains, the depression group similarly showed significant association with negative valence (Table S2 in Multimedia Appendix 1). Unlike in the primary analysis, a significant association was shown with the arousal/regulatory systems of the depression group. In the schizophrenia group, there were no significant associations as in the primary analysis. In the bipolar disorder group, unlike primary analysis, significant association was shown with positive valence.

Table 3. Regression model results of research domain criteria scores and length of hospital stay (N=732).

Variables	Depression (n=612)		Schizophrenia (n=83)		Bipolar disorder (n=37)	
	OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value
Research domain criteria scores						
Positive valence	0.975 (0.935-1.018)	.25	1.016 (0.897-1.157)	.81	1.297 (0.938-1.973)	.15
Negative valence	1.058 (1.006-1.114)	.03	1.090 (0.933-1.279)	.28	1.290 (0.967-1.860)	.11
Cognitive systems	1.01 (0.957-1.048)	.96	1.087 (0.952-1.252)	.22	1.145 (0.887-1.561)	.33
Systems for social processes	1.010 (0.966-1.058)	.66	0.959 (0.861-1.068)	.44	1.079 (0.881-1.361)	.47
Arousal/regulatory systems	0.957 (0.906-1.011)	.11	0.901 (0.759-1.057)	.21	0.537 (0.285-0.815)	.02
Sociodemographic features						
Age	1.000 (0.989-1.012)	.95	1.010 (0.975-1.051)	.59	1.020 (0.936-1.125)	.66
Charlson Comorbidity Index	0.996 (0.789-1.295)	.98	1.391 (0.259-24.352)	.75	0.057 (0.000-1.924)	.49
Sex	0.943 (0.634-1.394)	.77	1.246 (0.419-3.708)	.69	0.402 (0.014-5.742)	.52

[a] OR: odds ratio.

Discussion

Principal Findings

In this study, we identified statistically significant differences in the RDoC scores among psychiatric disorders and showed significant associations between the RDoC scores and length of stay for depression and bipolar disorder. The association between suicide and RDoC domains has been reported [17], but very few studies have analyzed how this relationship differs from disorder to disorder. In this regard, the present study investigated whether the RDoC scores derived by NLP differed for each disorder and whether they were related to clinical outcomes such as the length of hospital stay.

The depression group showed the highest negative valence scores among the disorder groups. Previous studies comparing the distribution of domains by diagnosis also showed differences in the negative valence scores for depression and bipolar disorder, and depression and schizophrenia [18]. Our findings not only confirm the previously established association between negative valence and suicide [19] but also suggest that negative valence is particularly associated with depression. Conversely, the schizophrenia and bipolar disorder groups scored higher than the depression group in the cognitive systems and systems for social processes, and no significant difference was found in the scores between the two groups. Several studies have suggested a significant overlap between schizophrenia and bipolar disorder [20], and similarities between these two disorders are prominent in cognitive and social functions [21,22]. Our results are in line with previous results and provide additional information that cognition and social function are important factors in suicide cases involving schizophrenia and bipolar disorder. In the arousal/regulatory systems, the bipolar disorder group scored significantly higher than the schizophrenia group, whereas no significant difference was found in the scores between the depression and bipolar disorder groups. Significant similarities in sleep features representing the arousal/regulatory systems between depression and bipolar disorder have been reported [23]. However, as schizophrenia and bipolar disorder are highly related to sleep disorders [24], it remains unclear whether the scores of the schizophrenia group in the arousal/regulatory systems are more significant than those of the bipolar disorder group.

In the current study, we found that negative valence scores were associated with a longer length of stay in the depression group (OR 1.058, 95% CI 1.006-1.114). The association found between negative valence and depression as well as suicide is consistent with previous findings [19,25]. In the schizophrenia group, no significant relationship was found between the RDoC domain and length of stay, whereas scores in the arousal/regulatory systems were associated with a shorter length of stay in the bipolar disorder group (OR 0.537, 95% CI 0.285-0.815). Contrary to our findings regarding bipolar disorder, a previous study has reported that higher arousal domain scores were associated with a longer length of stay for bipolar disorder [11]. However, sleep disturbance varies with the bipolar disorder phase [26]. These findings show that further consideration of the bipolar disorder phase is needed in interpreting the arousal domain scores with respect to bipolar disorder. Although previous studies found a significant association between the RDoC domain and length of hospital stay, some inconsistencies in prior significant relationships have been identified. For example, one study reported that a positive domain was associated with a shorter stay; however, another showed that a positive domain was associated with a longer stay [11,27]. Thus, the relationship may vary depending on the specific cohort. The association between the length of stay and RDoC domain is unclear for schizophrenia and differs from previous studies with respect to bipolar disorder because our work not only had a cohort different from that of previous studies but also analyzed the relationship between the length of stay and specific disorders.

Our findings show significant associations between the RDoC domains and length of hospital stay for depression and bipolar disorder. This result is consistent with those in existing literature reporting that the estimated RDoC domain scores were associated with the length of stay [27]. Moreover, significant differences and trends in the RDoC domains among depression, schizophrenia, and bipolar disorder were demonstrated. These findings are consistent with those of previous studies on the relationship between negative valence scores and major depressive disorders [25]. Recent publications suggest that cognitive and social functioning factors were observed in schizophrenia and bipolar disorder but not in depression, which is consistent with our findings [28]. On the other hand, using NLP to calculate the RDoC scores is more useful than using structural data alone [11]. For example, the RDoC of the cognitive domain extracted by NLP facilitated stratification of risk for dementia [29]. Our findings further validate of the usefulness and robustness of the RDoC scoring system, which identifies important clinical features in clinical notes. Furthermore, with this validated RDoC NLP tool, our study was conducted by integrating bilingual clinical notes into RDoC domains. Although prior research relied primarily on clinical notes written in English, our results show that the use of RDoC domains through NLP is appropriate for clinical notes that are not in English.

Limitations

Our study has a few limitations. First, even though we extracted database records of suicidal patients from 2010 to 2020, we could identify only 732 psychiatric admissions in 571 patients. To validate our findings more accurately, a large data set is required. Second, our study has analyzed the conditions most highly related to suicide, but other suicide-related conditions, such as substance use disorders and personality disorders, have not been considered. Because substance use disorders and personality disorders frequently coexist with depression, schizophrenia, and bipolar disorder [30], it was difficult to distinguish between the disorders. Third, the accuracy of the translation of Korean text into English was not evaluated because this was beyond the scope of this study. The accuracy and effectiveness of using clinical NLP algorithms on multilingual clinical documents should also be investigated and validated in future.

Conclusions

Our study showed that the estimates of dimensional psychopathology derived from NLP are associated with the length of hospital stay in suicidal patients with depression or bipolar disorder and vary significantly among suicidal patients with depression, schizophrenia, and bipolar disorder. Therefore, our findings suggest that more attention might be paid to negative valence for depression and arousal/regulatory systems for bipolar disorder in relation to suicide. Additionally, our results may increase the understanding of the differences in dimensional psychopathology among suicidal patients with depression, schizophrenia, and bipolar disorder. We hope that further investigations will clarify the differences in the RDoC scores of suicidal patients and associations between the RDoC scores of suicidal patients and clinical outcomes.

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Authors' Contributions

DYL and JP drafted the manuscript. JSN and HWR designed the study and critically reviewed the manuscript. RWP is primarily responsible for the final paper. JHH, EYL, and SJS provided critical opinions on the study design and manuscript. All authors have approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Association between sociodemographic features and research domain criteria scores.
[DOCX File , 27 KB - mental_v8i9e30827_app1.docx]

References

1. Mental health and substance use - suicide data 2021. World Health Organization. URL: https://www.who.int/teams/mental-health-and-substance-use/suicide-data [accessed 2021-06-28]
2. Omi T, Ito H, Riku K, Kanai K, Takada H, Fujimi S, et al. Possible factors influencing the duration of hospital stay in patients with psychiatric disorders attempting suicide by jumping. BMC Psychiatry 2017 Mar;17(1):99 [FREE Full text] [doi: 10.1186/s12888-017-1267-5] [Medline: 28320371]
3. Park S, Choi JW, Yi KK, Hong JP. Suicide mortality and risk factors in the 12 months after discharge from psychiatric inpatient care in Korea: 1989-2006. Psychiatry Res 2013 Jul;208(2):145-150 [FREE Full text] [doi: 10.1016/j.psychres.2012.09.039] [Medline: 23058096]
4. Schmutte T, Costa M, Hammer P, Davidson L. Comparisons between suicide in persons with serious mental illness, other mental disorders, or no known mental illness: Results from 37 US states, 2003–2017. Schizophr Res 2021 Feb:74-82 [FREE Full text] [doi: 10.1016/j.schres.2020.11.058]
5. Kim S, Choi K, Lee K, Kim D, Hong S, Lee H, et al. Risk factors for serious suicide attempts with high medical severity. Suicide Life Threat Behav 2020 Apr;50(2):408-421 [FREE Full text] [doi: 10.1111/sltb.12597] [Medline: 31642549]
6. Large M, Smith G, Sharma S, Nielssen O, Singh S. Systematic review and meta-analysis of the clinical factors associated with the suicide of psychiatric in-patients. Acta Psychiatr Scand 2011 Jul;124(1):18-19 [FREE Full text] [doi: 10.1111/j.1600-0447.2010.01672.x] [Medline: 21261599]
7. Bessaha M, Shumway M, Smith M, Bright C, Unick G. Predictors of hospital length and cost of stay in a national sample of adult patients with psychotic disorders. Psychiatr Serv 2017 Jun;68(6):559-565 [FREE Full text] [doi: 10.1176/appi.ps.201600312] [Medline: 28142382]
8. Dimitri G, Giacco D, Bauer M, Bird V, Greenberg L, Lasalvia A, et al. Predictors of length of stay in psychiatric inpatient units: Does their effect vary across countries? Eur Psychiatry 2018 Feb;48(1):6-12 [FREE Full text] [doi: 10.1016/j.eurpsy.2017.11.001] [Medline: 29331601]
9. Sanislow C, Pine D, Quinn K, Kozak M, Garvey M, Heinssen R, et al. Developing constructs for psychopathology research: research domain criteria. J Abnorm Psychol 2010 Nov;119(4):631-639 [FREE Full text] [doi: 10.1037/a0020909] [Medline: 20939653]
10. McCoy T, Castro V, Rosenfield H, Cagan A, Kohane I, Perlis R. A clinical perspective on the relevance of research domain criteria in electronic health records. Am J Psychiatry 2015 Apr;172(4):316-320 [FREE Full text] [doi: 10.1176/appi.ajp.2014.14091177] [Medline: 25827030]
11. McCoy JT, Yu S, Hart K, Castro V, Brown H, Rosenquist J, et al. High throughput phenotyping for dimensional psychopathology in electronic health records. Biol Psychiatry 2018 Jun;83(12):997-1004 [FREE Full text] [doi: 10.1016/j.biopsych.2018.01.011] [Medline: 29496195]
12. American Psychiatric Association. Diagnostic and Statistical Manual-Text Revision (DSM-IV-TR). Washington, DC: American Psychiatric Association; Jan 2000:256.
13. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders: DSM-5. Washington, DC: American Psychiatric Association; May 2013:20.
14. Hripcsak G, Duke JD, Shah NH, Reich CG, Huser V, Schuemie MJ, et al. Observational health data sciences and informatics (OHDSI): opportunities for observational researchers. Stud Health Technol Inform 2015;216:574-578 [FREE Full text] [Medline: 26262116]
15. Daniele F. Performance of an automatic translator in translating medical abstracts. Heliyon 2019 Oct;5(10):e02687 [FREE Full text] [doi: 10.1016/j.heliyon.2019.e02687] [Medline: 31687515]
16. Hwang T, Jung G, Lee CJ, Kim HY. Analysis of involuntary admissions in Korea through the admission management information system. Int J Law Psychiatry 2020;68:101542 [FREE Full text] [doi: 10.1016/j.ijlp.2020.101542] [Medline: 32033689]
17. McCoy JT, Pellegrini A, Perlis R. Research domain criteria scores estimated through natural language processing are associated with risk for suicide and accidental death. Depress Anxiety 2019 May;36(5):392-399 [FREE Full text] [doi: 10.1002/da.22882] [Medline: 30710497]
18. McCoy JT, Pellegrini A, Perlis R. Differences among research domain criteria score trajectories by diagnostic and statistical manual categorical diagnosis during inpatient hospitalization. PLoS One 2020;15(8):e0237698 [FREE Full text] [doi: 10.1371/journal.pone.0237698] [Medline: 32842139]
19. Glenn C, Kleiman E, Cha C, Deming C, Franklin J, Nock M. Understanding suicide risk within the research domain criteria (RDoC) framework: a meta-analytic review. Depress Anxiety 2018 Jan;35(1):65-88 [FREE Full text] [doi: 10.1002/da.22686] [Medline: 29064611]
20. Walker J, Curtis V, Murray RM. Schizophrenia and bipolar disorder: similarities in pathogenic mechanisms but differences in neurodevelopment. Int Clin Psychopharmacol 2002 Aug;17 Suppl 3:S11-9. [Medline: 12570067]
21. Cannon M, Jones P, Gilvarry C, Rifkin L, McKenzie K, Foerster A. Premorbid social functioning in schizophrenia and bipolar disorderimilarities and differences. Am J Psychiatry 1997 Nov;154(11):1544-1550 [FREE Full text] [doi: 10.1016/0924-9338(96)88868-7]

22. Dickerson F, Boronow J, Stallings C, Origoni A, Cole S, Yolken R. Cognitive functioning in schizophrenia and bipolar disorder: comparison of performance on the Repeatable Battery for the Assessment of Neuropsychological Status. Psychiatry Res 2004 Nov;129(1):45-53 [FREE Full text] [doi: 10.1016/j.psychres.2004.07.002] [Medline: 15572184]
23. Lai Y, Huang M, Chen H, Lu M, Chiu Y, Shen W, et al. Familiality and clinical outcomes of sleep disturbances in major depressive and bipolar disorders. J Psychosom Res 2014 Jan;76(1):61-67 [FREE Full text] [doi: 10.1016/j.jpsychores.2013.10.020] [Medline: 24360143]
24. Meyer N, Faulkner S, McCutcheon R, Pillinger T, Dijk D, MacCabe J. Sleep and circadian rhythm disturbance in remitted schizophrenia and bipolar disorder: a systematic review and meta-analysis. Schizophr Bull 2020 Mar:1126-1143 [FREE Full text] [doi: 10.1093/schbul/sbaa024] [Medline: 32154882]
25. Woody M, Gibb B. Integrating NIMH research domain criteria (RDoC) into depression research. Curr Opin Psychol 2015 Aug;4:6-12 [FREE Full text] [doi: 10.1016/j.copsyc.2015.01.004] [Medline: 25642446]
26. Zangani C, Casetta C, Saunders A, Donati F, Maggioni E, D'Agostino A. Sleep abnormalities across different clinical stages of bipolar disorder: a review of EEG studies. Neurosci Biobehav Rev 2020 Nov;118:247-257 [FREE Full text] [doi: 10.1016/j.neubiorev.2020.07.031] [Medline: 32738263]
27. McCoy JT, Wiste A, Doyle A, Pellegrini A, Perlis R. Association between child psychiatric emergency room outcomes and dimensions of psychopathology. Gen Hosp Psychiatry 2019;59:1-6 [FREE Full text] [doi: 10.1016/j.genhosppsych.2019.04.009] [Medline: 31034963]
28. Schwarz K, Moessnang C, Schweiger J, Baumeister S, Plichta M, Brandeis D, et al. Transdiagnostic prediction of affective, cognitive, and social function through brain reward anticipation in schizophrenia, bipolar disorder, major depression, and autism spectrum diagnoses. Schizophr Bull 2020 Apr;46(3):592-602 [FREE Full text] [doi: 10.1093/schbul/sbz075] [Medline: 31586408]
29. McCoy JT, Han L, Pellegrini A, Tanzi R, Berretta S, Perlis R. Stratifying risk for dementia onset using large-scale electronic health record data: a retrospective cohort study. Alzheimers Dement 2020 Mar;16(3):531-540 [FREE Full text] [doi: 10.1016/j.jalz.2019.09.084] [Medline: 31859230]
30. Williams R, Farquharson L, Rhodes E, Dang M, Fitzpatrick N, Quirk A, et al. Impact of co-morbid personality disorder on quality of inpatient mental health services for people with anxiety and depression. Personal Ment Health 2020 Nov;14(4):336-349 [FREE Full text] [doi: 10.1002/pmh.1484] [Medline: 32424943]

Abbreviations

ANOVA: analysis of variance
CCI: Charlson comorbidity index
CDM: common data model
DSM: Diagnostic and Statistical Manual of Mental Disorders
NIMH: National Institute of Mental Health
NLP: natural language processing
OMOP: Observational Medical Outcomes Partnership
OR: odds ratio
RDoC: research domain criteria

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