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Review

Benefits of Digital Health Resources for Substance Use Concerns in Women: Scoping Review

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Abstract

Background: Digital health resources are being increasingly used to support women with substance use concerns. Although empirical research has demonstrated that these resources have promise, the available evidence for their benefit in women requires further investigation. Evidence supports the capacity of interventions that are sex-, gender-, and trauma-informed to improve treatment access and outcomes and to reduce health system challenges and disparities. Indeed, both sex- and gender-specific approaches are critical to improve health and gender equity. Violence and trauma are frequent among those with substance use concerns, but they disproportionately affect those who identify as female or women, further underscoring the need for trauma-informed care as well.

Objective: The objective of this investigation was to evaluate the evidence supporting the efficacy or effectiveness of online or mobile interventions for risky or harmful substance use in adults who identify as female or women, or who report a history of trauma.

Methods: This scoping review is based on an academic search in MEDLINE, APA PsycINFO, Embase, Cochrane Central, and CINAHL, as well as a grey literature search in US and Canadian government and funding agency websites. Of the 7807 records identified, 465 remained following title and abstract screening. Of these, 159 met all eligibility criteria and were reviewed and synthesized.

Results: The 159 records reflected 141 distinct studies and 125 distinct interventions. Investigations and the interventions evaluated predominantly focused on alcohol use or general substance use. Evaluated digital health resources included multisession and brief-session interventions, with a wide range of therapeutic elements. Multisession online and mobile interventions exhibited beneficial effects in 86.1% (105/122) of studies. Single-session interventions similarly demonstrated beneficial effects in 64.2% (43/67) of study conditions. Most investigations did not assess gender identity or conduct sex- or gender-based analyses. Only 13 investigations that included trauma were identified.

Conclusions: Despite the overall promise of digital health interventions for substance use concerns, direct or quantitative evidence on the efficacy or effectiveness of interventions in females or women specifically is weak.

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KEYWORDS

women; female; gender-specific; digital health; internet; mobile app; technology; technology interventions; technology-based intervention; web-based intervention; substance use concerns; trauma

Introduction

Background

Despite the higher prevalence of substance misuse and substance use disorders in men compared with women, a substantial proportion of women do experience harms associated with substance use. Moreover, research suggests that substance use and associated harms have been increasing in women over time. For example, the frequency and volume of alcohol use in women increased substantially from the 2000s to 2010s [1,2]. Cannabis use has exhibited an increase over even shorter time periods, and recent estimates suggest that 10% of women in Canada self-reported having a dependence on some form of illicit drug [1,3]. Substance use in women is further associated with staggering personal and societal costs. In particular, it is strongly linked to mental health concerns, including depression and suicidal thoughts and behaviors [4], as well as physical health concerns, including morbidity and mortality [5]. Substance misuse has associated health impacts on maternal health, fetal and neonatal morbidity, prematurity, and small for gestational age. It also leads to parenting deficits related to psychological and environmental concerns [6,7]. Overall, societal costs associated with substance use are widespread and growing, as illustrated by increasing hospitalizations due to substance use [8] and increasing loss in productivity, which is estimated to be over Can $15 billion [7].

Sex-, Gender-, and Trauma-Informed Supports for Substance Use Concerns

Despite an increase in substance use among women, women are generally underrepresented in treatment settings [9]. Research has suggested that women are less inclined to seek treatment until negative consequences become severe [10,11]. Additionally, research has demonstrated that women experience specific barriers to care, from psychological barriers, such as stigma and discrimination, to practical barriers, such as decreased opportunity due to caregiving roles and responsibilities, relationship abuse and violence, etc [12]. Women are more likely to be principal caregivers to children and other family members, and concerns regarding the potential involvement of child protection services or other social services as a result of seeking support can be a particularly powerful deterrent. These barriers can thus delay treatment seeking, such that women presenting to specialized services exhibit both acute and complex needs to impact both treatment engagement and outcomes.

Evidence supports the capacity of interventions that are sex-, gender-, and trauma-informed to improve treatment access and outcomes and to reduce health system challenges and disparities. Indeed, both sex- and gender-specific approaches are critical to improve health and gender equity, attending to the biological factors that impact the response to substances and biological treatments, as well as the gendered experiences of substance use challenges and their management [13]. Trauma is critical to consider in this context. While specifics may vary, trauma is generally defined as an emotional consequence of a deeply distressing or disturbing event [14] that has overcome an individual’s ability to cope [13]. An elevated prevalence of substance use among those with a history of trauma supports a strong overall association between trauma exposure and substance misuse [15]. Strikingly, 75% of women and more than 25% of men who enter treatment for substance use disorders report histories of abuse and trauma [15-17]. Those with a history of trauma have been shown to experience more complications in treatment for substance use disorders, with higher levels of distress, lower treatment adherence, and longer courses, when compared with those without a history of trauma [18]. Despite high prevalence rates and significant implications, trauma is not frequently assessed or addressed in the treatment of substance use disorders [19]. Thus, although trauma and substance use concerns frequently co-occur, adults who identify as female or women are disproportionately affected by trauma and the impact of trauma on care. This health disparity further underscores the need for sex-, gender-, and trauma-informed interventions.

Current evidence-based best practice guidelines have therefore highlighted the importance of gender- and trauma-informed treatments for substance use concerns in women. Gender-informed practices include integrated treatment approaches addressing a wide range of women’s needs (eg, physical, social, and mental health needs, and child-centered services such as prenatal services, parenting programs, and child care) and are associated with improvements in recovery, parenting skills, and emotional health [20]. Trauma-informed practices, in turn, follow the principles of trauma awareness/acknowledgment; maintaining trust and safety; promoting choice and collaboration; maintaining focus on strength/skills building; attending to cultural, historical, and gender issues such as intimate partner violence; peer support; and mutual self-help. Trauma-informed care is also associated with improved service user experiences and clinical outcomes [21].

It is notable then that the gender- and trauma-informed practices most appropriate to women with substance use difficulties primarily comprise integrated psychosocial interventions, most commonly provided in-person and in group formats. Yet, in many jurisdictions, this model of care delivery is not possible to maintain during the COVID-19 global pandemic. Similar to other health care settings, substance use treatment centers serving women are increasingly turning to digital health solutions to provide support, particularly while physical distancing measures are necessary to protect public health. Digital health solutions may in fact overcome numerous barriers to care experienced by women and provide a valuable addition to the health system even beyond the current crisis.

In a recent review, Nesvåg and McKay [22] evaluated the feasibility and therapeutic benefits of digital interventions to prevent and treat substance use concerns. This review located 28 unique interventions, which were categorized as simple or complex based on the number of features. Simple interventions were generally mobile apps integrated within other services and supports, whereas complex interventions were more frequently delivered as stand-alone interventions, using a personal computer and/or a mobile app format. A large proportion of participants (70%-90%) found the interventions to be useful, and more than half of the studies found small to medium positive effects in comparison to a control group. This review supported the feasibility of digital health resources for substance use concerns, but found less consistent support for their efficacy or effectiveness. In a review centered on women of childbearing age, Hai et al [23] evaluated the efficacy of technology-based interventions for substance use, with a focus on randomized controlled trials. This review located 15 trials, and a meta-analysis of 13 trials supported the efficacy of the digital health interventions for alcohol use concerns specifically compared with control conditions.

This review extends the foundational work in several ways. First, Hai et al [23] specifically focused on studies conducted in women of childbearing age, precluding an evaluation of differential effects across sex or gender. Second, both Hai et al [23] and Nesvåg and McKay [22] specifically focused on randomized controlled trials; however, initial investigations as well as investigations with a focus on effectiveness and/or implementation outcomes in real-world settings may utilize different research designs. Third, previous reviews have not systematically extracted data regarding the trauma endorsed by samples, limiting the capacity to determine the degree to which this crucial clinical feature is integrated into research designs, analyses, and interpretations. The current investigation therefore conducted a scoping review to evaluate the nature of the evidence for the efficacy and/or effectiveness of digital health resources to treat substance use and/or associated risks or harms. Consistent with recommendations [24], we conducted a scoping review to evaluate the types of available evidences in the field, which we envisioned would therefore either act as a precursor to a systematic review or support the analysis of knowledge gaps, contingent upon the results. We therefore implemented a search strategy including a wide range of research designs and requiring a limited proportion of adults who identify as female or women, or who report a history of trauma, regardless of sex or gender. We focused on web-based interventions as classified by Barak et al [25], specifically self-guided interventions with or without adjunctive tailored human support. We did not incorporate remotely delivered synchronous interventions due to stakeholder-identified needs for digital interventions that do not necessitate clinician mediation or delivery and that may extend the capacity of the limited workforce to meet increasing clinical demands [26].

The aim of this investigation was to evaluate the current evidence for digital health resources for substance use concerns, with a focus on resources that have been evaluated in females or women, or in those who report a history of trauma, regardless of sex or gender. Although current resources may not have been designed to fully incorporate gender- and trauma-based principles, their therapeutic benefit in these groups is nevertheless an important consideration in evaluating currently available resources, as well as identifying priorities for both clinical and research initiatives.

Methods

Overview

The methodology for this scoping review was based on the framework developed by Arksey and O'Malley [27] and later refined by Levac et al [28]. The stages are briefly outlined as (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting the resources. Each stage is described below.

Stage 1: Identifying the Research Question

The scoping review was conducted to answer the following research questions:

1. What digital health resources have been evaluated in those who identify as female/women or those reporting a history of trauma, regardless of sex or gender?
2. What digital health resources have empirical support for their efficacy/effectiveness in those who identify as female/women or those reporting a history of trauma, regardless of sex or gender?

For the purpose of this study, a scoping review was defined as a type of research synthesis that aims to "map the literature" on a particular topic or research area and provide an opportunity to identify key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking, and research [29]. Through answering the above questions our objective was to evaluate the nature of the evidence base for the efficacy and/or effectiveness of digital health resources for reducing substance use and/or associated harms in those identifying as female/women or in those reporting a history of trauma, regardless of sex or gender.

Stage 2: Identifying Relevant Studies

A comprehensive search strategy was developed by a librarian (RB) in consultation with the research team. The following databases were searched from inception: MEDLINE (including Epub ahead of print, in-process, and other nonindexed citations), APA PsycINFO, Embase, Cochrane Central, and CINAHL. No language limits were applied at this stage. For the searches, combinations of controlled vocabulary in the form of database-specific subject headings and relevant free-text keywords were included. The database searches were conducted in June 2020. The full MEDLINE search strategy is available for viewing in Multimedia Appendix 1.

In addition, nonpeer reviewed (grey) literature was also retrieved. The research team conducted a web search of Canadian and US Government and Funding Agencies in Canada and the United States using Google from July to August 2020. These searches were conducted using variations of the following (including but not limited to): "substance use," "drug use," "alcohol use," or "addiction;" "online intervention," "digital health," "eHealth," or "mobile health;" and "women" or "female."

Stage 3: Study Selection

Studies were selected according to the following eligibility criteria:

1. Language: We included articles in English.
2. Date: We included articles from database inception to the date of extraction (June 30, 2020).
3. Publication type: We only considered original research articles, including secondary analyses. Dissertations, commentaries, conference proceedings, letters, editorials, and reviews were excluded to ensure presence of sufficient methodology and data needed to map and evaluate the nature of the evidence.
4. Sample: We considered adults aged 18 years or older, who endorsed or exhibited risky or harmful substance use. Similar to previous reviews [22,23], we did not include nicotine or caffeine. A minimum of 20% of participants was required to identify as female and/or women, or to report a trauma history, regardless of sex or gender. Although in many contexts, a higher proportion would be more appropriate and/or necessary to ensure power of sex- or gender-based analyses, this lower limit permits broad sampling of evidence to evaluate current practices.
5. Setting: We considered all settings (eg, health care, forensic, and educational).
6. Design: We included all prospective designs (eg, single vs multiple arms and augmentation vs stand-alone intervention). Randomization or a comparison/control group was not required.
7. Intervention: We considered web- or mobile-based interventions targeting substance use or substance use disorder symptoms. All theoretical orientations and durations of treatments were included; however, formats that were computer-based, but not online, or that were interactive were excluded (eg, telephone, video, and text-based interactive psychosocial interventions with a clinician and social networking/platforms such as peer support discussion boards).
8. Outcomes: We considered substance use or substance use disorder symptoms. Outcomes that were focused only on acceptability or feasibility were excluded.

Following the initial extraction and removal of duplicates, two research staff independently (1) screened the titles and abstracts of all unique records, (2) conducted full-text reviews for all records not excluded, and (3) extracted data from included studies. Team members demonstrated substantial agreement during title and abstract screening (96% agreement; κ=0.74) and during the full-text review (92% agreement; κ=0.84). Discrepancies were resolved by consensus, with the support of a member of the investigation team as needed (LQ).

Stage 4: Charting the Data

Procedures were consistent with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews (PRISMA-ScR) guidelines [30]. The following data were extracted from records included in synthesis: study design features (eg, setting and randomized controlled trial), sample features (eg, size and demographic information), intervention (eg, duration and components), outcomes (eg, instruments and indicators), and bias and fidelity indicators. Two research staff independently extracted data, and discrepancies were resolved by consensus.

Stage 5: Collating, Summarizing, and Reporting the Results

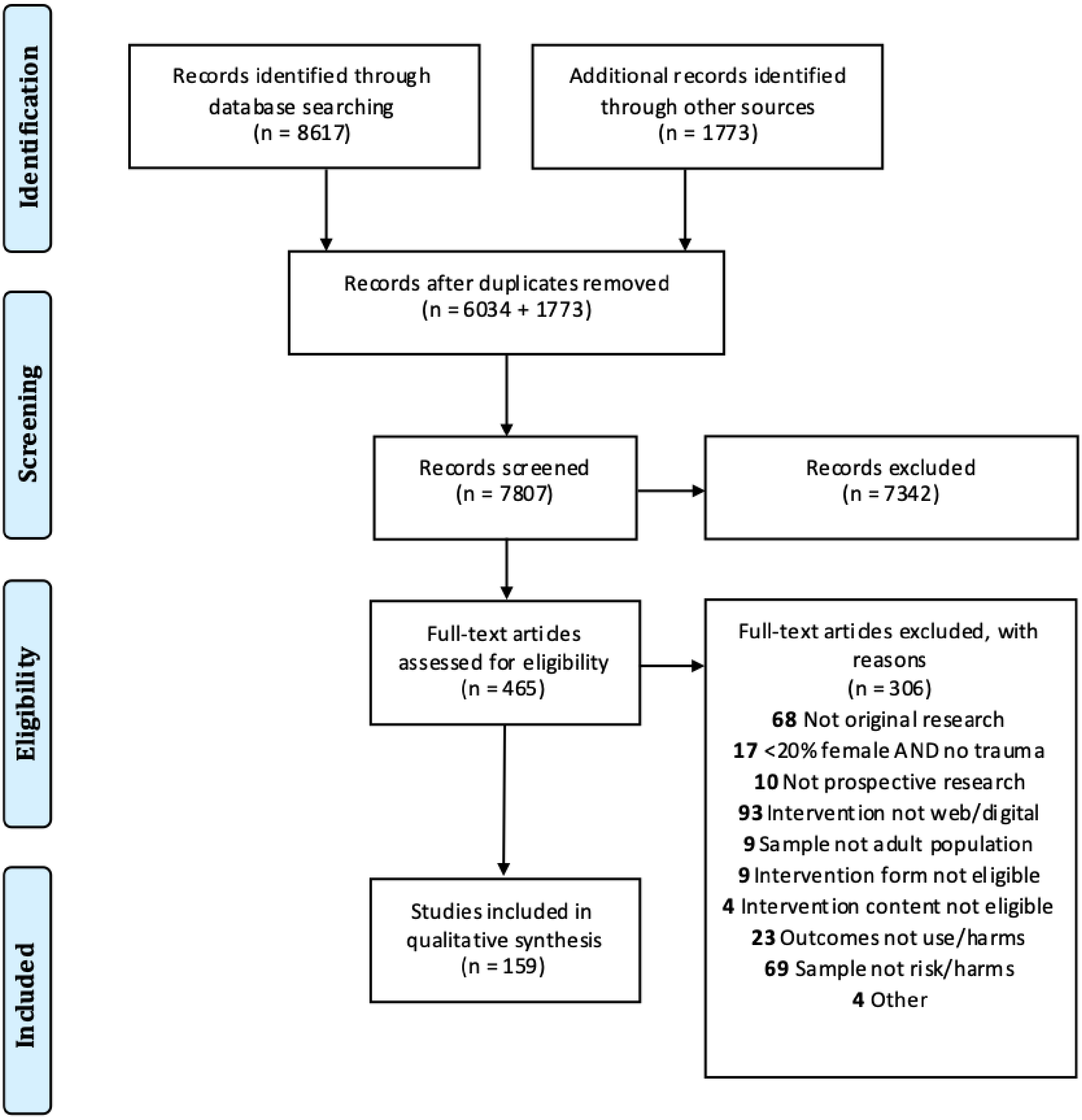
The Cochrane Risk of Bias Tool was used to evaluate bias at the study level across the following six domains: sequence generation, allocation concealment, blinding, incomplete data, selective reporting, and overall risk [31]. Each domain was given a rating of high, low, or some concerns of bias.

Results

Study Identification

The study selection process is illustrated in Figure 1. We located a total of 8617 published and 1773 grey literature records. A total of 7807 records remained after removing duplicates, and then, 465 remained following the screening of titles and abstracts. Records excluded at this first stage most commonly did not report original data or did not include critical design (eg, not original research and not a prospective design), sample (eg, adults with harmful/risk substance use), or intervention features (eg, online/mobile intervention targeting substance use or harms). Of the 465 remaining records, 306 were excluded because they did not include original (n=68) or prospective (n=10) research; did not include an adult sample (n=9) endorsing substance use risk or harms (n=69) with the minimum proportion of females/women or trauma (n=17); or did not include online or mobile interventions (n=93) targeting substance misuse (n=23). A total of 159 records were therefore included in this review. These 159 records reflected 141 distinct studies, including 125 distinct interventions.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram.



Study Characteristics

The study characteristics are provided in Table 1. In-depth characteristics of the included studies are described in Multimedia Appendix 2 and Multimedia Appendix 3, and the intervention characteristics are shown in Multimedia Appendix 4. The majority of studies were conducted in the United States (94/161, 58.4%). The other locations were the European Union (38/161, 23.6%), United Kingdom (7/161, 4.3%), Australia and New Zealand (11/161, 6.8%), Canada (7/161, 4.3%), and others (<4%). Studies included one to six conditions (mean 2.3, median 2), with the majority (n=149) randomizing participants to conditions. The majority of studies included control conditions (n=115), including treatment as usual (n=31), assessment only (n=20), waitlist (n=12), and other control conditions specifically relevant to the research question. Sample sizes ranged from 13 to 4165 (mean 453, median 217), and sample types included clinical (50/159, 31.4%), community (56/159, 35.2%), college/university (40/159, 25.2%), and veteran samples (7/159, 4.4%) and others (5/159, 3.1%). The mean age of the participants ranged from 18 to 53 years (mean 31.83, median 34). The majority of studies were focused on alcohol use, risks, and/or harms (109/159, 68.5%), although a substantial minority focused on multiple substances or any substance (28/159, 17.6%), cannabis specifically (12/159, 7.5%), opioids specifically (4/159, 2.5%), or other specific substances (<3% each).

Table 1. Characteristics of the included studies (N=159).

Parameters and characteristics	Studies, n (%)[a]
Study metadata	
Study design	
Randomized controlled trial	122 (76.3%)
Secondary analyses	18 (11.3%)
Single-arm studies	19 (11.9%)
Location[b]	
United States	94 (58.4%)
Canada	7 (4.4%)
European Union	38 (23.6%)
United Kingdom	7 (4.4%)
South America	1 (0.6%)
Australia and New Zealand	11 (6.8%)
Asia	3 (1.9%)
Population characteristics	
Sample size	
≤100	41 (25.6%)
101-500	66 (41.3%)
501-1000	39 (24.4%)
>1000	14 (8.8%)
Mean age (years)[c]	31.83
Percentage women/female	
≤10%	3 (1.9%)
11%-50%	95 (59.4%)
51%-99%	54 (33.8%)
100%	8 (5.0%)
Study characteristics	
Target substance	
Alcohol	110 (69.2%)
Cannabis	12 (7.6%)
Opioids	4 (2.5%)
Any substance	28 (17.6%)
Other substances	5 (3.1%)
Conducted sex- and gender-based analyses	
Yes	27 (17.0%)
No	123 (77.3%)
N/A[d]	9 (5.7%)
Assessed gender	
Yes	19 (12.0%)
No	140 (88.0%)
Assessed trauma	
Yes	13 (9.1%)

Parameters and characteristics	Studies, n (%)[a]
No	147 (90.9%)
Intervention characteristics (n=190)	
Language	
English	150 (79.0%)
Spanish	3 (1.6%)
Swedish	15 (7.9%)
German	6 (3.2%)
Norwegian	2 (1.1%)
Multiple	6 (3.2%)
Other	5 (2.6%)
Nature of the intervention	
Single-session intervention	68 (35.8%)
Multisession intervention	122 (64.2%)
Mode of delivery	
Mobile (app)	27 (14.2%)
Mobile (text)	13 (6.8%)
Online	148 (77.9%)
Combined (online + mobile)	2 (1.1%)

[a] Percentages were rounded and may not sum to 100.

[b] Numbers do not add up to 159 as two studies were conducted in multiple locations.

[c] Mean age was not reported in nine studies.

[d] N/A: not applicable.

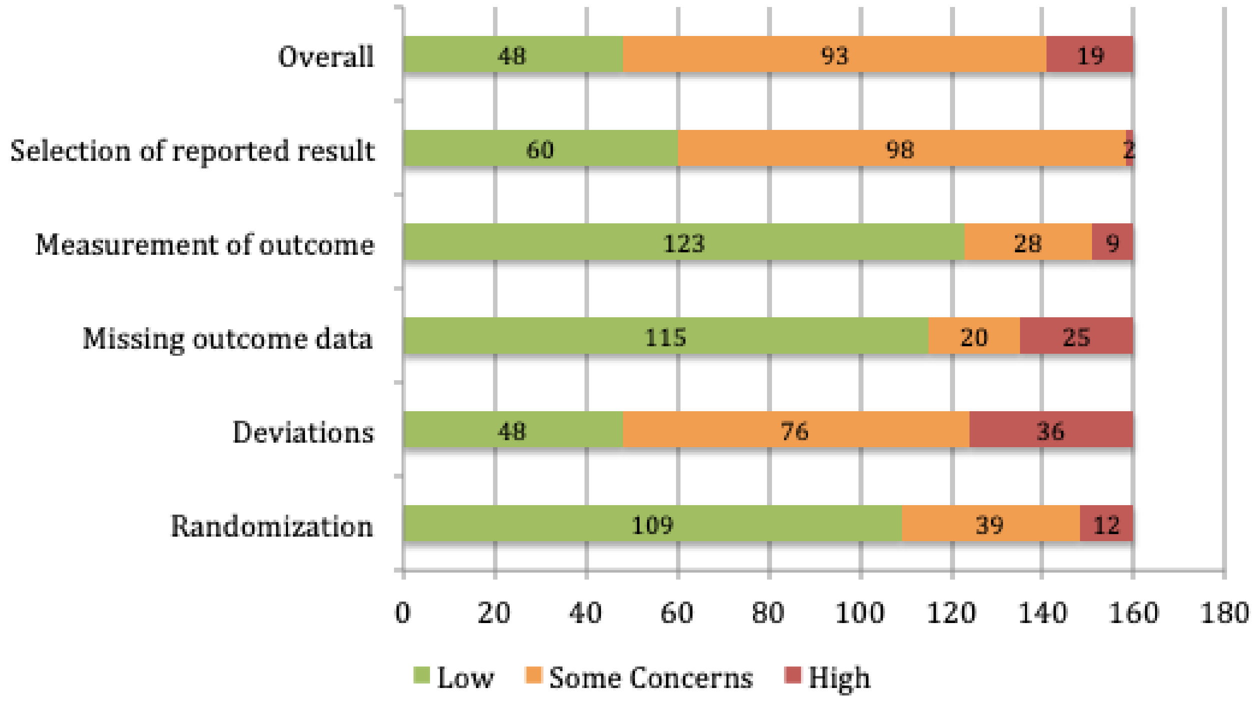
Intervention Characteristics

Digital health resources included multisession interventions (122/190, 64.2%) with multiple components or modules, such as screening and assessment, motivational enhancement, psychoeducation, and cognitive and behavioral skills building. Multisession interventions were available online (82/122, 67.2%), on mobile devices (mobile apps [25/122, 20.5%] and text [13/122, 10.7%]), and in a combination of both online and mobile methods (2/122, 1.6%). A substantial minority comprised single-session interventions (68/190, 35.8%), which were primarily available online (67/68, 99%) rather than on mobile devices (mobile apps [1/68, 2%]). There were no single-session interventions that were provided over text or that comprised a combination of both online and mobile methods. Each of these broad categories of digital health resources will be discussed in turn below. The digital health intervention duration ranged from one session (n=68) to 12 months, with other frequent durations including 4 weeks (n=7), 8 weeks (n=10), and 12 weeks (n=28). A substantial minority did not report or include a follow-up period (n=35). Follow-up durations ranged from 2 weeks to 2 years, with the most frequent periods including 1 month (n=37), 3 months (n=49), and 6 months (n=52). Overall, interventions were primarily in the English language (150/190, 78.9%), although others were available in multiple languages (6/190, 3.2%) or other specific languages such as Swedish (15/190, 7.9%) and others (German [6/190, 3.2%], Norwegian [2/190, 1.1%], Spanish [3/190, 1.6%], other [5/190, 2.6%]; all <4%). In line with the study focus as reviewed above, the majority of interventions themselves targeted alcohol use, risks, and/or harms (95/124, 76.6%) in their content, with a substantial minority including a treatment targeting multiple substances or any substance (15/124, 12.1%), cannabis specifically (11/124, 8.9%), or other specific substances or substance combinations (<2% each).

Study Quality or Bias

Overall, the majority of studies were found to exhibit features associated with some concerns of bias (93/160, 58.1%), with 11.9% (19/160) associated with high bias and 30.0% (48/160) associated with low bias, according to the Cochrane Risk of Bias Tool (Figure 2). More specifically, 68.1% (109/160) of studies were evaluated to have low bias associated with the randomization process (Domain 1), suggesting that adequate processes were put in place within these studies to minimize issues with randomization. The 39 studies associated with some concerns reported limited information on randomization methods or the concealment of assigned interventions, while the 12 with high bias did not randomize participants.

Figure 2. Risk of bias distributions.



Domain 2 examined the risk of bias due to deviations from the intended interventions. Approximately 48% (76/160, 47.5%) of studies were evaluated as having some concerns of bias in this domain, mostly due to the use of analyses that were not appropriate to estimate the effect of assignment to the intervention, or the lack of adequate information regarding deviations from the planned protocol. The 22.5% (36/160) of studies with high bias tended to have issues regarding both of these points, whereas the 30.0% (48/160) of studies with low bias used intention-to-treat analyses to estimate the effect of assignment and had adequate blinding measures in place.

Domain 3 examined risk of bias due to missing outcome data, with 71.9% (115/160) of studies being evaluated as having low bias. Low bias in this domain signified that outcome data were available for nearly all participants or that adequate measures were put in place to evaluate bias due to missing outcome data. The 12.5% (20/160) of studies with some concerns were evaluated as such if it was possible that the results were biased by missing outcome data, such that study withdrawal occurred due to participants' health status, whereas the 15.6% (25/160) of studies with high bias were evaluated as such if it was *likely* that study withdrawal occurred for this reason.

Domain 4 examined risk of bias in measurement of the outcome variables. Approximately 77% (123/160, 76.9%) of studies were evaluated to have low bias in this section, due to appropriate outcome measures being used and appropriate blinding if outcomes were assessed by outcome assessors or participant blinding if outcomes were assessed using self-report measures. The 17.5% (28/160) of studies evaluated as having some concerns in this domain were characterized by some likelihood that measures of outcomes could have been influenced by the intervention received, and the 5.6% (9/160) of studies rated as having high bias in this domain were found to have inadequate information in this regard.

Domain 5 examined risk of bias in the selection of the reported results. Approximately 61% (98/160, 61.3%) of studies were rated as having some concerns in this domain, particularly due to lack of prespecified analysis plans. The 37.5% (60/160) of studies with low risk of bias were found to have prespecified analysis plans and report all outcome measures and analyses in accordance with these plans. The 1.3% (2/160) of studies evaluated as having high risk of bias were found to be potentially selective in reporting outcome measurements and analyses, based on the results. All domains were coded according to a standardized scoring algorithm. Detailed information regarding the risk of bias for each study is presented in Multimedia Appendix 5. See Multimedia Appendix 6 for the references for all studies.

Study Outcomes

Overall, studies concluded that digital health resources for substance use or associated harms were efficacious or effective (155/190, 81.6%). The proportion of participants who identified as female or women ranged from 7% to 100% (mean 48%, median 46%; six studies were below 20%, but were eligible as over 20% endorsed trauma). In the vast majority of cases, participants identified as female, as only 16 studies explicitly assessed gender identity. Many studies appeared to use the terms sex and gender interchangeably (n=41). For example, indicating that gender was assessed (rather than sex) and specifying that reported genders were female and male. Sex- and gender-based analyses were conducted in only 17.0% (27/159) of studies, with 77.4% (123/159) of studies not conducting such analyses and 5.7% (9/159) not applicable (ie, no females or women were included in the sample, or the sample included only females or women). Thus, although digital health resources were found to be efficacious or effective in general, this was quantitatively confirmed for females or women in only 13.7% (26/190) of studies, with 81.1% (154/190) of studies not reporting relevant analyses and 5.3% (10/190) finding that the intervention was not effective for female or women participants. Only 13 of the studies reported that at least 20% of participants had a trauma history, and only seven of these reported that at least 20% of participants were female or women, *and* reported trauma (ie, six studies included at least 20% of participants with a trauma history, but less than 20% were female or women; these studies were nevertheless retained to present the nature of the evidence for those who have been exposed to violence or trauma). These studies included two studies of single-session interventions as follows: BSAFER (developed for any substance [32]; demonstrated effectiveness at a 3-month follow-up in a small sample) and VetChange (developed for alcohol [33]; demonstrated effectiveness over 1, 3, and 6 months). Two studies evaluated a mobile app (A-CHESS) developed for any substance and delivered over 6 to 8 months, which demonstrated effectiveness in an entirely female sample [34], as well as a mixed sample [35], although sex- or gender-based analyses were not conducted in the latter. Another study evaluated a mobile text message intervention for alcohol in young adults following emergency room treatment, with improvements at a 3-month follow-up [36]. Finally, two widely investigated interventions (CBT4CBT and TES) developed for any substance and delivered over 12 weeks were evaluated in samples involving females and trauma, and although both interventions were effective, sex- or gender-based analyses were not conducted [37,38].

A total of 122 study conditions comprised online multisession interventions, primarily targeting alcohol (n=53) or any substance (n=19), although more targeted interventions for cannabis and opioids were present as well. These interventions included both openly available and commercial products, which varied in their provision of screening, assessment, or monitoring; however, most included psychoeducation, goal setting, cognitive and behavioral skills training, and links to resources. Primary outcomes were most frequently substance consumption, although substance use harms or substance use disorder symptoms were also included. Overall, 87% (73/84) of these relatively intensive interventions exhibited acute impacts on primary outcomes following up to 8 or 12 weeks of treatment; in some cases, these were retained in subsequent follow-up assessments.

Mobile interventions included both apps (n=27) and text-based messaging interventions (n=13). Mobile apps targeted alcohol (n=21) and any substance (n=4) or cannabis (n=3), and 87% (73/84) of these apps demonstrated improvements in the primary outcomes after approximately 4 to 12 weeks of use. Text-based messaging interventions targeted alcohol (n=9) or cannabis (n=1), and 85% (11/13) demonstrated benefits following 2 to 12 weeks of use.

A total of 67 study conditions evaluated brief interventions, which were primarily delivered online (n=66) as compared to via a mobile device (n=1). The majority of these brief interventions addressed harmful or risky alcohol use, with only a small number addressing general drug use (n=10) or cannabis use (n=3). These brief interventions frequently took the form of noncommercial programs that provided initial screening and personalized normative feedback, as well as psychoeducation and resources. The primary outcome was most frequently substance consumption, primarily quantity or frequency (eg, number of standard alcoholic drinks per week and binge or heavy drinking frequency). Approximately 64% (43/67) of these brief interventions did exhibit short-term impacts on the primary outcomes.

Discussion

Principal Results

The empirical investigations of the efficacy or effectiveness of digital health resources for adults who identify as female or women, or who report a history of trauma, appear to be principally conducted in the United States and Europe, with the majority in the English language. These investigations and the interventions evaluated predominantly focused on alcohol use or associated harms/risks, although a substantial minority of investigations was broadly applicable to substance use in general. The majority of studies randomized participants to study conditions, with a range of active and control conditions evident across studies. Similar to other reviews of psychosocial interventions, a substantial proportion of investigations was judged to have some concerns associated with bias, primarily related to participant or assessor blinding, lack of intent-to-treat analysis, or lack of a reported prespecified or registered analytical plan. Lower bias was evident regarding randomization, missing data, and outcome measurement.

The digital health resources evaluated included multisession and brief (ie, single) session interventions, with a wide range of therapeutic elements. Across all interventions, the primary outcome was most frequently substance use quantity and frequency. More intensive online and mobile interventions, frequently several months or more in duration and including numerous therapeutic components, exhibited moderate to strong effects in the vast majority of studies. Brief interventions, which consisted of a single session of varied duration (but most commonly less than 1 hour), demonstrated efficacy in most studies, although it was notable that these effects decreased over longer follow-ups in many studies.

Overall, studies that included a substantial proportion of adults who identified as female or women concluded that digital health resources for substance use or associated harms were efficacious or effective (155/190, 81.6%). A minimum threshold of 20% of the sample identifying as female or women, or endorsing trauma, was implemented to ensure the relevance of evidence reviewed to the research question. This eligibility requirement resulted in the exclusion of a limited number of records (n=17), which shared many of the study and intervention features described above. Notably, in many contexts, a much higher proportion would be required to conduct sex- or gender-based analyses and to support generalizability to our target populations. In fact, the majority of studies did include 40% or more of participants who were female or women, with larger proportions more common in community and trainee samples. Yet, most investigations did not assess gender identity, and many used sex and gender terms interchangeably. Further, sex- or gender-based analyses were not conducted in the majority of studies (n=113); thus, direct or quantitative evidence for the efficacy or effectiveness of interventions in females or women specifically is weak.

Evidence for adults reporting a history of trauma was even more limited. Only 13 studies were found that met this liberal inclusion criterion, and even then, the association between trauma history and clinical outcomes was not evaluated. There is a critical need to assess and report trauma in the evaluation of digital health resources in this context to identify those most likely to be of benefit to adults with a trauma history. Of note, the current results appear unlikely to be the result of lower access to individuals with past or current experiences of violence and trauma. Among women presenting to treatment, significantly higher rates of sexual abuse have been observed in comparison to community samples of women meeting criteria for the diagnosis of substance use disorders, suggesting that experiences of trauma may play a role in the process of treatment initiation [10,39]. In fact, 61% of people in a population of treatment-seeking men and women specifically cited the experience of a recent traumatic event as the reason for seeking treatment for their substance misuse, demonstrating a clear need for a trauma-focused approach [39].

Comparison With Prior Work

Similar to the current investigation, previous systematic reviews and meta-analyses have highlighted the large number of digital interventions for alcohol, with a preponderance of brief interventions with small immediate benefits but low evidence for longer-term clinically significant effects [40]. Evidence for digital interventions for other substances is promising but more limited [41].

The most recent and focused investigation of digital health resources for women with substance use disorders focused on the childbearing age. Notably, the current broader synthesis noted that, in fact, there appears to be a dearth of studies in older adult samples as well as studies in other important groups. For example, studies in samples across the lifespan, across racial backgrounds, and with other important social determinants of health and those who face barriers to care (eg, rural communities, homeless or houseless individuals, forensic samples, and adults of varied physical and mental abilities) are critical to conduct. Thus, although a range of sample types was evident in the current review, future research would benefit from extending across the lifespan and including other types of samples with more varied demographic and clinical features.

Limitations

This investigation focused on a specific category of digital health resources, which necessarily limits its scope. The consideration of virtual psychotherapy, digital recovery support networks, and other forms of resources would be a valuable extension of this work. Similarly, this investigation focused on adults reporting or exhibiting substance use risks or harms, and interventions targeting substance use or associated risks or harms, which would preclude larger-scale population health interventions targeting a broader range of lower-risk individuals as well as interventions with lifestyle or health/wellness foci. Focused reviews of these broader groups and interventions would benefit a range of stakeholders. This review focused on adults who identify as female or women and neglected other sex and gender groups. Thus, increased attention to treatment outcomes across the gender continuum is needed. Finally, the incorporation of other key identity features, particularly those related to race, culture, and ethnicity, is critical to examine how the intersections of these different components of identity are linked to treatment outcomes. Very limited research in this area has been conducted to date, highlighting this key gap.

Conclusions

This project represents a synthesis of available evidence for digital health resources for adults who identify as female or women with substance use concerns. Although substance use has been increasing in these individuals, adults who identify as female or women are underrepresented in in-person clinical services and exhibit unique treatment barriers, preferences, and needs. Importantly, trauma is elevated in this group, highlighting the clinical priority of interventions that are sensitive to not only gender-specific psychoeducation and skills building, but also trauma-informed approaches. Although this synthesis simultaneously provides promising support for the therapeutic benefit of digital health resources for this priority population, it also highlights critical clinical and research priorities. Increased assessments of both sex and gender identities, and the implementation of sex- and gender-based analyses are critical in future empirical investigations of digital health resources. Increased integration of trauma and other key participant features is also needed to contribute to the further development of these interventions. Trauma, intersectionality, and key social determinants of health are critical to understand not only the value of these resources but also how to successfully implement them in varied geographical regions and health systems.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy for MEDLINE.
[DOCX File , 121 KB - mental_v8i6e25952_app1.docx]

Multimedia Appendix 2
Study demographic characteristics.
[DOCX File , 174 KB - mental_v8i6e25952_app2.docx]

Multimedia Appendix 3
Study design characteristics.
[DOCX File , 153 KB - mental_v8i6e25952_app3.docx]

Multimedia Appendix 4
Intervention characteristics.
[DOCX File , 85 KB - mental_v8i6e25952_app4.docx]

Multimedia Appendix 5
Risk of bias.
[DOCX File , 57 KB - mental_v8i6e25952_app5.docx]

Multimedia Appendix 6
References for articles included in the scoping review.
[DOCX File , 61 KB - mental_v8i6e25952_app6.docx]

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Original Paper

Factors Predicting Trial Engagement, Treatment Satisfaction, and Health-Related Quality of Life During a Web-Based Treatment and Social Networking Trial for Binge Drinking and Depression in Young Adults: Secondary Analysis of a Randomized Controlled Trial

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Abstract

Background: Mental health and alcohol use problems are among the most common causes of disease burden in young Australians, frequently co-occur (comorbidity), and lead to significant lifetime burden. However, comorbidities remain significantly underdetected and undertreated in health settings. Digital mental health tools designed to identify at-risk individuals, encourage help-seeking, or deliver treatment for comorbidity have the potential to address this service gap. However, despite a strong body of evidence that digital mental health programs provide an effective treatment option for a range of mental health and alcohol use problems in young adults, research shows that uptake rates can be low. Thus, it is important to understand the factors that influence treatment satisfaction and quality-of-life outcomes for young adults who access e–mental health interventions for comorbidity.

Objective: In this study, we seek to understand the factors that influence treatment satisfaction and quality-of-life outcomes for young adults who access e–mental health interventions for comorbid alcohol and mood disorders. The aim is to determine the importance of personality (ie, Big Five personality traits and intervention attitudes), affective factors (ie, depression, anxiety, and stress levels), and baseline alcohol consumption in predicting intervention trial engagement at sign-up, satisfaction with the online tool, and quality of life at the end of the iTreAD (Internet Treatment for Alcohol and Depression) trial.

Methods: Australian adults (N=411) aged between 18 and 30 years who screened positive for depression and alcohol use problems signed up for the iTreAD project between August 2014 and October 2015. During registration, participants provided information about their personality, current affective state, alcohol use, treatment expectations, and basic demographic information. Subsequent follow-up surveys were used to gauge the ongoing trial engagement. The last follow-up questionnaire, completed at 64 weeks, assessed participants' satisfaction with web-based treatment and quality-of-life outcomes.

Results: Multiple linear regression analyses were used to assess the relative influence of predictor variables on trial engagement, treatment satisfaction, and quality-of-life outcomes. The analyses revealed that the overall predictive effects of personality and affective factors were 20% or lower. Neuroticism constituted a unique predictor of engagement with the iTreAD study in that neuroticism facilitated the return of web-based self-assessments during the study. The return of incentivized follow-up assessments predicted treatment satisfaction, and state-based depression predicted variance in quality-of-life reports at study completion.

Conclusions: Our findings suggest that traditional predictors of engagement observed in face-to-face research may not be easily transferable to digital health interventions, particularly those aimed at comorbid mental health concerns and alcohol misuse among young adults. More research is needed to identify what determines engagement in this population to optimally design and execute digital intervention studies with multiple treatment aims.

Trial Registration: Australian New Zealand Clinical Trials Registry (ACTRN): 12614000310662; http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=365137&isReview=true.

International Registered Report Identifier (IRRID): RR2-10.1186/s12889-015-2365-2

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KEYWORDS

digital mental health; personality; negative affect; study engagement; life quality

Introduction

Background

Mental health and alcohol use disorders are the leading causes of disability among young adults globally [1,2]. This trend is reflected in Australia, with alcohol misuse and poor mental health reported as the primary contributors to disease burden among Australian youth, including young adults [3]. The burden of disease increases when substance use and mental health disorders co-occur. For example, comorbidity of alcohol use disorder and major depressive disorder is associated with elevated risks of alcohol dependence, higher instances of attempted suicide, and lower levels of functioning and life satisfaction [4,5]. Consequently, treatment prognoses for this population tend to be relatively poor [6,7].

Complicating the path to recovery, young Australians in their teens and 20s see their general practitioners or mental health professionals less frequently than their older counterparts [8]. Recent research found that across 1306 adults presenting for assessment of their general practitioners, comorbid alcohol use and major depressive disorders were correctly detected in only 21% of cases [9]. This situation highlights the need to improve the identification of comorbid disorders because high nondetection rates constitute a major barrier to access appropriate and timely treatment.

Digital technologies offer a promising opportunity to identify comorbid disorders and enhance access to high-quality mental health care for young adults [10,11]. Digital services can function as stand-alone programs or in conjunction with face-to-face or web-based clinical support. These types of services are acceptable to young people and align with recent findings that young people use digital apps for numerous purposes (including supporting their health and well-being) at a greater rate than any other age group [12]. Previous research indicates that 44% of Australians aged between 16 and 25 years use the internet to access health information [13]. A recent review found that face-to-face help-seeking among young people aged between 12 and 25 years may improve after using computerized mental health programs and services [14]. However, sustained engagement with digital interventions has proved difficult, and limited participation and high attrition rates are common [11]. This is concerning because the amount of exposure to an intervention is often an important prerequisite for intervention outcomes [15].

Studies that have evaluated engagement in digital health interventions suggest that it may be an important contributor to participant satisfaction and quality of life at the conclusion of a research study or treatment program. For example, in a post hoc analysis of a randomized controlled trial evaluating the effectiveness of an online support group on primary care patients' mental health, Geramita et al [16] found that those who engaged more frequently with a study-specific online support group reported significant improvements in health-related quality of life 6 months after the trial phase had ended compared with participants who had engaged the least. Consequently, evaluating engagement with mental health treatment protocols has been identified as critical for improving intervention impact and success [17]. Although engagement with digital interventions is not identical to engagement in clinical trials of these interventions, dropout rates in clinical trials can reflect disengagement rates with digital interventions in naturalistic settings when sample bias and trial *push factors* are kept to a minimum [18-20].

Person-based characteristics can predict engagement with health treatment protocols and intervention success in younger adult samples. In particular, personality patterns, such as high levels of conscientiousness and low levels of neuroticism, predicted adherence to study protocols in trials for smoking cessation therapy, asthma control, and health-related quality of life [21-23], whereas negative emotional states and unfavorable attitudes toward treatments can negatively influence engagement and treatment satisfaction displayed by young adults in clinical trials across a variety of health conditions [24-29]. Personality patterns of low conscientiousness, high neuroticism, and extraversion have consistently been associated with problematic levels of alcohol consumption among adolescents and young adults [30], indicating that personality may influence both the formation of and recovery from health-related complications in young adulthood. This highlights the usefulness of considering young adults' personality, affect, and treatment beliefs as predictors of engagement with study protocols. Clarifying the unique role played by each of these factors may help to remedy the poor uptake of web-based mental health interventions [11,31].

Objectives

This study aims to examine the relative importance of personality factors (ie, conscientiousness and neuroticism), negative emotional states (ie, stress, anxiety, and depression), recent alcohol use, and treatment expectations in predicting engagement with a web-based mental health study designed to reduce depressive symptoms and incidences of heavy episodic drinking (*binge drinking*) in young adulthood. In addition, we examined the predictive strength of personality, negative emotions, alcohol consumption, treatment expectations, and study engagement on participants' self-reported treatment satisfaction and quality of life at the end of the web-based mental health study. Specifically, it was hypothesized that a pattern of low neuroticism, high conscientiousness, lower emotional distress, lower alcohol consumption, and greater expectations of treatment success at sign-up would predict higher levels of subsequent study engagement, treatment satisfaction, and quality-of-life ratings at the last assessment point. It was further predicted that higher study engagement levels during the trial would predict greater treatment satisfaction and quality of life at the last assessment point. To our knowledge, this is the first study to assess these predictors simultaneously within a randomized controlled trial design that evaluates the effectiveness of a web-based mental health program to reduce the severity of comorbid substance use disorder and major depression among young Australian adults. In doing so, our study seeks to contribute to the literature on web-based mental health program acceptance among young adults in line with the recommendations of Clarke et al [11].

Methods

Overview

The iTreAD (Internet Treatment for Alcohol and Depression) trial study protocol was prospectively registered with the Australian and New Zealand Clinical Trials Registry (ACTRN12614000310662) and approved by the UNSW Sydney Human Research Ethics Committee (HC13299). The protocol has been previously published [32].

Participants and Procedures

Recruitment to iTreAD occurred between August 2014 and October 2015. Following an initial screener, a total of 421 eligible candidates from Australia (aged between 18 and 30 years) who reported current depressive symptoms and alcohol misuse and had internet access completed the informed consent process and baseline survey and were randomly allocated to one of three conditions: (1) web-based self-assessments, (2) web-based self-assessments with an additional digital mental health program, or (3) web-based self-assessments, digital mental health programs, and an additional clinician-guided digital forum (refer Kay-Lambkin et al [32] for further details on the study design). In total, 10 participants subsequently withdrew their consent to participate in the iTreAD study and were removed from the analysis. The final sample consisted of 411 participants, of which 135 were allocated to the web-based self-assessment control group, 131 to the web-based self-assessment and digital mental health program group, and 145 to the joint web-based self-assessment, digital mental health program, and clinician-guided forum group. Most participants were female (252/411, 61.3%) and had a mean age of 23 (SD 3.67) years.

The overall study duration was 64 weeks. During this time, all participants were asked to complete 12 monthly web-based self-assessments and four follow-up surveys at 26, 39, 52, and 64 weeks after their initial baseline assessment. Participants were reimbursed up to Aus $20 (US $15.44) for their baseline assessment and for each follow-up assessment they completed, regardless of participation rates in any of the three study conditions. No reimbursement was provided for the 12-monthly web-based self-assessments. Only participants allocated to either of the two treatment groups gained access to their respective web-based intervention components.

Measures

Personality

Conscientiousness was measured using the 9-item *Conscientiousness* subscale of the Big Five Inventory (BFI) [33], which asks participants to rate their agreement with statements such as, "I see myself as someone who does a thorough job." Neuroticism was measured using the 2-item *Neuroticism* subscale of the BFI short form [34], which asks participants to rate their agreement with statements such as, "I see myself as someone who gets nervous easily." Both the long and short forms of the BFI have been found to be reliable and valid measures of the Big Five trait dimensions [33-36].

Negative Affective States

Recent experiences of negative affective states were measured using the Depression, Anxiety, and Stress Scale-21 items (DASS-21) [37]. The DASS-21 has been demonstrated to have good psychometric properties in clinical, nonclinical, and adolescent samples and has been used in previous research assessing affective states of web-based intervention users [38-40]. An example item for depression is, "I couldn't seem to experience any positive feeling at all."

Alcohol Consumption

Heavy drinking and probable alcohol dependence were assessed using the 3-item Consumption Short Form of the Alcohol Use Disorders Identification Test-Concise (AUDIT-C) [41]. The AUDIT-C is a valid and reliable measure to screen for possible alcohol use disorders similar to the AUDIT long form [41,42]. An example item is, "How often did you have six or more drinks on one occasion?" with responses ranging from 0 (*never*) to 4 (*daily*). Overall AUDIT-C scores range from 0 to 12, with a score of 3 or above warranting further assessment of whether an alcohol use disorder may be present.

Treatment Expectations and Satisfaction

Treatment expectations at the beginning of the study were measured by asking participants, “By the end of treatment, how much improvement in binge drinking and depression do you think could occur as a result of internet delivered treatment?” Participants responded to this question in increments of 10 points ranging from the lowest (0-10) to highest expected improvement (91-100). Treatment satisfaction at the end of the study was measured using the general 8-item Client Satisfaction Questionnaire [43], which has demonstrated concurrent validity among Australians seeking treatment for alcohol and substance abuse [44]. An example item for client satisfaction is, “In an overall general sense, how satisfied are you with the service you received?”

Study Engagement

We considered returned web-based self-assessments (0-12) and follow-up questionnaires (0-4) as indicators of participants’ engagement with the iTreAD study. Web-based self-assessments were part of the iTreAD treatment protocol because reflecting on one’s recent mood and alcohol consumption was thought to have a mild therapeutic effect [45], and the completion of follow-up questionnaires constituted an indicator of study adherence. Thus, the self-assessments and follow-up questionnaires captured elements of treatment and study protocol engagement in the iTreAD trial. No other engagement indices were shared across the experimental and control groups.

Quality of Life

Participants’ health-related quality of life was assessed using the 20-item standard version of the Assessment of Quality of Life questionnaire (AQoL-6D) [46]. The instrument considers various physical and psychological indicators of quality of life and general functioning. The validity of its components has been confirmed in Australian adult samples [47]. An example item is, “How often do you feel in control of your life?” Higher scores on the AQoL-6D were indicative of *lower* perceived quality of life.

Analytic Plan

With regard to the primary outcomes of the iTreAD trial, multilevel regression models revealed significant decreases in depression severity and binge drinking episodes throughout the study; however, these improvements did not vary by treatment condition (Kay-Lambkin et al, unpublished data, April 2021). This pattern of results suggested that there were no systematic differences between groups in the outcome measures, either at baseline or as a result of any intervention. Therefore, we collapsed the three trial conditions across all outcome measures to retain a sufficiently powered sample size for the analysis regarding study engagement. After collapsing across groups, 390 participants completed all relevant measures at registration. A total of 190 participants completed the treatment satisfaction questionnaire, and 191 participants completed the quality-of-life assessment at the last assessment point at 64 weeks. This reduction in available data was because of the study attrition and optional completion of the questionnaire components. Using G*Power 3.1 (Heinrich Heine University Düsseldorf) [48], power calculations indicated that a sample size of 205 was required to detect small-to-medium effects typical in personality research with α of .05, a power of 0.80, and 9 predictor variables. These power calculations indicated that the treatment satisfaction and quality-of-life analyses were slightly underpowered and would be more suitable for detecting medium-sized effects.

Predictor variables were identified based on the literature, indicating a likely impact on engagement. These variables were the personality traits of conscientiousness and neuroticism, the negative affective states of depression, anxiety, stress, alcohol use, and treatment expectations at the outset of the study. The BFI subscales of neuroticism and conscientiousness were used to describe personality trait dimensions. The DASS-21 subscales of depression, anxiety, and stress were used as predictor variables of negative affect. AUDIT-C scores were used to indicate alcohol consumption levels, and the single-item measure “By the end of treatment, how much improvement in binge drinking and depression do you think could occur as a result of internet delivered treatment?” assessed at baseline was used as a proxy for treatment expectations. The total number of returned study questionnaires (ie, web-based self-assessments and follow-up questionnaires) were computed to describe indices of study engagement. The sum scores of the 8-item Client Satisfaction Questionnaire and AQoL-6D were used to measure treatment satisfaction and quality of life, respectively, at the end of the study.

Multiple linear regression analyses were performed using SPSS Statistics for Windows, version 25 (IBM Corporation) to assess the extent to which baseline levels of personality, negative affect, alcohol consumption, and treatment expectations might predict subsequent study engagement and to assess the ability of personality, negative affect, alcohol consumption, treatment expectations, and study engagement to predict treatment satisfaction and quality of life at the end of the study. The resulting prediction models reveal the unique and combined contributions of the predictor variables that help explain the proportion of the total variance of each outcome variable. As we considered three outcomes, we tested a total of three model predictions.

Results

Sample Characteristics

Table 1 presents the descriptive and between-group statistics of the iTreAD study participants. There were no significant differences in key variables between groups, including treatment satisfaction at the end of the study (mean 23.90, SD 5.17; $F_{2,196}$=2.14; P=.12), except for engagement. On average, participants in the control condition returned around two additional questionnaires (mean 6.51, SD 4.19) from the web-based self-assessment component compared with participants in experimental conditions 1 (mean 3.75, SD 3.87) and 2 (mean 4.43, SD 4.19; $F_{2,408}$=16.59; P<.001). It is possible that these differences were because of limited engagement options in the control condition (ie, questionnaire assessment only), whereas the experimental conditions offered web-based activities in addition to the questionnaire completion options.

Table 1. Scale response anchors: means, SDs, and between-group statistics on key variables.

Variable	Scale anchors	Control group (n=135)		Experimental group 1 (n=131)		Experimental group 2 (n=145)		*F* test (df)	*P* value
	Range	Mean (SD)	n[a] (%)	Mean (SD)	n[a] (%)	Mean (SD)	n[a] (%)		
Age (years)[b]	18-30	23.24 (3.59)	129 (95.6)	23.2 (3.67)	128 (97.7)	23.68 (3.74)	134 (92.4)	0.71 (2, 388)	.494
Conscientiousness	1-5	3.35 (0.66)	128 (94.8)	3.25 (0.65)	128 (97.7)	3.26 (0.66)	138 (95.2)	0.82 (2, 391)	.44
Neuroticism	1-5	3.84 (1.06)	127 (95.1)	3.87 (1.02)	128 (97.7)	3.84 (1.08)	138 (95.2)	0.03 (2, 390)	.97
Depression	0-42	25.22 (9.53)	133 (98.5)	26.43 (8.5)	130 (99.2)	25.74 (9.40)	144 (99.3)	0.58 (2, 404)	.56
Anxiety	0-42	16.72 (8.78)	133 (98.5)	17.88 (8.74)	130 (99.2)	17.97 (9.87)	144 (99.3)	0.78 (2, 404)	.46
Stress	0-42	23.56 (8.30)	133 (98.5)	24.97 (8.51)	130 (99.2)	24.71 (8.49)	144 (99.3)	1.05 (2, 404)	.35
Alcohol consumption	0-12	7.66 (1.99)	135 (100)	7.55 (2.16)	131 (100)	7.57 (2.05)	143 (98.6)	0.11 (2, 406)	.90
Treatment expectation	0-100	46.23 (22.04)	130 (96.3)	47.44 (21.77)	129 (98.5)	45.07 (22.48)	138 (95.2)	0.38 (2, 394)	.68
Self-assessments	0-12	6.51 (4.19)	135 (100)	3.75 (3.87)	131 (100)	4.43 (4.19)	145 (100)	16.59 (2, 408)	<.001
Follow-ups	0-4	2.35 (1.61)	135 (100)	1.92 (1.73)	131 (100)	2.14 (1.66)	145 (100)	2.21 (2, 406)	.11
Treatment satisfaction[c]	8-32	22.9 (5.72)	72 (53.3)	24.56 (4.84)	57 (43.5)	24.39 (4.73)	70 (48.3)	2.14 (2, 196)	.12
Quality of life[d]	20-99	39.51 (9.63)	73 (54.1)	40.28 (11.24)	57 (43.5)	41.27 (11.67)	70 (48.3)	0.48 (2, 197)	.62

[a] Responses to items were optional. Actual numbers ranged from 57 to 145 per group.

[b] Age, personality, emotional distress, and treatment expectation statistics were computed at registration.

[c] Treatment satisfaction and quality of life were assessed at trial completion after 64 weeks postbaseline.

[d] Lower scores on the quality-of-life measure indicate higher life quality.

Table 2 lists Pearson correlations between variables. Conscientiousness showed consistent weak-to-moderate negative correlations with neuroticism, depression, anxiety and stress levels, and alcohol consumption (*r* ranged between −0.20 and −0.26) and was associated with higher levels of study engagement (the correlation with self-assessment returns was *r*=0.12 and with follow-up returns was *r*=0.11) and higher reported quality of life at the end of iTreAD at 64 weeks (*r*=−0.25). Conversely, higher initial reported stress and anxiety levels as well as alcohol consumption were negatively associated with web-based self-assessment returns (*r*=−0.15 and *r*=−0.12, respectively), and higher initial levels of alcohol consumption were negatively associated with returns of follow-up assessments (*r*=−0.14). Neuroticism and negative affect at baseline showed moderate correlations with decreased quality of life at the 64-week follow-up (*r* ranged between 0.23 and 0.41). In addition, lower perceived quality of life was associated with lower levels of treatment satisfaction at the 64-week follow-up (*r*=−0.20). Treatment satisfaction was positively correlated with the number of returned follow-up assessments (*r*=0.18) in this study.

Table 2. Pearson correlations between key variables[a].

Variable	1	2	3	4	5	6	7	8	9	10
1. Conscientiousness										
r	—[b]	—	—	—	—	—	—	—	—	—
P value	—	—	—	—	—	—	—	—	—	—
2. Neuroticism										
r	−0.24	—	—	—	—	—	—	—	—	—
P value	<.001	—	—	—	—	—	—	—	—	—
3. Depression										
r	−0.24	0.20	—	—	—	—	—	—	—	—
P value	<.001	<.001	—	—	—	—	—	—	—	—
4. Anxiety										
r	−0.26	0.44	0.45	—	—	—	—	—	—	—
P value	<.001	<.001	<.001	—	—	—	—	—	—	—
5. Stress										
r	−0.20	0.46	0.53	0.69	—	—	—	—	—	—
P value	<.001	<.001	<.001	<.001	—	—	—	—	—	—
6. Alcohol consumption										
r	−0.12	−0.06	0.21	0.11	0.12	—	—	—	—	—
P value	.02	.21	<.001	.02	.02	—	—	—	—	—
7. Treatment expectation										
r	0.08	−0.00	0.07	0.08	0.13	−0.07	—	—	—	—
P value	.10	.96	.18	.13	.01	.18	—	—	—	—
8. Self-assessments										
r	0.12	0.05	−0.07	−0.15	−0.12	−0.08	0.05	—	—	—
P value	.02	.35	.18	.003	.02	.10	.32	—	—	—
9. Follow-ups										
r	0.11	0.03	−0.03	−0.10	−0.06	−0.14	0.08	0.70	—	—
P value	.03	.56	.49	.05	.22	.006	.09	<.001	—	—
10. Treatment satisfaction										
r	0.04	0.05	−0.04	0.06	0.04	−0.11	0.14	−0.01	0.18	—
P value	.54	.53	.56	.43	.54	.14	.05	.90	.01	—
11. Quality of life[c]										
r	−0.25	0.23	0.41	0.35	0.40	0.08	−0.01	−0.05	−0.13	−0.20
P value	<.001	.001	<.001	<.001	<.001	.25	.93	.44	.08	.005

[a] Personality, emotional distress, and treatment expectation statistics were computed at registration; treatment satisfaction and quality of life were assessed at trial completion 64 weeks postbaseline. Responses to items were optional. Actual n ranged between 192 and 415.

[b] Not applicable.

[c] Lower scores on the quality-of-life measure indicated higher life quality.

Regression Models

For model 1, personality, negative affect, alcohol consumption, and treatment expectation variables were included as predictors of iTreAD study engagement, as indicated by the return of web-based self-assessments (Table 3) and follow-up questionnaires (Table 4). The models predicting self-assessment ($F_{7,382}$=3.09; *P*=.003) and follow-up returns ($F_{7,382}$=2.61; *P*=.01) were significant. However, the predictors only accounted for about 5% of the variance in study engagement (R^2=0.05), indicating that personality, negative affect, alcohol consumption, and expectations of treatment success together played a minor role in determining continuous study participation. Neuroticism remained a statistically significant predictor of study engagement, although its unique predictive power was low. Neuroticism alone accounted for approximately 2% of the variance in web-based self-assessments. In other words, an increase of about one point (0.71) in the neuroticism dimension was predictive of returning an additional web-based self-assessment.

Table 3. Standard regression results for personality, negative affect, and treatment expectations predicting engagement with web-based self-assessments (n=390)[a].

Model	*b* (SE)	β	Pearson *r*	*sr* [b]	Structure coefficient
Constant	1.81 (1.93)	N/A[c]	N/A	N/A	N/A
Conscientiousness	0.67 (0.34)	.10	0.12	0.10	0.500
Neuroticism[d]	0.71 (0.24)	.18	0.05	0.15	0.203
Depression	0.02 (0.03)	.04	−0.07	0.03	−0.289
Anxiety	−0.07 (0.03)	−.14	−0.14	−0.10	−0.595
Stress	−0.05 (0.04)	−.10	−0.11	−0.07	−0.474
Alcohol consumption	−0.06 (0.11)	−.03	−0.11	−0.03	−0.319
Treatment expectation	0.01 (0.01)	.07	0.05	0.06	0.228

[a] R^2=0.05; adjusted R^2=0.04.

[b] *sr*: the semipartial correlation.

[c] N/A: not applicable.

[d] $P<.01$.

Table 4. Standard regression results for personality, negative affect, and treatment expectations predicting engagement with follow-up questionnaires (n=390)[a].

Model	*b* (SE)	β	Pearson *r*	*sr* [b]	Structure coefficient
Constant	1.81 (0.75)	N/A[c]	N/A	N/A	N/A
Conscientiousness	0.23 (0.13)	.09	0.11	0.09	0.519
Neuroticism	0.18 (0.09)	.12	0.04	0.10	0.164
Depression	0.01 (0.01)	.04	−0.05	0.03	−0.243
Anxiety	−0.02 (0.01)	−.09	−0.09	−0.07	−0.435
Stress	−0.01 (0.02)	−.06	−0.07	−0.04	−0.313
Alcohol consumption	−0.08 (0.04)	−.10	−0.13	−0.10	−0.617
Treatment expectation	0.01 (0.00)	.08	0.08	0.08	0.393

[a] R^2=0.05, adjusted R^2=0.03.

[b] *sr*: the semipartial correlation.

[c] N/A: not applicable.

Model 2 (presented in Table 4) examined the predictive strength of personality, negative affect, treatment expectations, and study engagement on participants' satisfaction with the iTreAD program. Contrary to expectations, the overall model only approached significance ($F_{9,180}$=1.90; P=.06), indicating that the variance of satisfaction with the treatment program could not be explained by the prediction model. However, the study engagement variable of follow-up assessments showed a significant association with treatment satisfaction in the overall model. The return of follow-up assessments explained 2.5% of the variance in treatment satisfaction, whereby the completion of about 2 (1.6) additional questionnaires was predictive of a 1-point increase in treatment satisfaction.

Personality, negative affect, treatment expectations, and study engagement were used to predict the self-reported quality of life at study cessation in model 3 (Tables 5 and 6). The prediction model was significant ($F_{9,181}$=6.34; P<.001). The combined predictors accounted for approximately 20% of the variance in quality of life (R^2=0.24; adjusted R^2=0.20). Only depression scores at baseline had a significant influence on subsequent quality-of-life ratings and, given the other variables in the model, only accounted for about 3% of the variance in quality of life. In other words, a 0.3-point increase on the DASS-21 depression measure uniquely accounted for a 1-point increase on the AQoL-6D (ie, a 1-unit decrement in life quality).

Table 5. Standard regression results for personality, negative affect, treatment expectations, and study engagement predicting treatment satisfaction (n=190)[a].

Model	*b* (SE)	β	Pearson *r*	*sr* [b]	Structure coefficient
Constant	16.78 (3.88)	N/A[c]	N/A	N/A	N/A
Conscientiousness	0.32 (0.63)	.04	0.06	0.04	0.194
Neuroticism	0.23 (0.43)	.05	0.05	0.04	0.180
Depression	−0.06 (0.05)	−.11	−0.07	−0.09	−0.252
Anxiety	0.03 (0.06)	.06	0.05	0.04	0.167
Stress	0.03 (0.07)	.04	0.03	0.03	0.099
Alcohol consumption	−0.10 (0.19)	−.04	−0.09	−0.04	0.310
Treatment expectation	0.03 (0.02)	.13	0.13	0.13	0.446
Self-assessments	−0.14 (0.11)	−.11	−0.00	−0.10	0.003
Follow-ups[d]	1.63 (0.54)	.25	0.20	0.22	0.677

[a] R^2=0.09; adjusted R^2=0.04.

[b] *sr*: the semipartial correlation.

[c] N/A: not applicable.

[d] $P<.01$.

Table 6. Standard regression results for personality, negative affect, treatment expectations, and study engagement predicting quality of life (n=191)[a].

Model	*b* (SE)	β	Pearson *r*	*sr* [b]	Structure coefficient
Constant	38.40 (7.23)	N/A[c]	N/A	N/A	N/A
Conscientiousness	−1.94 (1.17)	−.12	−0.25	−0.11	−0.502
Neuroticism	0.65 (0.81)	.06	0.25	0.05	0.506
Depression[d]	0.30 (0.09)	.27	0.39	0.22	0.802
Anxiety	0.08 (0.11)	.07	0.34	0.05	0.688
Stress	0.17 (0.13)	.14	0.39	0.08	0.788
Alcohol consumption	−0.19 (0.36)	−.04	0.10	−0.03	0.202
Treatment expectation	−0.03 (0.03)	−.06	−0.01	−0.06	−0.014
Self-assessments	0.19 (0.20)	.07	−0.04	0.06	0.084
Follow-ups	−1.74 (1.01)	−.13	−0.16	−0.11	−0.331

[a] R^2=0.24; adjusted R^2=0.20; lower scores on the quality-of-life measure indicated higher quality of life.

[b] *sr*: the semipartial correlation.

[c] N/A: not applicable.

[d] $P<.01$.

Discussion

Principal Findings

We hypothesized that a combination of personality traits (conscientiousness and neuroticism), recent feelings of negative affect (depression, anxiety, and stress), recent alcohol use, and expectations of treatment effectiveness could predict subsequent study engagement within a young adult–focused web-based intervention trial (iTreAD). We further hypothesized that personality, negative affect, alcohol use, treatment expectations, and study engagement would predict treatment satisfaction and self-reported quality of life at the end of iTreAD. We expected that conscientiousness, treatment expectations, and study engagement would exert a positive influence on study engagement and outcomes, whereas neuroticism, negative affect, and greater alcohol consumption at baseline would pose obstacles to study engagement and derive any intended benefit. This study sought to extend the existing literature by combining these predictive factors into a single model to test the overall magnitude of influence and discern the unique contributions of predictor variables.

As there were no previous studies known to us that had assessed predictors of engagement, treatment satisfaction, and quality-of-life outcomes simultaneously, we had no a priori expectations regarding the shared and unique contributions of predictor variables in explaining outcomes. Our results indicated that the combined effects of personality, negative affect, alcohol use, and attitudes in predicting study engagement were relatively low. Although conscientiousness, anxiety, stress, and alcohol consumption showed significant zero-order correlations with our measures of study engagement, only 5% of the variance in study engagement exhibited by young Australian adults could be attributed to personality, negative affect, alcohol use, and treatment expectations at the time of study registration, when considering all predictor variables. This is a clinically important finding, indicating that this range of presenting characteristics supporting engagement in mental health services in previous research was not as salient in a population of young adults with comorbid depression and alcohol use problems. It is well recognized that comorbid substance use and mental disorders are among the strongest factors associated with nonengagement with mental health treatment [49], and young people represent a particular subgroup of our community who are among the hardest to engage in treatment [6]. Although treatment engagement is a complex and multidimensional issue, a review of people with mental illness highlighted the potential for digital tools to remove many of the traditional barriers to access mental health treatment, to encourage ongoing psychoeducation, to outreach to people in environments in which they feel comfortable and safe, and to promote autonomy and empowerment [6]. These issues may be particularly important for young people considering treatment for sensitive mental health problems and for people with comorbidities who may experience service fragmentation and disconnection when seeking care. It may be that the digital environment offered our study population an opportunity that overcame some of these typical predictors of engagement. Future research should seek to understand digital tools in this context, particularly given that our study still reported high levels of attrition over time.

Among the predictors of study engagement, and contrary to expectations, only elevated neuroticism levels at baseline seemed to be associated with increased numbers of monthly web-based self-assessments returned. Previous studies demonstrated that neuroticism could indeed be beneficial for performance because of individuals’ increased tolerance for negative affect [50], which may have played a supportive role in participants’ willingness to complete self-assessments in this study. These findings resemble what previous researchers have coined *healthy neuroticism*, where a combination of neurotic self-awareness and conscientious decision making indicates engaging in favorable health behaviors such as increased doctor visits and fewer risky behaviors such as alcohol consumption and smoking [51-54]. Importantly, Weston and Jackson [52] found that *healthy neurotics* were more successful than other personality types in implementing effective behavior change *after* disease onset, suggesting that awareness of a chronic condition facilitated healthful actions particularly well in this group. Hence, it is possible that among treatment-seeking young people, moderate levels of neuroticism are beneficial to increase the chances of ongoing engagement with a digital mental health intervention study.

Concerning treatment satisfaction, the prediction model did not yield statistical significance, indicating that our predictors did not explain substantive variance in treatment satisfaction. Reductions in the adjusted R-squared value compared with the initial R-squared value indicated that the variables entered were in fact detrimental to explaining variance in treatment satisfaction. Although the overall model did not reach the statistical level of significance, it is worth noting that, in line with zero-order correlations, completion of incentivized follow-up assessments was uniquely predictive of satisfaction ratings at the conclusion of the study. Participants were invited to complete follow-up assessments 26, 39, 52, and 64 weeks after study registration and were reimbursed each time they returned a follow-up assessment. It is possible that the ongoing reflection on symptom scores combined with positive reinforcement through the incorporation of a tangible monetary reward system facilitated satisfaction with the study overall. This may hint toward the utility of supervision and blended care models, where some clinician guidance takes place alongside digital mental health therapy. Furthermore, personality, emotional distress, the severity of alcohol consumption, and even treatment allocation did not seem to affect satisfaction with the trial negatively. Satisfaction ratings with the study were good across all the conditions. These results warrant further exploration of factors influencing young adults’ satisfaction with web-based treatment components in particular, given the increasing focus on providing web-based health tools to young, digitally native populations [14].

Most notably, personality, affect, treatment expectation, and engagement variables together predicted about one-fifth of the variance in quality-of-life responses at the end of the iTreAD study. Although there were numerous moderate-sized zero-order associations with quality of life, when all predictors were included within one model (and with this, the sizable correlations between the predictor variables were accounted for), only depression remained a unique contributor to the variance in quality of life. These results underscore that depressive symptoms are a robust contributor to poor functioning in young people facing problems with alcohol and deserve attention in the design and delivery of digital mental health interventions.

Strengths and Limitations

Although the strength of this analysis lies in the simultaneous inspection of predictive factors, several limitations warrant consideration. First, our study’s engagement measures were somewhat limited in scope. Although our study engagement variables captured both treatment and trial engagement, only one common aspect of the treatment protocol (monthly web-based self-assessments) could be considered for the analysis. Ideally, web-based treatment engagement metrics would comprise several treatment components, such as the number of log-ins and module completion rates within the digital mental health intervention [55]. Power requirements prevent such an approach in our analyses; however, future research should attempt to uncover person-based predictors of web-based treatment engagement using more content-valid engagement measures. Second, although the decision as to which variables to include in this analysis was informed by the existing literature, the results revealed that the overall contribution of personality, affect, alcohol use, and expectations in predicting markers of treatment success were small, indicating that other, more important factors determined engagement in this digital treatment trial. Third, because of the optional completion of study components and study attrition, analyses including variables assessed at the conclusion of the study (ie, treatment satisfaction and quality of life) were slightly underpowered and thus needed to be interpreted with caution.

Conclusions

Taken together, our findings suggest that web-based mental health trials should continue to consider and aim to treat initial levels of depression to optimally improve quality-of-life experiences at the conclusion of the intervention period. In addition, neuroticism may constitute a positive predictor of subsequent engagement with the treatment protocol, and study adherence incentivized through monetary rewards may indicate improved satisfaction with the digital service overall.

Digital mental health interventions have the potential to become an integral part of health promotion strategies aimed at young people [11]. However, to meet this objective, web-based treatments need to capture their target audience's demands and deliver health information and mental health support in a comprehensive, effective, and engaging way. Our findings suggest that traditional predictors of engagement observed in face-to-face and even some web-based research may not be easily transferable to evaluate digital health interventions, particularly those aimed at comorbid mental health concerns and alcohol misuse among young adults.

Future research should continue to assess which factors and their combinations reliably and substantially predict young adults' engagement with digital mental health tools. As a next step, similar to face-to-face psychotherapy recommendations [56], supervised and tailored approaches to digital health and mental health promotion may yield the most engaging prospect as interventions can be personalized and delivered in a manner that suits the person undertaking web-based treatment [15].

Conflicts of Interest

None declared.

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Abbreviations

AUDIT-C: Alcohol Use Disorders Identification Test-Concise
AQoL-6D: Assessment of Quality of Life questionnaire
BFI: Big Five Inventory
DASS-21: Depression, Anxiety, and Stress Scale-21 items
iTreAD: Internet Treatment for Alcohol and Depression

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Original Paper

Typology and Impact of YouTube Videos Posted in Response to a Student Suicide Crisis: Social Media Metrics and Content Analyses

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Abstract

Background: Videos relating to suicide are available on YouTube, but their characteristics and impacts have seldom been examined.

Objective: This study aimed to examine YouTube videos posted in response to a sudden spate of student suicides in Hong Kong during the 2015-2016 school year and evaluate the impacts of those videos.

Methods: Keyword search was performed on YouTube, and relevant videos were identified. Video typology was examined through content analysis, specifically grouping the videos by who uploaded the videos, what presentation formats were used in the videos, whether the videos were originally created by the uploaders, and whether the videos disclosed the uploaders' personal experiences with suicide. Impacts of the videos were assessed in terms of reach (measured by view count), engagement (measured by comment count), and insights (measured as to what extent the comments to each video could reveal personal suicide risk and attitude toward help-seeking). Statistical analysis was conducted to compare the impacts of different types of videos. The 7 most impactful videos that were originally created by the YouTubers were selected for further analysis. They were compared with 7 videos uploaded by the same YouTubers right before the student suicide videos and 7 right after the student suicide videos. The comparison focused on their impacts and the network structure of the comments to those videos.

Results: A total of 162 relevant YouTube videos were identified. They were uploaded by 7 types of stakeholders, and the most common format was one person talking to the camera. A total of 87.0% (141/162) of the videos were originally created by the uploaders and only 8.0% (13/162) of the videos disclosed uploader personal experiences with suicide. The uploader profiles being popular or top YouTubers and the video containing disclosure of the uploader's personal experiences were found to be significantly correlated with greater impacts ($P<.001$). Focusing on the 7 most impactful original videos, it is found that those videos generated more engagement, especially more interactions between the viewers, and more insights than regular videos uploaded by the same YouTubers.

Conclusions: When responding to a youth suicide crisis, videos made by key opinion leaders on YouTube sharing their own experiences of overcoming suicide risks could generate significant positive impacts. These types of videos offer a precious opportunity to craft online campaigns and activities to raise suicide prevention awareness and engage vulnerable youth.

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KEYWORDS

suicide; suicide prevention; social media; infodemiology; internet; digital health; YouTube; impact evaluation; network visualization

Introduction

Youth suicide is an alarming public health problem. Suicide is the second leading cause of death among young people aged 15 to 24 years globally and accounts for over 16% of all deaths among youth [1]. Social media is a ubiquitous form of communication for young people nowadays, and this has become a double-edged sword for suicide prevention [2-5]. On one hand, social media may increase the availability and accessibility of suicide method information or connect suicidal people to form suicide pacts. On the other hand, social media can also offer a new channel for raising public awareness and for suicidal people to disclose their feelings and look for help [6]. Making good use of social media to engage at-risk youngsters and connect them with preventive resources is imperative for youth suicide prevention.

YouTube, a video-sharing site which has over a billion users globally, is one of the most popular social media sites [7]. A couple recent studies used keyword search to identify YouTube videos about suicide in English or German and conducted content analyses on the most-viewed videos or a random sample of the returned videos [8,9]. One study applied existing media guidelines of responsibly reporting suicide to evaluate the appropriateness of suicide-related YouTube videos in the German language and found that those videos exhibited more potentially harmful than protective characteristics [8]. However, the other study applied the open coding method to summarize the content themes exhibited in YouTube videos about teen suicide in English and found that the majority of them were educational or raised awareness of suicide prevention [9]. Another approach is to assess the impacts of a specific YouTube video using social media metrics [10]. The commonly evaluated metrics include: (1) reach (ie, number of views); (2) engagement (ie, number of comments or responses); and (3) insights (ie, whether the audience engagement is positive, neutral, or negative) [11]. Furthermore, a study has applied a machine learning method to automatically identify YouTube comments in the Traditional Chinese language that showed suicide risk for further intervention [12]. Nonetheless, compared to other online media, such as search engines, online forums, Facebook, Twitter, and Weibo (a Chinese social media), YouTube has been the focus of relatively fewer studies as related to suicide.

In the 2015-2016 school year (from September 1 to August 31), 33 students unfortunately died by suicide in Hong Kong, of which the majority were teenagers and the most common method was jumping from height [13,14]. The significant increase of incidents was alarming when compared to 19 student suicides in each of the 2013-2014 and 2014-2015 school years [14]. When 11 student suicides occurred during the period between February 12 and March 28, 2016, the seeming cluster triggered intense media coverage and online discussion. To curb the crisis of student suicides, the Hong Kong government set up a committee on student suicide prevention on March 30, 2016, constituting public health experts, psychiatrists, psychologists, social workers, school principals and teachers, parents, youth leaders, and government officials. Responding to the committee's advice, local press reduced sensational reporting of student suicides and published more preventive information, which was found to be associated with a subsequent decrease in student suicides toward the end of 2016 [13]. During the process, various community members spontaneously made use of YouTube to voice their thoughts and opinions regarding student suicides.

The series of events, which will be referred as the student suicide crisis hereafter, offered a precious opportunity for us to observe what role YouTube can play when a youth suicide crisis is in the spotlight. Combining the approaches of both content analysis and impact assessment, this study specifically examined what YouTube videos were posted in response to the student suicide issue in Hong Kong and what impacts those videos generated. Specifically, our research questions include the following:

- What kinds of videos are publicly accessible on YouTube regarding the student suicide crisis?
- How much impact did different kinds of videos generate in terms of reach, engagement, and insights?
- Which types of videos were more likely to generate greater impacts?

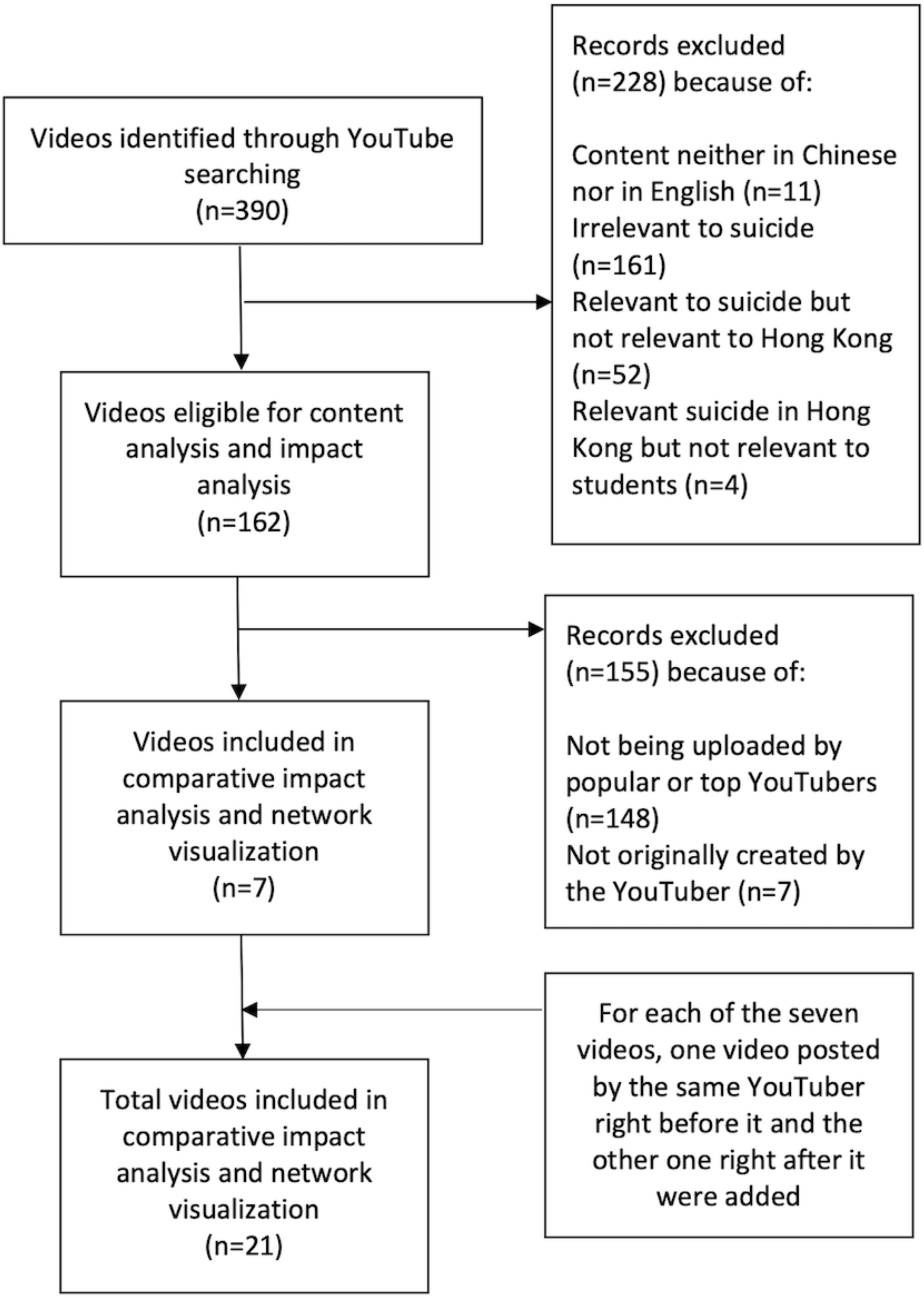
As the study was exploratory and data-driven in nature and there was no previous study on the same topic, we had no hypothesis regarding those questions.

Methods

Data Collection

The data collection procedure is illustrated in Figure 1. Using YouTube's open application programming interface, videos were searched and downloaded with the Traditional Chinese keywords relating to student suicides that were frequently being used in local newspapers when reporting the student suicide crisis. The query was written as [學生自殺 (student suicide), 學童自殺 (school children suicide) OR 學生跳樓 (student jumping from height) OR 學業壓力 (academic pressure) OR 珍惜生命 (cherish life)]. The search period was restricted to the 2015-2016 school year (ie, from September 1, 2015, to August 31, 2016). Data such as the title and description of each video, URL, uploader's user names and self-report profiles, upload date, as well as the numbers of views, likes, dislikes, comments, and replies were downloaded up until June 8, 2017. Readers are reminded that there are two layers of comments on YouTube, of which the first layer are the comments directly address to the video and the second layer are the replies to some of the first layer comments. YouTube counts the total number from both layers when reporting the number of comments. To protect YouTube users' privacy, their user names were replaced by nonidentical numbers in this paper.

Figure 1. Procedure of video searching, screening, and analysis.



The search initially yielded 390 videos. Each video was assessed on its relevance with the student suicide crisis and only videos meeting the following criteria were eligible for further review: the video must be presented in the Chinese language, either Cantonese or Mandarin, and the video's content should be reporting or addressing the series of student suicides that happened during the specified period in Hong Kong. A total of 162 videos were found to be eligible for further analyses. The full-text content of the comments and replies to the 162 videos and the user IDs of those who posted comments and replies were then downloaded.

After we analyzed the impact metrics of the eligible videos, 7 videos were identified as the most impactful. An additional analysis on the impacts of the 7 videos was conducted. For each of the 7 videos (hereinafter referred as the student suicide videos), one video posted by the same YouTuber right before the incident video (hereinafter referred as the prevideo) and another video right after the incident video (hereinafter referred as the postvideo) were identified and the metadata of the comments and replies were downloaded. By comparing the impact metrics of the student suicide video with the impact metrics of the same YouTuber's previdеos and postvideos, we aimed to identify special impacts of the student suicide videos by controlling the uploaders' profiles.

Content Analyses

The content of the videos and video uploader profiles as described in the About section of the 162 relevant videos were reviewed. Two authors (QC and FI) examined the 162 videos together and categorized the 162 video uploaders and video format by intensive discussions. The two authors reached a full consensus on the final coding scheme and results.

Video uploaders were first differentiated as either an organization or an individual, according to the descriptions in their About Us page. Furthermore, they were categorized into 7 groups: (1) traditional media (media outlets that operate not only YouTube channels but also publish offline formats such as newspapers, TV, or radio channels); (2) online organizations (media or professional organizations that only publish content online); (3) government bodies, which include the Hong Kong government's information department and the police force; (4) politicians, who are mostly local legislators; (5) top YouTubers (individuals operating YouTube channels with 100,000 or more subscribers); (6) popular YouTubers (individuals operating YouTube channels with 10,000 to 100,000 subscribers); and (7) regular YouTubers (individuals operating YouTube channels with fewer than 10,000 subscribers). The first 3 categories were all self-presented as organizations, whereas the other 4 were all individuals.

The video formats were categorized into 4 groups: (1) simple speech, which is one person talking in front of a camera; (2) conversations, which are often talk shows, panel discussions, or debates at legislative meetings; (3) news or documentaries, which are often news reports or feature reports produced by media professionals; and (4) fictional performances, which include one short film created by a group of students and a music video. Each video was assigned to only one type of uploader and one type of video format. In addition, whether a video was originally created by the uploader and whether the video disclosed the uploader's personal experiences with suicidal thoughts or behaviors were also marked.

As for the comments, the two authors first randomly selected 100 comments and individually conducted open coding on their content, focusing on the impact measurements. The two then compared their codes and discussed their interpretations. Based on their discussions, a coding scheme was generated. The scheme categorized 3 common themes from the comments: displaying positive or negative attitudes toward the subject video, disclosing that the commenter was having or has had suicidal thoughts or behaviors before, and showing supportive or discouraging tendencies toward help-seeking. For theme 3, comments showing supportive tendencies to help-seeking included those showing willingness to seek help, showing support to people who needed help, and sharing experiences of how they received help from others. Comments showing discouraging tendencies to help-seeking were those indicating that existing help resources were useless. Another 100 comments were randomly selected and the two authors individually annotated whether a comment exhibiting one of the 3 themes. The interrater reliability between the two authors was then examined by Krippendorff alpha and the result was .94, indicating high reliability [15]. Thereafter, one of the two authors (FI) completed the coding of all comments following the coding scheme.

Statistical Analyses

Among the 3 impact metrics, reach and engagement were measured by the numbers of views and comments, which were directly extracted from the YouTube archive data. Insights were measured by counting how many comments showed a theme identified by the content analysis. Comparing different categories of video impacts, a Kruskal-Wallis rank sum test was employed to examine the variance due to nonnormality of the impact metrics. All statistical analyses were performed using SPSS (version 23, IBM Corp).

During the data analysis, we noted that 7 videos that were uploaded by popular and top YouTubers who disclosed their personal experiences with suicide generated significantly greater impacts than other videos. In view of their special influence, a further analysis focusing on the 7 videos was conducted to rule out the possible effects from their large number of subscribers on the impact metrics. Specifically, we compared the 7 student suicide videos with their corresponding previdеos and postvideos made by the same 7 YouTubers. Descriptive statistics were used to quantify the number of total comments and the number of unique users who only commented on the student suicide videos but not on the previdеos and postvideos. Furthermore, the lengths of comments (ie, number of words) were compared between the student suicide prevention videos and the previdеos and postvideos by *t* test.

Network visualization was also used to compare the interaction network structures between the student suicide videos and the previdеos and postvideos. Based on the comment data, the network graph depicts each unique user ID as a node and a comment as a directed edge from who posted the comment to whom the comment was addressed. Three network graphs were produced to illustrate the commenting structures at the moment of the previdеos, the student suicide videos, and the postvideos. The network graphs were visualized with the open-source software Gephi.

Results

Typology of the Videos

As shown in Table 1, the majority of the videos were uploaded by traditional media (52/162, 32.1%) and online organizations (44/162, 27.2%), followed by regular YouTubers (35/162, 21.6%), politicians (12/162, 7.4%), popular YouTubers (10/162, 6.2%), government bodies (5/162, 3.1%), and top YouTubers (4/162, 2.5%). All videos showed a general tendency to support suicide prevention, although they had varied views on what prevention measures might be effective or ineffective. Most of the videos were shot in a simple speech format (ie, one person talking in front of a camera; 82/162, 50.6%), followed by professionally edited news clips or documentaries (56/162, 34.6%) and conversations between multiple people (22/162, 13.6%). Only two videos (2/162, 1.2%) were fictional performances. About 87% (141/162) were originally created by the uploaders, with 8% (13/162) disclosing personal experiences on how to battle with suicidal thoughts or behaviors. The remaining 13% (21/162) were news clips or video records of legislative meetings or other public activities created by the uploaders.

Table 1. Categories of YouTube videos responding to the student suicide issue and a comparison on their reach and engagement (n=162).

Category	Videos, n	Number of views			Number of comments		
		Median (range)	Mean rank	Chi-square (*P* value)	Median (range)	Mean rank	Chi-square (*P* value)
By uploader profile	—[a]	—	—	39.3 (<.001)	—	—	36.6 (<.001)
Traditional media	52	1700 (51-45,143)	97.31	—	.75 (0-45)	86.66	—
Online organizations	44	476 (7-41,237)	79.56	—	.28 (0-34)	67.22	—
Regular YouTubers	35	151 (22-373,478)	53.46	—	.39 (0-104)	72.87	—
Politicians	12	275 (22-22,712)	61.63	—	.56 (0-21)	79.71	—
Popular YouTubers	10	5784 (121-16,015)	115.10	—	18.50 (0-229)	128.40	—
Government bodies	5	148 (71-698)	48.60	—	.20 (0-1)	61.20	—
Top YouTubers	4	97,215 (72,049-13,1596)	159.50	—	965.50 (402-1582)	160.50	—
By video format	—	—	—	5.3 (.15)	—	—	4.6 (.20)
One person talking	82	351.50 (22-373,478)	74.80	—	.53 (0-1582)	81.52	—
News or documentary	56	1308 (44-45,143)	93.04	—	.71 (0-45)	85.40	—
Two or more people talking	22	489.50 (7-6280)	76.55	—	.28 (0-24)	68.00	—
Fictional performance	2	1266.50 (281-2252)	87.75	—	5.00 (1-9)	119.75	—
Original creation	—	—	—	0.004 (.95)	—	—	.10 (.75)
Yes	141	499 (7-131,596)	81.41	—	.56 (0-104)	81.11	—
No	21	536 (27-343,478)	82.10	—	.57 (0-1582)	84.14	—
Disclosure of personal experience	—	—	—	9.4 (.002)	—	—	11.9 (.001)
Yes	13	5764 (81-121,719)	119.69	—	4.33 (0-1260)	119.35	—
No	149	433 (7-343,478)	78.17	—	.48 (0-1582)	78.20	—

[a] Not applicable.

Relationships Between Video Characteristics and Video Impacts

Table 1 and Multimedia Appendix 1 compared different types of video impacts. Results showed that disclosing uploader's personal experience with suicide was significantly correlated with greater impacts in all dimensions except for the number of comments criticizing the video and the number of comments negative to help seeking. In other words, videos with this feature demonstrated greater positive impacts than those without it, but there was no significant difference from those without it in terms of negative impacts.

Uploader profiles were found to be another factor related to the video impacts. Pairwise post hoc test of Kruskal-Wallis rank sum test (see details in Multimedia Appendix 2) found that, in terms of reach, top YouTubers outperformed politicians, government bodies, and regular YouTubers but not popular YouTubers, traditional media, or online organizations. This might be attributed to that fact the YouTube channels of popular YouTubers, traditional media, and online organizations also have substantial numbers of subscribers, which laid a foundation for higher view counts. In terms of engagement, top YouTubers further outperformed traditional media and online organizations, and only popular YouTubers reported comparable numbers of comments with top YouTubers. Among the 7 types of uploaders, government body videos received the smallest numbers of views (median 148, maximum 698) and comments (median 0.20, maximum 1). In terms of insights, top YouTubers even significantly outperformed popular YouTubers except for the number of comments showing negative attitude toward help-seeking. In summary, although those uploaders with larger numbers of subscribers mostly generated greater reach, top and popular YouTuber videos were more engaging, and top YouTuber videos were able to stimulate more insightful comments. This phenomenon might be explained by the disclosing of the uploaders' personal experiences with suicide because most of the student suicide videos uploaded by the top YouTubers mentioned their own suicidal thoughts when they were students and how they overcame the thoughts by getting help from their friends or family members. In contrast, half of the videos uploaded by popular YouTubers were reposting news clips or just sharing other people's experiences of suicidal thoughts.

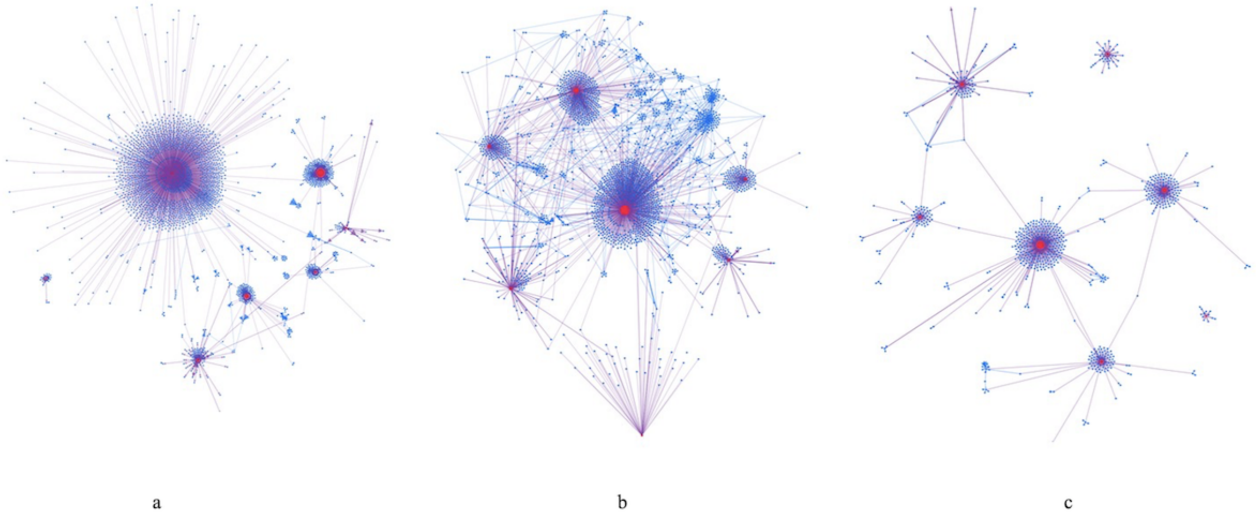
Informed by the results, we decided to focus on the 7 videos uploaded by top and popular YouTubers (referred as KOLs, or key opinion leaders) who disclosed their personal experiences with suicide to conduct additional analysis on their impacts.

KOL Student Suicide Videos Versus Their Regular Videos

The 7 selected videos were uploaded by 7 different YouTubers. For each of the videos, one prevideo and one postvideo uploaded by the same YouTuber were included for the comparison. The prevideos and postvideos were found to be related to internet gaming, traveling, or other entertainment topics, which are regular trendy content created by those KOLs.

As shown in Multimedia Appendix 3, compared with the prevideos and postvideos, the student suicide videos received fewer view counts but attracted more and longer comments. Those KOLs also had been more active in replying to their viewer comments regarding the student suicide videos (29 vs 60 replies) than their regular videos (5 vs 33 replies). The only exception was one top YouTuber's prevideo (ie, Top 2 in Multimedia Appendix 3), in which a new video game was introduced, that received more comments than his student suicide video (1946 vs 1259). However, his prevideo received fewer second layer replies than his student suicide video (161 vs 404). In addition, his prevideo's first layer comments and second layer replies were both significantly shorter than his student suicide video's (*P*<.001; see details in Multimedia Appendix 3). The results suggested that even with the same influential YouTubers, their student suicide videos could generate more in-depth interactions among their viewers. Multimedia Appendix 3 also demonstrates that 83.1% (133/160) to 96.8% (637/658) of the users who commented on the student suicide videos did not post any comments on the same YouTuber's prevideos and postvideos, suggesting that they may not be actively engaged by those regular videos. Figure 2 illustrates the social network structures of the comments. The prevideo and postvideo comments network figures (Figure 2a and 2c) were rather similar. They both had 7 centralized clusters surrounding the 7 KOLs, and both were dominated by purple edges, reflecting that regular viewers were generally commenting to the KOLs. The 7 clusters were not well connected with each other, if not at all, suggesting little overlapping between users who commented to different KOLs' regular videos. By contrast, blue edges in Figure 2b were more noticeable, indicating more interactions among regular viewers which distracted the KOLs' centralization role. In addition, the 7 clusters became better connected with each other directly or indirectly in Figure 2b.

Figure 2. Network graph comparison of the comments to the 7 most impactful student suicide videos with their pre- and post-videos uploaded by the same YouTubers: (a) comments to the pre-videos (2187 nodes, 2398 edges), (b) comments to the student suicide-related videos (2175 nodes, 2816 edges), and (c) comments to the post-videos (721 nodes, 825 edges). Notes: Red nodes denote video uploaders and blue nodes denote users who posted comments. Purple edges denote first layer comments from commenters to the video uploaders and blue edges denote replies from commenters to commenter.



Discussion

Principal Findings

To the best of our knowledge, this study is the first to examine the typology and impact metrics of YouTube videos responding to a student suicide crisis. When a spate of student suicides occurred in Hong Kong, various community members voiced their concerns through YouTube videos and, fortunately, we found the videos were generally supportive of suicide prevention and encouraged young people to cherish their lives. The results highlighted the important role of YouTube KOLs, including popular and top YouTubers who create their own original content, in suicide prevention. Although other YouTube channels with large numbers of subscribers, such as traditional media and online organizations, could also achieve a substantial reach, KOL videos, especially those disclosing their own experiences with overcoming suicidal thoughts, exhibited more outstanding performance in terms of engagement and insights. Those videos might have resonated with viewers and validated their feelings more, especially for those who also had suicidal thoughts. In addition, there were more peer interactions in the comments to those KOL student suicide videos, which might have made the viewers feel less lonely and encouraged further disclosure of their experiences and feelings. The findings add new evidence to the potential positive effects of social media when the media content is about suicide prevention [13,16,17]. It is noted that popular YouTubers can achieve comparable impacts to top YouTubers in most of the dimensions. Therefore, when there is a dearth of top YouTubers and they are too costly to be partner with, we could engage popular YouTubers on a larger scale as an alternative to achieve desirable impacts.

This study found that the local government bodies and professional organizations did release suicide prevention videos on YouTube addressing the student suicide crisis, but their impacts were far smaller than the KOL videos. Notably, the 14 videos uploaded by top and popular YouTubers generated significantly more views and comments than the 49 videos uploaded by government bodies and online organizations (465,596 views and 4509 comments vs 206,630 views and 86 comments). The findings suggests that, if professional organizations and government bodies would like to make use of YouTube to raise awareness of suicide prevention among young people and engage vulnerable youth, they might be more effective by leveraging KOL influences and life experiences to create videos rather than producing their own videos. Although not captured in this study, we should be aware that occasional incidents of YouTube videos showing suicide scenes or the process of suicidal behaviors or containing tips on how to commit suicide have been reported by the news media. Therefore, suicide prevention professionals are advised to have in-depth discussions with KOLs to understand their background and views on suicide and suicide prevention, if a formal collaboration is going to be established.

Comparing the same KOLs' regular videos, their student suicide videos were particularly engaging in terms of the number and length of comments and the interaction among the audience. The finding could encourage KOLs to produce more of these kinds of videos because it would be beneficial for them to engage their followers and form a healthy and caring online community.

Meanwhile, the findings also deserve suicide prevention professionals' attention and follow-up. The comments offered valuable insights to uncover at-risk individuals, discern what people appreciate or dislike in a suicide prevention video and why people at risk would seek help or not. Even though some comments were negative or discouraging to help-seeking, they have provided critical feedback for future improvements of social support in society. Furthermore, in view of some KOLs' genuine interests in suicide prevention, gatekeeper training and support should be provided to them to empower them with the appropriate skills to communicate with their followers who are at risk of suicide and refer those in need of professional care and interventions. As disclosed in the comments of the student suicide videos, there were users who were at risk of suicide or indicated willingness to help with suicide prevention activities. For the former, suicide prevention professionals can work with the KOLs to engage vulnerable individuals and refer them to suicide prevention services such as online 24/7 emotional support services [18]. For the latter, they can be engaged as gatekeepers to promote suicide prevention in the online social network or within their own social circles. It would be helpful if a connected care model can be established to facilitate online gatekeepers to refer vulnerable youth to offline professional services.

Limitations

A few limitations of the study should be noted. First, some relevant videos may not be included in the study if those videos did not explicitly include the keywords that we employed or were uploaded in the private domain. There might also be private communications between the YouTube users that could not be captured in this study. Second, since the reviewed videos were posted on different dates, direct comparison of the number of views and comments of the videos was seemingly unfair. Nonetheless, the vast majority of views and comments on the YouTube videos were received on the first week after release, and the data collection date in this study was at least 5 months after the release dates of those videos. This can minimize the bias in the discrepancies of the data. The cutoff of subscriber numbers for defining popular and top YouTubers in this study was adopted from the common practice in the marketing industry in Hong Kong in 2017. As the number of users of YouTube varies in different contexts, the cutoff of popular and top YouTubers is also context-sensitive. Other researchers need to check the up-to-date marketing reference to identify KOLs in their own context.

Conclusion

Youth suicide prevention is a global challenge. During the difficult times of COVID-19, the risk of suicide is also increasing [19]. This study demonstrates that, when responding to a public crisis of youth suicide, videos made by YouTube KOLs sharing their own experiences of overcoming suicide risks could generate significant positive impacts. Suicide prevention professional and government bodies should take the opportunity to collaborate with those KOLs to deliver online campaigns and interventions to raise awareness of suicide prevention and engage vulnerable youth. Also, the KOLs themselves can seize the opportunity to provide support for their followers. Participating in promoting mental wellness would likely enhance their public image and reachability to the social media users. In the meantime, more empirical evaluations of this type of videos are imperative to further identify effective measures that can make the best of social media for suicide prevention.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Comparison of the insights different types of videos generated.
[DOCX File , 15 KB - mental_v8i6e15551_app1.docx]

Multimedia Appendix 2
Pairwise post hoc tests on the relationships between different types of videos and their impacts.
[DOCX File , 30 KB - mental_v8i6e15551_app2.docx]

Multimedia Appendix 3
Comparing the top 7 impactful student suicide-related videos with their pre- and post-videos uploaded by the same YouTubers.
[DOCX File , 16 KB - mental_v8i6e15551_app3.docx]

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Abbreviations

KOL: key opinion leader

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Viewpoint

COVID-19 and Open Notes: A New Method to Enhance Patient Safety and Trust

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Abstract

From April 5, 2021, as part of the 21st Century Cures Act, all providers in the United States must offer patients access to the medical information housed in their electronic records. Via secure health portals, patients can log in to access lab and test results, lists of prescribed medications, referral appointments, and the narrative reports written by clinicians (so-called open notes). As US providers implement this practice innovation, we describe six promising ways in which patients' access to their notes might help address problems that either emerged with or were exacerbated by the COVID-19 pandemic.

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KEYWORDS

COVID-19; patient portals; electronic health records; patient safety; patient-centered care

COVID-19 has left an indelible legacy on patient care. Tragic numbers of lives have been lost to the virus, and it is not known how many excess deaths are due to reduced access to services or patients delaying health care [1]. With enforced isolation and savage stresses on essential workers, mental health and well-being have been affected [2]. The pandemic has also given rise to a new chronic condition: *long COVID*. Prevalence and susceptibility are poorly understood but patients may experience persistent symptoms including fatigue, body or muscle pains, insomnia, headaches, depression, and anxiety for months after their acute illness [3]. Compounding these problems are racial inequities in vaccine distribution and fears among certain segments of the public about the trustworthiness of vaccines [4,5]—a reticence, recent evidence suggests, is heightened among white politically conservative men [6].

Despite all the tragedy wrought by COVID-19, the pandemic has been a catalyst for innovating new practices in medicine.

In Spring 2020, in the space of a few short weeks, with the enforcement of physical distancing and stay-at-home rules to avoid transmission of the virus, patients and doctors were compelled to use different forms of communication [7]. In the United States, for example, telemedicine—the use of phones and videos for clinical visits—soared from fewer than 2% of primary care visits in 2019 to more than 35% by April 2020 [8]. Complementing telemedicine, and perhaps overshadowed by the pandemic, another practice innovation—allowing patients to access their own clinical records—is also taking hold [9]. As of April 5, 2021, as part of the 21st Century Cures Act, all providers in the United States must offer patients access to the medical information housed in their electronic records [10,11]. Via secure health portals, patients can log in to access lab and test results, lists of prescribed medications, referral and appointment times, and the words written by clinicians (so-called *open notes*). With few permitted exceptions, information that was previously hidden from view and the eyes of patients must now be available.

Open notes are not without precedent. By December 2020, around 55 million patients across 260 health systems in the

United States and Canada were offered access to their clinical notes. In other countries, such as Sweden, the practice is advanced, and during the pandemic, studies show substantial increases in use of the nationwide health portal [12]. Prepandemic, approximately 80,000 new users logged into the Swedish portal each month; since June 2020, this number steadily reached more than 100,000 new users per month, peaking in November 2020 at 165,000. Health systems in the United States have seen similar upticks in patient portal registration throughout the pandemic, in some cases due to the technology for telemedicine visits being offered only through portal log-in. This indicates that the pandemic not only increased use among already existing portal users but also spurred adoption among new patients.

Promising evidence suggests that open notes might play a role in mitigating challenges with care, some of which emerged with the pandemic and some which have been exacerbated by COVID-19. We reflect on six ways in which open notes might help meet some of the challenges of COVID-19.

1. In light of the uptick in telemedicine, with social distancing measures in place, patients and clinicians have been compelled to rapidly navigate new modes of visits, and it is not yet known whether the quality of patient-clinician communication has been affected. Against these uncertainties, there is compelling evidence that open notes may help strengthen clinician-patient exchanges [9]. Large-scale online surveys conducted prior to the pandemic show that when patients can readily access their notes they better understand and remember their care plan, including the reasons why treatments have been prescribed and when (and why) referrals and follow-up appointments are scheduled [13,14].
2. During the pandemic, when many face-to-face ambulatory visits are still delayed or not possible, caregivers have faced considerable challenges in supporting family and friends. Unable to accompany patients to clinical visits or see loved ones in the hospital, they have lost important opportunities to find out what is going on and to fully participate in care. However, open notes may help to close this information gap. In studies, considerable numbers of patients report sharing notes with others [13]. Such access may be even more important for older adult patients or those who rely on care partners by helping them, and their carers, to understand treatment plans and to remember to access test results or follow up with referrals.
3. Open notes could also play a crucial role in closing the chasm of health disparities further deepened by COVID-19 [15]. Compared with White patients, Black, Hispanic, and Asian patients in the United States are more likely to report that reading their notes enhances trust in their doctors. In surveys, historically marginalized patients such as those who identify with an ethnic or racial minority group, persons with lower incomes, those with fewer years of formal education, or those whose first language differs from their clinician are the most enthusiastic about open notes when they log in to portals [16,17]. On the other hand, the "digital divide" in health care—driven by lack of broadband internet access [18], lack of email address or use, and low digital literacy—remains a barrier to the adoption of patient portals among these patient populations [19]. Although there is evidence this digital divide is narrowing, with greater commitment to safety net interventions such as patient outreach programs or the distribution of WiFi-enabled tablets, patients who have the most to gain from reading their notes could reap the benefits.
4. COVID-19 has taken a toll on mental health. However, patients with anxiety or depression who read their notes may benefit from better understanding their clinicians' recommendations, helping them to stay on track with their care plan. In a large-scale survey of nearly 20,000 patients prescribed medications, 14% of patients who accessed their notes reported doing a better job adhering to their medications [20]. For patients with mental health diagnoses the figures were higher: 20% of patients with serious mental illnesses such as major depression, bipolar disorders, or schizophrenia and 18% of patients with other mental health diagnoses said they were more likely to take their prescribed medications after reading their clinical notes [14]. Preliminary findings from psychotherapy also show that open notes can improve the therapeutic alliance between patients and therapists, help build trust, and deepen patients' understanding about what goes on in therapy sessions [21].
5. Patients experiencing symptoms of long COVID may feel marginalized or uncertain about their health care. In multiple surveys, patients who access open notes report feeling more empowered and engaged with managing their health [13,22,23]. As an asynchronous communication tool, open notes can serve as an online extension of the visit, helping improve a sense of control and engagement with care. This may be especially important for offering reassurance to patients with long COVID whose symptoms are still poorly understood [24,25].
6. Working under the considerable pressures wrought by the pandemic, it is not yet known whether patient safety has been negatively affected by human error [9]. Studies conducted prior to the pandemic show that around 1 in 5 patients who read their notes can, and do, perceive errors [26]. With more eyes on the charts, patients can help clinicians to correct inaccuracies or omissions and improve the feedback loop in care—all the more essential as a patient safety mechanism when routines have been disrupted and clinicians and patients are laboring under high levels of stress.

The effects of COVID-19 will be with us for years to come, but perhaps the most important memorial will be clinicians, patients, and care partners seizing on novel opportunities to improve care. Open notes do not offer a magic solution to the challenges of the pandemic, but by partnering with patients and families, through an invitation to read notes and be on the same page as their clinicians, it may offer an important new strategy to improve engagement, increase trust, and demonstrate respect for patients.

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Conflicts of Interest

None declared.

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Original Paper

Design and Implementation of an Informatics Infrastructure for Standardized Data Acquisition, Transfer, Storage, and Export in Psychiatric Clinical Routine: Feasibility Study

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Abstract

Background: Empirically driven personalized diagnostic applications and treatment stratification is widely perceived as a major hallmark in psychiatry. However, databased personalized decision making requires standardized data acquisition and data access, which are currently absent in psychiatric clinical routine.

Objective: Here, we describe the informatics infrastructure implemented at the psychiatric Münster University Hospital, which allows standardized acquisition, transfer, storage, and export of clinical data for future real-time predictive modelling in psychiatric routine.

Methods: We designed and implemented a technical architecture that includes an extension of the electronic health record (EHR) via scalable standardized data collection and data transfer between EHRs and research databases, thus allowing the pooling of EHRs and research data in a unified database and technical solutions for the visual presentation of collected data and analyses results in the EHR. The Single-source Metadata ARchitecture Transformation (SMA:T) was used as the software architecture. SMA:T is an extension of the EHR system and uses module-driven engineering to generate standardized applications and interfaces. The operational data model was used as the standard. Standardized data were entered on iPads via the Mobile Patient Survey (MoPat) and the web application Mopat@home, and the standardized transmission, processing, display, and export of data were realized via SMA:T.

Results: The technical feasibility of the informatics infrastructure was demonstrated in the course of this study. We created 19 standardized documentation forms with 241 items. For 317 patients, 6451 instances were automatically transferred to the EHR system without errors. Moreover, 96,323 instances were automatically transferred from the EHR system to the research database for further analyses.

Conclusions: In this study, we present the successful implementation of the informatics infrastructure enabling standardized data acquisition and data access for future real-time predictive modelling in clinical routine in psychiatry. The technical solution presented here might guide similar initiatives at other sites and thus help to pave the way toward future application of predictive models in psychiatric clinical routine.

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KEYWORDS

medical informatics; digital mental health; digital data collection; psychiatry; single-source metadata architecture transformation; mental health; design; implementation; feasibility; informatics; infrastructure; data

Introduction

Scientific Background

Psychiatric disorders represent one of the leading causes of disability worldwide. In the challenge to provide advanced treatment and prevention strategies for psychiatric disorders, previous research has focused on better understanding of the neurobiological basis of affective disorders [1]. However, the translation of such findings into clinical application remains an unresolved problem up to now. For this reason, the focus of psychiatric research has shifted from sole neurobiological characterization at the group level toward the application of multivariate machine learning methods trained on multimodal data for individualized prediction of clinical outcomes [2,3]. Multivariate machine learning applications have been proven to be innovative and powerful tools in translational psychiatric research. In this regard, the successful utilization of machine learning algorithms for individualized predictions of treatment response [4-6], depression severity [7], disease risk [8], differential diagnosis [9,10], and relapse risk [11] has yielded the first promising results. However, up to now, several obstacles have prevented the successful transfer of individual predictive modeling to clinical routine application, as discussed in recent reviews [12-15]. In this regard, the gap between homogeneous well-characterized samples acquired in experimental studies [16] and heterogeneous unvalidated data from day-to-day clinical routine has proven to be a major obstacle in the translation of predictive models to clinical application. Hence, ecologically valid predictive models would require access to standardized real world data collected at the point of care [17].

Importantly, large-scale studies reporting the successful application of multivariate models trained on data from electronic health records (EHRs), including features such as diagnosis and procedures, laboratory parameters, and medications for the prediction of suicide risk or weight gain following antidepressant treatment have demonstrated the capacity and generalizability of predictive models trained on real-world data [18-20]. Further extension of EHRs via standardized collection of predictive variables such as known risk factors might further enhance the potential of this novel data entity for predictive analytics in psychiatry [21,22]. Standardized electronic collection of patient-reported outcomes that has previously been shown to improve clinical outcomes such as survival in patients with cancer represents another possibility to enrich EHR data. Similarly, combining data from EHRs with research data might provide new opportunities for the discovery and validation of psychiatric endophenotypes as demonstrated via recent validation of a polygenic risk score in a Danish population study [23]. However, future application of predictive models for personalized diagnostic and treatment requires their validation via clinical trials that, in turn, critically depend on the availability of the informatics infrastructure for the application of predictive models in routine care. The required informatics infrastructure should facilitate the acquisition of standardized real world data at the point of care, potential enrichment with patient-reported outcomes or research data, and subsequent access to data for clinicians and researchers. However, while these technical requirements are already available in selected clinical settings, for example, in the United States [24], they are up to now absent in the clinical working environment of psychiatry hospitals in many European countries. More concretely, ORBIS, the EHR system that is the market leader in Germany, Austria, and Switzerland, does not currently support standardized form metadata, clinical data, or annotated data sets. Our approach thus addresses the currently unmet need to (1) implement the technical requirements for standardized data acquisition and analysis in one of the most widely used EHR systems in Europe and (2) to specifically design a technical solution, including appropriate data collection routines, for the domain of clinical psychiatry.

This study aims to present the design and implementation of the technical requirements to address the aforementioned challenges with the ultimate goal of providing the basis for a successful future translation of predictive models to clinical application in psychiatric disorders. The implementation of the outlined technical solution will ultimately allow the evaluation of the potential of predictive models for the clinical management of psychiatric disorders under real-world conditions. In detail, we present the design and implementation of the informatics infrastructure, including technical solutions for (1) extension of the EHR via standardized electronic collection of patient-reported outcomes, (2) data transfer between EHRs and research databases, (3) pooling of EHRs and research data in a unified database, and (4) visual presentation of the analyses results in the EHRs.

Objective of This Study

The main objective of this study was the design and successful implementation of the informatics infrastructure required to train and validate predictive models in day-to-day clinical application in psychiatry as part of the SEED 11/19 study [25]. Our study consisted of the following steps in detail:

1. Implementation of standardized documentation forms in EHRs.
2. The set-up of an interface for direct data transfer between clinical documentation systems and a database for predictive analysis.
3. The set-up of a unified database that allows pooling of clinical data with further research data for predictive analysis.
4. Visual presentation of relevant data entities and results of predictive analysis in EHRs at the point of care.

Methods

Setting

The Münster University Hospital in Germany is a tertiary care hospital with 1457 beds and 11,197 staff who treated 607,414 patients (inbound and outbound) in 2019 [26]. The department for psychiatry and psychotherapy at the University Hospital treated 1341 cases in the study period from February 25, 2019 to July 31, 2020 (1042 cases in 2018 [27,28]). Validation was carried out by 25 doctors and 61 specialists from the health care sector.

System Details

The EHR system ORBIS by Dedalus Healthcare is used at Münster University Hospital in more than 40 clinics and is the market leader in Germany, Austria, and Switzerland with over 1300 installations [29]. The EHR system has an 8700 GB Oracle database, 7938 users, and 1927 user sessions per day (status at July 2020) at Münster University Hospital. No standardized metadata form, clinical data, and annotated data sets are supported.

Requirement Engineering

To address the study aims, the following requirements were identified through focus groups including physicians and researchers at Münster University Hospital in Germany.

1. Extension of the EHR via standardized data collection: At first sight, the widely established usage of electronic documentation systems in clinical routine might supplement the notion of a fast translation of predictive models. However, until now, the majority of clinical data is still acquired and stored in an unstructured way that cannot be directly used for predictive modeling. Extension of EHR data via standardized forms of data collection in routine care is therefore required to provide a sufficient database for the development of predictive models. Importantly, the technical solution should be flexible and allow to update the content of the collected EHR data. Content-wise, in an initial step, standardized extension of EHR data should include assessment of symptomatology in order to allow both patient stratification at baseline as well as outcome measurement following intervention. Furthermore, standardized assessment of known risk factors, including life events and sociodemographic data, appears meaningful.
2. Data transfer: Routine EHR data storage systems are usually strictly separated from research databases for safety reasons and hence are not directly accessible for predictive analyses. Training and validation of predictive models based on EHR data requires the set-up of interfaces and a database in which EHR data can be transferred and subsequently stored in a standardized way. In line with our study aim, the technical solutions should be scalable and allow data transfer in real time. EHR data transferred and stored in the database must be accessible for researchers in order to allow the development of predictive models.
3. Combination of EHRs and research data: Again, since routine EHR data storage systems are strictly separated from research databases, pooling of EHR and research data is not possible within state-of-the art EHR databases. Pooling EHR with research data in a unified database would allow the enrichment of predictive models trained on EHR data by adding already existing research data and furthermore to validate EHR data based on research data. To this end, in order to combine each patient’s EHR and research data, a unified scalable research database is needed that allows the integration of EHRs and research data acquired via experimental studies.
4. Presentation of standardized data within the EHR: Once collected, clinically useful standardized data as well as results of any analysis must be transferred back to the main EHR system in real time and presented to the clinician at the point of care.

Solution Requirements

An informatics infrastructure enabling real-time clinical predictive modeling based on the single-source architecture was derived from the named requirements. Custom metadata must be supported. The Clinical Data Interchange Standards Consortium (CDISC) Operational Data Model (ODM) (version 1.3.2) was used as a flexible standard for exchange and archiving of metadata within the framework of clinical studies [30,31]. Mobile apps must be able to communicate with the architecture. Automatic data transfer into the database of the EHR system and from the EHR system to a research database was carried out via a communication server. ODM files were transported automatically to the database of the EHR system with Health Level 7 (HL7) messages [32]. NextGen Connect [33] was used as a communication server. HL7 version 2.5 and message type ORU^R01 were used. The plausibility and completeness of form data were validated by the clinical users.

Analysis of Technical and Clinical Feasibility

The technical feasibility was demonstrated by the implementation of an infrastructure that enables clinical predictive modeling in real time. Java version 1.8.0_181 [34], JavaScript ECMAScript 6 [35], TypeScript version 3.7.2 [36], and the proprietary language of the EHR system were used as programming languages. MongoDB Java Drivers version 3.9.1 [37] and Json-lib version 2.4 [38] were used as third-party libraries. MongoDB version 4.2.3 [39] was used as a research database, Docker version 19.03.13 [40] for operating system–level virtualization, and Red Hat Enterprise version 7.8 [41] as research server. The clinical feasibility was determined by piloting the architecture in the clinic for psychiatry and psychotherapy and for a prospective analysis of the clinical documentation forms used. The clinical users of the system were 25 doctors and 61 health care sector specialists. The stakeholder of the study at Münster University Hospital is the Institute for Translational Psychiatry, Department of Psychiatry. Evaluation began on February 25, 2019 and ended on July 31, 2020. EHR data from daily clinical routine (eg, laboratory data, diagnostic codes) and self-reports/patient-reported outcomes that were experimentally collected as an extension of the clinical routine documentation as part of the SEED research project were examined. The following evaluation criteria were analyzed: (1) measurement of data completeness in the created documentation forms, (2) measurement of data completeness in the research database, (3) monitoring of system stability, and (4) monitoring of data transfer. SPSS Statistics version 25 (IBM Corp) [42] was used for descriptive data analysis. Adobe Photoshop version 11.0 [43] and Microsoft Visio version 16.0.4849.1000 [44] were used to depict the workflow.

Results

System Architecture

The Single-source Metadata ARchitecture Transformation (SMA:T) was used as the software architecture [45]. SMA:T is an extension of the EHR system of the Münster University Hospital and uses module-driven software development [46] to generate standardized applications and interfaces. Every SMA:T form has a generic built-in interface for exchanging standardized data. Embedded applications [45] were used as the application type. These are linked to an ODM file in the EHR database, from which a documentation form is generated. All metadata and clinical data are available in the ODM developed by CDISC version 1.3.2. Patient-reported outcomes are recorded via Mobile Patient Survey (MoPat) [47,48] on mobile devices (generation 6 iPads) and via the web application Mopat@home (a modified version of the tablet-based web app MoPat) [49] for follow-up assessments following discharge from inpatient treatment. Collected data are transferred to the communication server via an HL7 message and from there to the database of the EHR system. Data are sent in the OBX-5 segment of the HL7 message. SMA:T provides database storage. A reference to the imported clinical data is saved. Clinical data are automatically inserted by SMA:T when the documentation form is opened for the first time. A unique ID from the HL7 header is used for this purpose. Each ID is linked to an imported clinical record. The structure of the architecture is shown in Figure 1. Data transfer to the research database takes place via the researcher module from SMA:T. This provides a front end to the EHR system and an extension of the communication server for data transfers. Both prospective and retrospective standardized data exports of EHR data points are supported, specifically, vital signs, laboratory data, medication data, and administrative data. Each data export can be customized by individual parameters. The following parameters are supported: name of data export, export interval, database query, destination parameters for electronic data capture systems, or research databases. MongoDB and RedCap [50] are currently provided as destination templates in the EHR system. The destination portfolio can easily be expanded with interface functions of SMA:T. The research database is embedded in a Docker container of a virtualized Red Hat Enterprise Linux server. The data flow from EHR to electronic data capture is shown in Figure 2. The software architecture is shown in Figure 3.

Figure 1. Unified Modeling Language sequence diagram of the data collection workflow. In process steps 1-3, the patient completes the forms and sends data to the communication server. In process steps 4-8, the communication server sends data to the electronic health record system and creates a blank documentation form. This form is populated with imported data. In process steps 9-13, SMA:T creates the documentation form with metadata and imported data. EHR: electronic health record; HL7: Health Level 7; MoPat: Mobile Patient Survey; ODM: operational data model; SMA:T: Single-source Metadata ARchitecture Transformation.

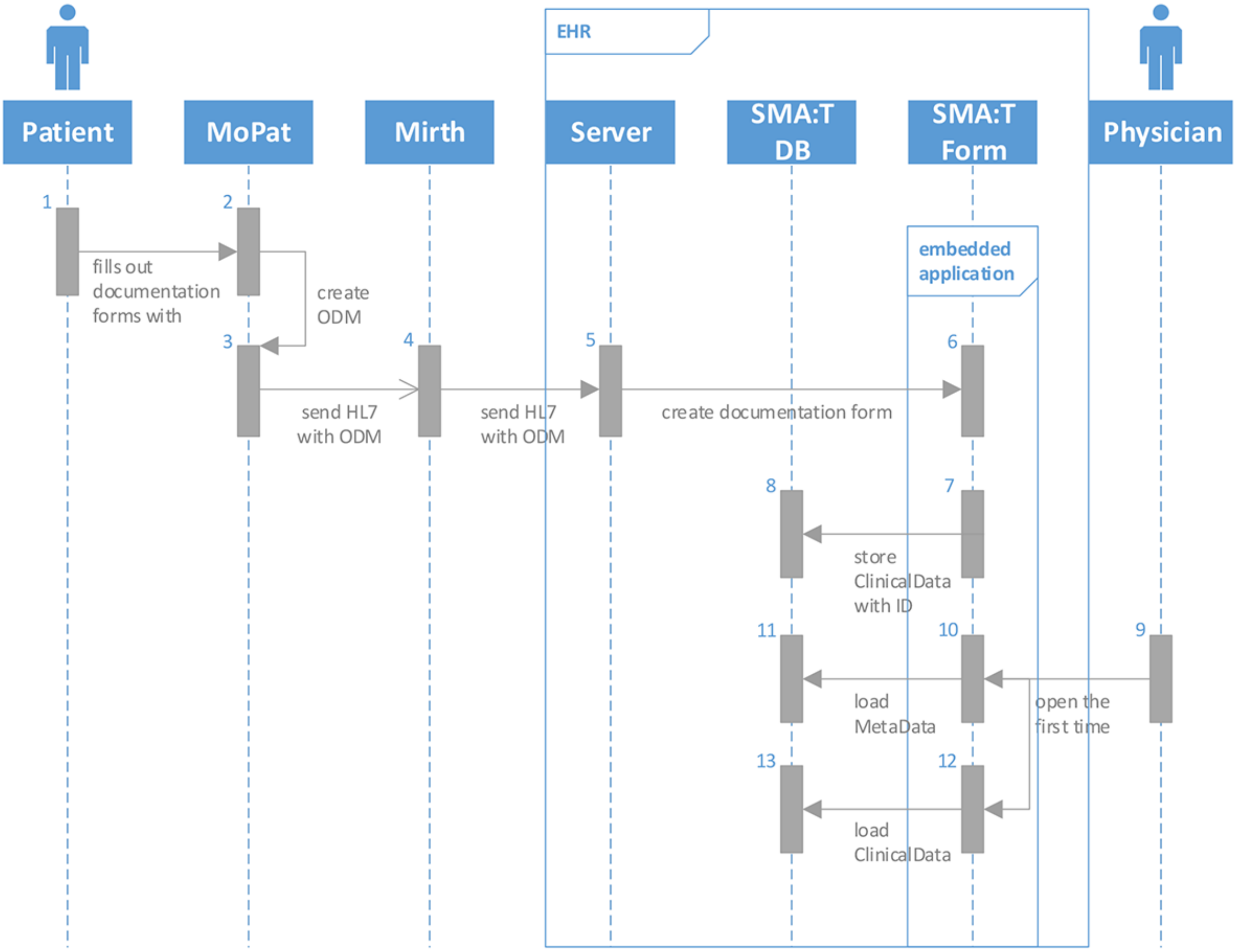


Figure 2. Unified Modeling Language sequence diagram of the data extraction workflow. In process steps 1-8, a study query is created with SMA:T and a generic operational data model file is saved in the database of the electronic health record system. In process steps 9-18, a generic Mirth Channel is created based on the study query. In process steps 19-20, data points are automatically extracted from the electronic health record system and transferred to the study database using operational data model standard format. EDC: electronic data capture; EHR: electronic health record; HDD: Hard Disc Drive; HL7: Health Level 7; LOC: Lines Of Code; MoPat: Mobile Patient Survey; ODM: operational data model; SMA:T: Single-source Metadata ARchitecture Transformation.

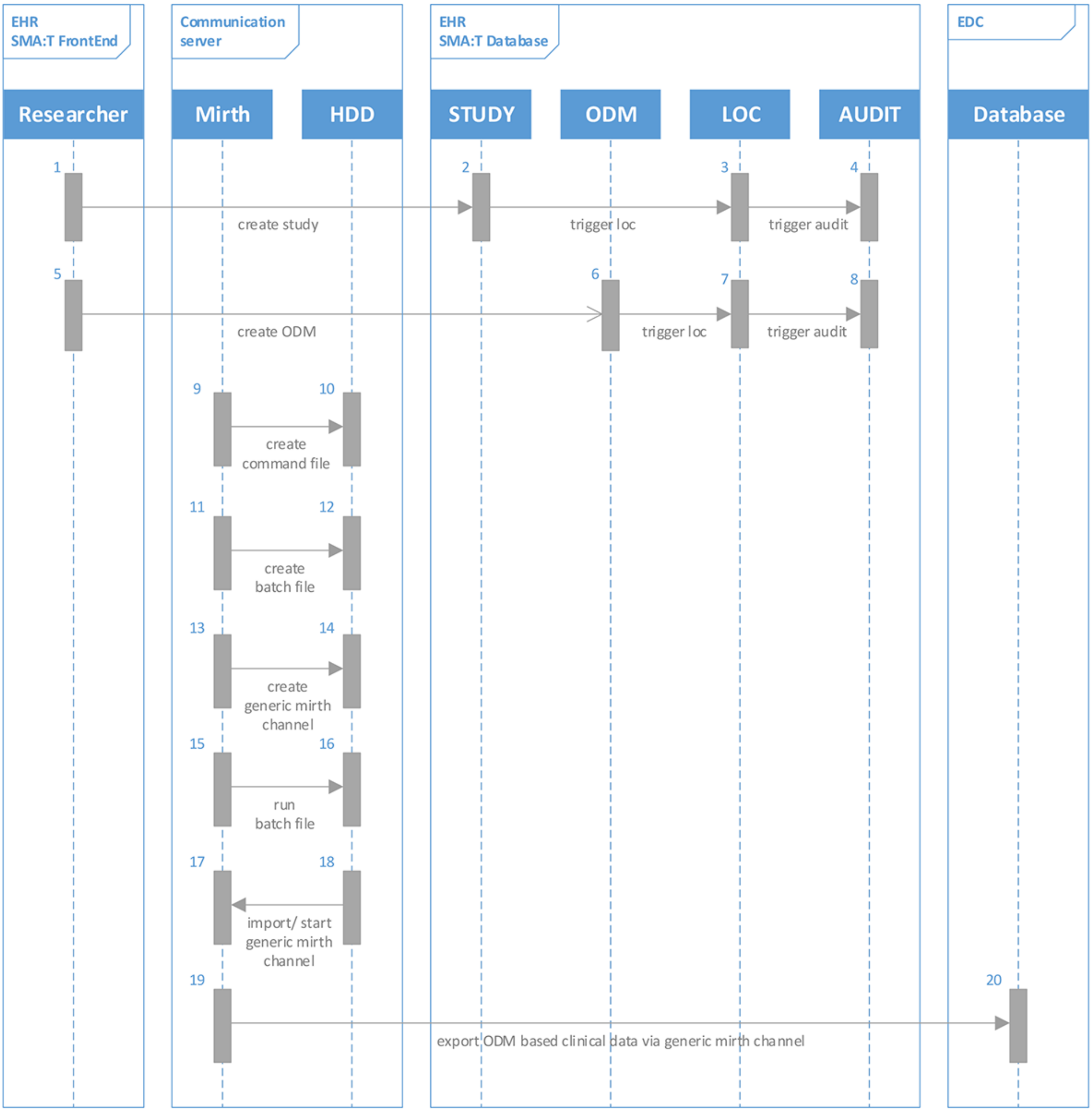
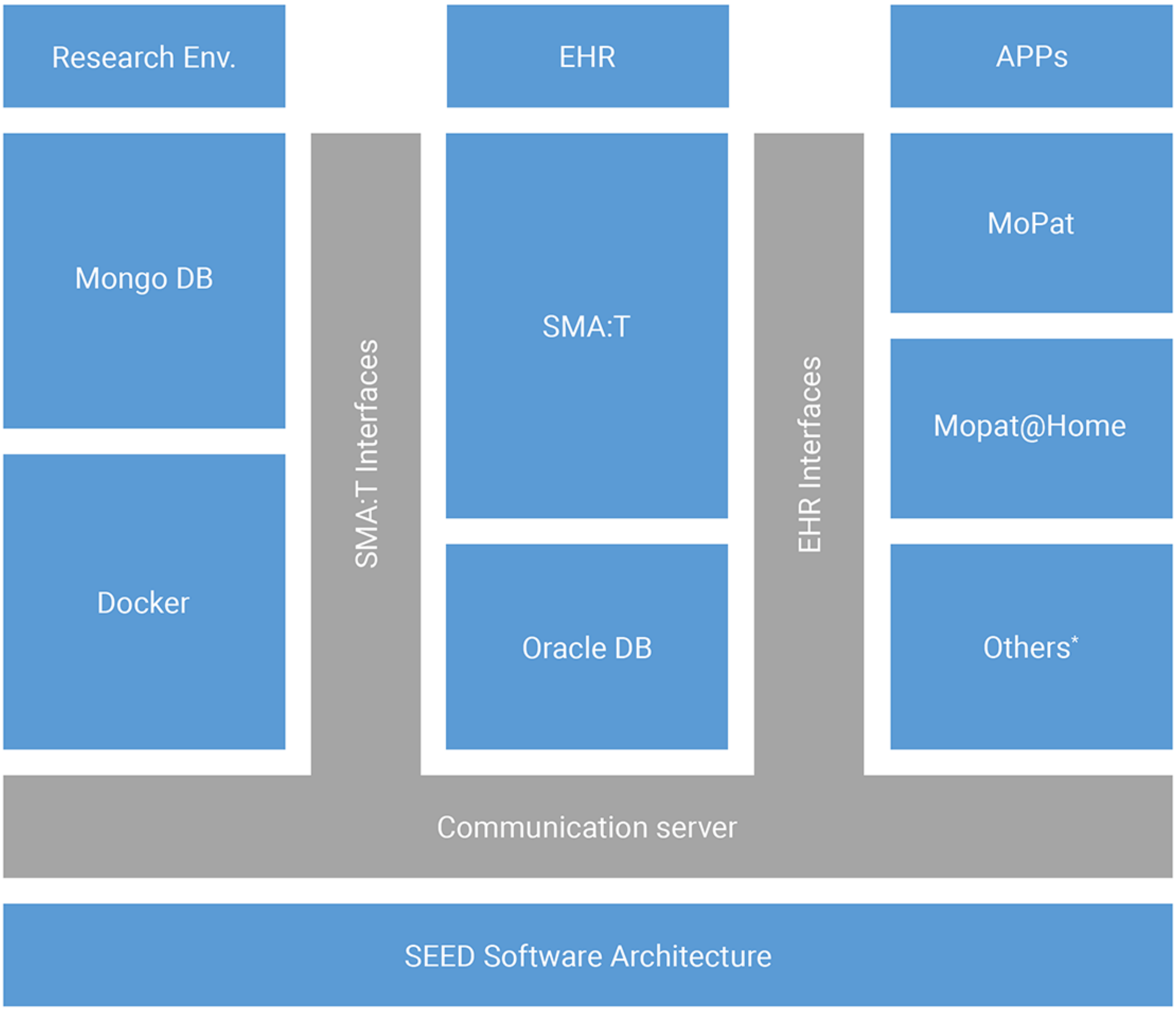


Figure 3. SEED software architecture of the Münster University Hospital. EHR: electronic health record; MoPat: Mobile Patient Survey; SMA:T: Single-source Metadata ARchitecture Transformation; *supports custom applications.



System Implementation

The implementation of the architecture is divided into 4 areas: data collection, data transfer, data storage, and data visualization. Agile methods were used for Project Life Cycle and Development Cycle [51].

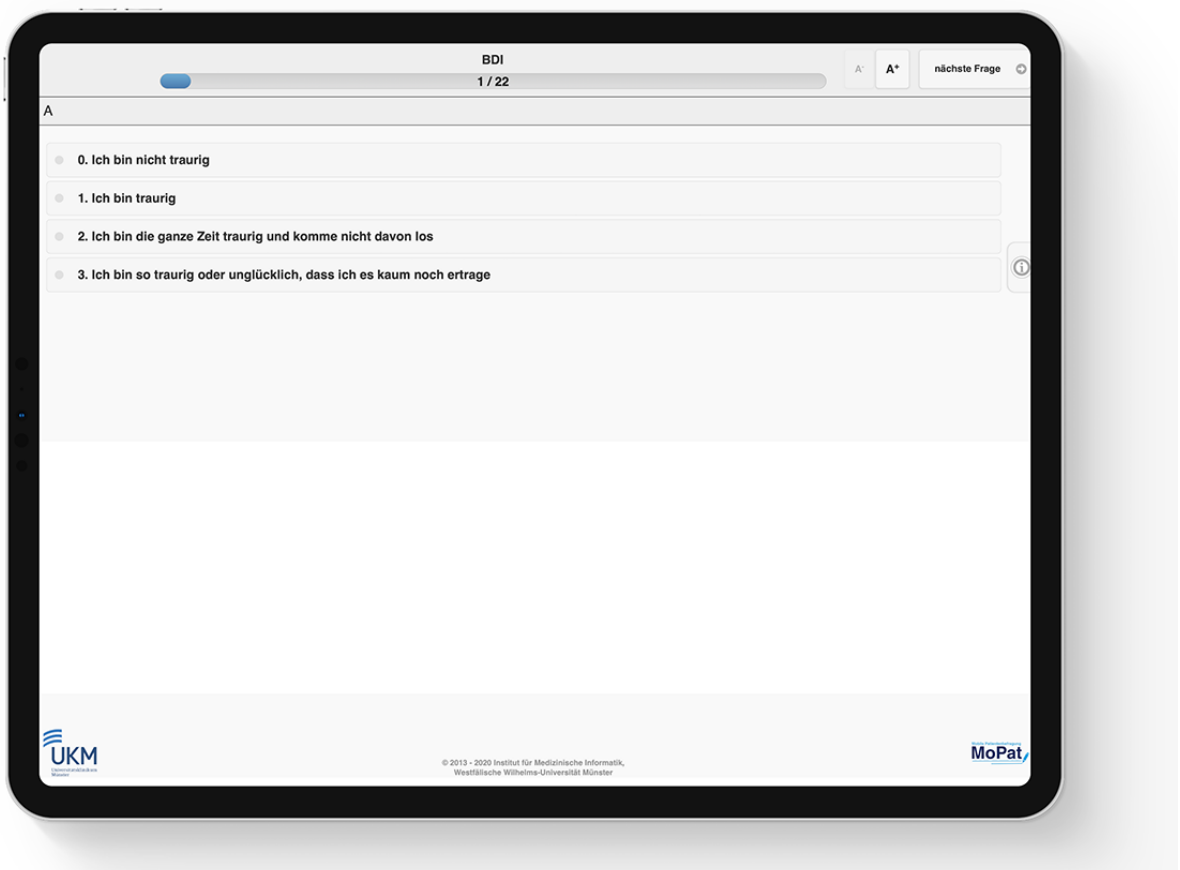
Data Collection

SMA:T provides 2 options for data collection, namely, the EHR system in clinical routine and dedicated web applications. Data input via web applications can be designed freely. In this study, EHR data generated as part of clinical routine documentation comprised, among others, laboratory data, medication, information on diagnosis, time of admission, and length of stay and are presented in detail in Table 1. MoPat [47,48] was selected for the collection of patient-reported outcomes. After input of the patient case ID, staff handed the patient an iPad with the MoPat app. Patients were then guided through a series of documentation forms comprising different questionnaires and they entered data on the mobile device (Figure 4). The iPad was then returned to the medical staff. Further details regarding the collection of patient-reported outcomes during inpatient treatment have previously been described [25]. In brief, the self-reports applied in this study are based on well-established questionnaires and scales in the domain of psychiatry and clinical psychology. In addition, to the retention of single item information, sum scales were calculated based on the recommendations provided in the original manuals and references [52-58]. In addition, Mopat@home was used for the collection of patient-reported outcomes following discharge. To this end, patients were sent an email, which provided a link to a website in which the above referenced questionnaires were presented and could be filled out [49].

Table 1. Research documentation used in the Department of Psychiatry.

Name of the documentation form	Items
SEED ClinicalData Admission Date & Time	4
SEED ClinicalData Classification	2
SEED ClinicalData Diagnosis-Related Groups/Diagnosis	3
SEED ClinicalData Electroconvulsive Therapy	11
SEED ClinicalData Laboratory Assessments	7
SEED ClinicalData Medication	5
SEED ClinicalData Patient	4
SEED ClinicalData Vital Signs	3

Figure 4. One item of Beck Depression Inventory presented in the MoPat app (clinic for psychiatry and psychotherapy at Münster University Hospital).



A

○ 0. Ich bin nicht traurig

○ 1. Ich bin traurig

○ 2. Ich bin die ganze Zeit traurig und komme nicht davon los

○ 3. Ich bin so traurig oder unglücklich, dass ich es kaum noch ertrage

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Data Transfer

SMA:T provides 2 types of data transfer in the present scenario, that is, data transfer into the EHR system and transfer into the electronic data capture system. MoPat sends data to the EHR system via the communication server of the University Hospital. Data are saved in the ClinicalData structure of the ODM format. The ODM document is embedded in an HL7 message. Each HL7 message creates a form in the EHR system. The header of the HL7 message determines which form is automatically created. Data transfer to the electronic data capture takes place via SMA:T interfaces. Both retrospective and prospective data exports in real time are supported. When a study query was activated via the EHR frontend, metadata and corresponding structured query language statements were read by the SMA:T extension of the communication server. SMA:T uses its code library and channel framework to generate unique Mirth channels. These send a database query to the EHR system and transfers the output directly to the electronic data capture system. Both metadata (clinical documentation form) and clinical patient data are provided by SMA:T in the ODM format. Data records are combined into an ODM document. In this study, SMA:T converts the resulting XML-based ODM document into JavaScript Object Notation format [59] (JODM format [60]). The JavaScript Object Notation schema [61] of JODM [60] is open source and currently limited to Study and ClinicalData nodes, including all subnodes of the ODM in version 1.3.2.

Data Storage

Data storage addresses metadata and clinical data. Metadata of clinical documentation forms are stored centrally in the SMA:T database. The SMA:T database model is part of the EHR database model. Metadata and clinical data are available in the ODM format. MoPat also supports ODM format; therefore, the same data model can be used for both systems. Clinical data are clearly identified by unique object identifiers and the associated object identifier on the documentation form.

Data Presentation

Usability principles were applied to visualize data [62-64]. A one-column layout was implemented according to the requirements of the 10 web form design guidelines [65]. Those forms are displayed via SMA:T within the EHR system (see Multimedia Appendix 1 and Multimedia Appendix 2). SMA:T supports item-based real-time notifications as well as centralized notification services to display analysis results in real time.

Technical and Clinical Feasibility

As part of the study, 11 standardized documentation forms with 202 items were created for the clinic for psychiatry and psychotherapy (Table 2): Beck Depression Inventory [66], Big Five Inventory (BFI-2-S) [67], Big Five Inventory (BFI-2-XS) [68], Childhood Trauma Questionnaire [69], Family Mental History [70], Hamilton Depression Scale [71], Narcissistic Admiration and Rivalry Questionnaire [72], Symptom Checklist-90 Somatization Scale [73], sociodemographic questionnaire [74], questions on individual disease course [75], and questions on somatic comorbidities [76]. Data models without license restrictions are available in the portal of medical data models. A documentation form is a document from the EHR system (see Multimedia Appendix 1) and consists of several items. An item consists of an input field and the associated label. For example, 1 item from Multimedia Appendix 1 is the drop-down box labeled A; 5866 instances were created by the patients and automatically transferred to the EHR system of the Münster University Hospital without errors. An instance is a form created by a user; 412 cases from 317 patients were processed by 86 users (Table 3). A case is defined as an inpatient stay or an outpatient visit to a hospital or clinic. Of the 123 of the medical staff of the clinic for psychiatry and psychotherapy, 86 (69.9%) worked with those documentation forms. The data quality could be improved by the ODM. Metadata was a critical step in building a generic and automated workflow. All items are now provided with a unique object identifier, have a typing of the data types, and a code list for converting text into numeric values. Automatic generation of documentation forms was accepted in routine clinical use. Standardized data transfer from the communication server into the EHR system was completed without error. It was possible to display all items (n=202) from ODM structures in full by using the generic workflow. Clinical data from 317 patients was stored in the EHR database; 96.7% (4360/4509) of the scores could be calculated and transferred into the EHR system (Beck's Depression Inventory [52,53], Big Five Inventory [54], Childhood Trauma Questionnaire [55], Hamilton Depression Scale [56], Narcissistic Admiration and Rivalry Questionnaire [57], and Symptom Checklist-90 Somatization Scale [58]) (Table 4), and 111,842 items were completed by patients on mobile devices (Table 5). Approximately 99.3% (91,329/91,974) of forms with scores (91,974 items/645 uncompleted items) were completed and 88.1% (12,617/14,318) of forms without scores (14,318 items/1701 uncompleted items) were completed. The validity of the acquired data on depressive symptomatology was already analyzed in a feasibility study [25]. Eight standardized documentation forms with 39 items were created for the retrospective data export (Table 1): SEED ClinicalData Admission Date & Time [77], SEED ClinicalData Classification [78], SEED ClinicalData Diagnosis-Related group/Diagnosis [79], SEED ClinicalData electroconvulsive therapy [80], SEED ClinicalData Laboratory Assessments [81], SEED ClinicalData Medication [82], SEED ClinicalData Patient [83], and SEED ClinicalData Vital Signs [84]. A total of 96,323 instances of vital signs, laboratory data, medication data, and administrative data could be automatically transferred from the EHR system to the research database (Table 6). Retrospective ODM-based data export worked correctly without technical errors, and 585 instances were created by the patients with Mopat@home and transferred to the research database via SMA:T (Table 7).

Table 2. Routine documentation used in the Department of Psychiatry.

Name of the documentation form (n=11)	Items (n=202)
Beck Depression Inventory	23
Big Five Inventory (BFI-2-S)	35
Big Five Inventory (BFI-2-XS)	20
Childhood Trauma Questionnaire	34
Family Mental History	14
Hamilton Depression Scale	25
Narcissistic Admiration and Rivalry Questionnaire	9
Symptom Checklist-90 Somatization Scale	14
Sociodemographic questionnaire	5
Questions on individual disease course	18
Questions on somatic comorbidities	5

Table 3. Number of instances created for each documentation form: the counts of patients, patient cases, and users are shown.

Name of the documentation form	Cases	Patients	Instances	Users
Beck Depression Inventory	380	307	1266	50
Big Five Inventory (BFI-2-S)	358	303	559	25
Big Five Inventory (BFI-2-XS)	258	217	692	19
Childhood Trauma Questionnaire	313	303	354	33
Family Mental History	315	305	343	31
Hamilton Depression Scale	350	296	516	42
Narcissistic Admiration and Rivalry Questionnaire	357	302	558	20
Symptom Checklist-90 Somatization Scale	360	303	564	18
Sociodemographic questionnaire	315	305	344	26
Questions on individual disease course	315	305	342	26
Questions on somatic comorbidities	313	303	328	10

Table 4. Data quality of patient-based documentation regarding score calculation.

Name of the documentation form	Instances	Scores	Missing data[a]
Beck Depression Inventory	1266	1238	28
Big Five Inventory (BFI-2-S)	559	540	19
Big Five Inventory (BFI-2-XS)	692	656	36
Childhood Trauma Questionnaire	354	320	34
Hamilton Depression Scale	516	502	14
Narcissistic Admiration and Rivalry Questionnaire	558	550	8
Symptom Checklist-90 Somatization Scale	564	554	10

[a] Missing data frequency is determined by missing data entries.

Table 5. Data on the completeness of the documentation forms.[a]

Name of the documentation form	Items	Completed items	Uncompleted items
Beck Depression Inventory	29,118	29,015	103
Big Five Inventory (BFI-2-S)	19,565	19,519	46
Big Five Inventory (BFI-2-XS)	13,840	13,739	101
Childhood Trauma Questionnaire	12,036	11,985	51
Family Mental History	4802	4354	448
Hamilton Depression Scale	12,384	12,076	308
Narcissistic Admiration and Rivalry Questionnaire	5031	5012	19
Symptom Checklist-90 Somatization Scale	7896	7879	17
Sociodemographic questionnaire	1720	1715	5
Questions on individual disease course	6156	5453	703
Questions on somatic comorbidities	1640	1095	545

[a] In this context, completeness means that the documentation form contains values in all data points.

Table 6. Number of retrospectively transferred research documentation forms (electronic health record to electronic data capture).[a]

Name of the documentation form	Instances in electronic health records
SEED ClinicalData Admission Date & Time	245
SEED ClinicalData Classification	8260
SEED ClinicalData Diagnosis-Related Groups/Diagnosis	1163
SEED ClinicalData Electroconvulsive therapy	452
SEED ClinicalData Laboratory Assessments	22,886
SEED ClinicalData Medication	14,244
SEED ClinicalData Patient	245
SEED ClinicalData Vital Signs	48,828

[a] Electronic health record data were extracted with generic study queries in the Single-source Metadata ARchitecture Transformation system.

Table 7. Number of instances created with Mopat@home for each documentation form.

Name of the documentation form	Instances
Beck Depression Inventory	65
Big Five Inventory (BFI-2-S)	64
Childhood Trauma Questionnaire	65
Family Mental History	65
Narcissistic Admiration and Rivalry Questionnaire	64
Symptom Checklist-90 Somatization Scale	66
Sociodemographic questionnaire	66
Questions on individual disease course	65
Questions on somatic comorbidities	65

Discussion

Answers to the Study Questions

The aim of this study was the design and implementation of an informatics infrastructure enabling standardized data acquisition at the point of care and subsequent accessibility of clinical data for analytic purposes, which is required for future application of predictive models in day-to-day clinical routine in psychiatry. In this study, we have shown the overall technical feasibility of the implemented solution. Standardized documentation forms were implemented to extend EHR data domains and to improve data quality in the EHR system. An automated transfer of data into the EHR system and the research database was implemented, thus enabling the pooling of EHR data with already existing research data from ongoing cohort studies. This system was accepted by clinical staff from the Department of Psychiatry of Münster University Hospital in Germany. Widespread use of documentation forms could be demonstrated. Standardized electronic data collection in the EHR at the point of care was successfully implemented. The latter solution can similarly be applied for the presentation of results from predictive models.

Strengths and Weaknesses of This Study

The major strengths of this study are standardized acquisition, transfer, storage, and export of data in real time with a generic informatics infrastructure. This system fulfills the prerequisites for future predictive modelling in clinical routine in psychiatry [85-87]. Standardized data transfer in ODM format provides scalability in the context of complex medical data structures. The Define-XML standard, an extension of the ODM standard, is mandated by regulatory authorities such as Food and Drug Administration for metadata [88]. Compliance with regulatory standards is the major advantage of our infrastructure regarding future clinical studies. The data format had to be converted due to the research database, which is a limitation. MongoDB was chosen for rapid analysis of large amounts of data in previous work [89]. Standardized automatic data transfer into research databases was possible for both retrospective and prospective research questions. The data of the EHR system was responsible for the number of documentation forms for the retrospective export. Data export can be configured centrally from the EHR system in compliance with local data protection regulations. Our approach is scalable because ORBIS EHR systems are used in more than 1300 hospitals in Germany, Austria, and Switzerland. The evaluation concentrated on technical and clinical feasibility. Limitations include the lack of elaborated standardized evaluations of the user experience of the system by clinical staff. Moreover, further evaluation is necessary in order to assess the sustainable benefit in everyday clinical practice. Although the feasibility and acceptability of the implemented data input interface has been demonstrated in a recent publication [24] and the wide-spread use of the implemented data presentation format in the EHR indicates acceptability, it appears important to note that no further feedback from clinicians (ie, in the form of structured interviews or questionnaires) has been acquired, which limits the informative value regarding user satisfaction. This important issue should therefore be addressed by future works based on elaborated user feedback. Of note, the projected acquisition of data from several hundred cases per year based on our set-up results in a database of modest scale was comparable to that by successfully established deep learning models in other fields of medicine [90]. Yet, it appears important to take into account that that the current state-of-the-art machine learning approaches in psychiatric research are based on cohorts with smaller sample sizes that were acquired over a period of multiple years [91-93]. The present initiative that aims to train predictive models on data from clinical routine documentation thus offers a perspective to significantly increase sample sizes in machine learning research in psychiatry. The training of predictive models as well as their validation in clinical applications is not within the scope of the this study but will be the focus of subsequent work building on the technical infrastructure outlined in this study. Importantly, as our standardized data acquisition protocol covers established risk factors and symptom profiles that have in part already been successfully used for predictive analytics in psychiatric cohort studies [91,93], it appears reasonable to assume their predictive validity for the intended prediction of symptom trajectories and functional outcomes in future work.

Results in Relation to Other Studies

Through our study, we extend a previous line of research on predictive modeling based on EHR data. While previous studies have demonstrated empirical evidence for the predictive validity of EHR data in psychiatric use cases [18-20], to the best of our knowledge, our study is the first to not only report on the design but also on the successful implementation and technical feasibility of the informatics infrastructure for standardized acquisition, transfer, storage, and access of real world data for analytic purposes in psychiatric care, which is the basic requirement for the application and validation of predictive models in future clinical studies. Although we are not aware of any other study that has reported successful implementation of a comparable informatics infrastructure in psychiatric clinical routine, several preliminary reports should be taken into account. Complementary to the work presented in this study, Khalilia et al [94] described a Fast Healthcare Interoperability Resources (FHIR) web modeling service that was tested on a pilot intensive care unit dataset. A multi-source approach was used. No binding standard is used for clinical studies; instead, the standard Observational Medical Outcomes Partnership Common Data Model was applied [95] and an FHIR server and database are required for this system, which might limit potential implementations at multiple sites, considering that many EHR systems currently do not yet use an FHIR server. Of note, we are aware of several large-scale efforts aiming to translate predictive models into psychiatric practice [96] that, once implemented, might serve as a future base for comparison of system stability and performance. Importantly, the presented infrastructure represents a flexible solution that allows compatibility with existing initiatives and concepts of data standardization such as the Common Data Elements repository of the National Institutes of Health [97]. The choice of the ODM as the data standard implies the automatic provision of a metadata provider for each item. Thus, data points can be enriched with additional codes based on standards such as the Systematized Nomenclature of Medicine Clinical Terms or the Unified Medical Language System [98,99]. The integration takes place via the alias node or the SMA:T schema extension of the ODM. This makes it possible to enrich the survey data with additional metadata. International standardizations are hence compatible with the operating data model based on a 1-1 mapping of item definition nodes.

Generalizability of This Study

The informatics infrastructure for standardized data acquisition, transfer, storage, and export in real time for future predictive modelling outlined in this study is an important step in the complex process toward the implementation of machine learning and clinical decision support solutions in routine care. Our study shows that this approach is technically feasible. Owing to the standardization, this concept is also scalable for other medical areas. Data warehouse applications of a heterogeneous hospital landscape can be implemented with this software architecture. In addition to local artificial intelligence applications, multi-site implementations of the architecture could also transfer pseudonymized data points into a global predictive model. The implementation of national and international predictive models in medicine would be possible.

Future Work

Artificial intelligence systems rely on high-quality data. In the future, artificial intelligence applications might send real-time evaluations directly back into the EHR system. Clinical staff could access and respond to calculated predictions. Selected data will be provided in a modular dashboard. Medical device regulation needs to be taken into account for implementation of such systems. Direct data transfer back from the clinic would be possible. Real-time adjustments of the prediction models would thus be possible. Standardization of clinical routine documentation via SMA:T can provide high-quality structured data points. It is planned to augment this database with further research data from existing cohort studies, for example, covering neuroimaging and genetic data. Specific prediction models can be trained in this way with the same architecture. Generic model pipelines can be set up. Model clusters can be set up to answer complex medical questions. Basically, SMA:T forms a solid technical infrastructure for the implementation of artificial intelligence solutions in medicine. Scheme extensions of the ODM standard can be implemented to optimize communication between systems. Observational and interventional studies are warranted to evaluate the predictive validity of machine learning models in psychiatric routine. For multi-center studies, SMA:T needs to be reimplemented in the respective EHR environments to process CDISC ODM files. A software blueprint is available [45]. If SMA:T and MoPat are already in use, the architecture can be set up within a short time frame of approximately 1 week. The generic concept of the architecture enables the reuse of our data models, database queries, and server architecture. Retrospective database queries might have to be reimplemented in the EHR environments. The necessary data can be used from our repository on GitHub [100]. Another important consideration is the potential future enrichment of EHR data with mobile assessments, including ecological momentary assessments and passive sensor data derived from smartphones. Recent reports on successful real-time prediction of depressive symptoms based on ecological momentary assessment data supplement this notion [101]. Thus, future studies should explore technical solutions that allow data transfer between EHRs and patients' smartphones. Future work will evaluate the predictive potential of the acquired data entities by training and validating machine learning models for an individual level prediction of treatment response, functional outcome, and depression relapse. In accordance with findings from previous machine learning approaches in psychiatric cohort studies, in a first step, well-established predictive algorithms such as support vector machines will be trained on features covering risk and symptom profiles, sociodemographic variables, medication, and treatment history [7,91,93]. Yet importantly, as opposed to previous cohort studies, the technical infrastructure outlined in this study will allow to train and validate predictive models in naturalistic patient samples in routine care.

Conclusions

The presented informatics infrastructure enabling standardized data acquisition, transfer, storage, and export in real time for future predictive modelling in clinical routine in psychiatry is technically feasible. The outlined architecture provides a technical basis for the application, first and foremost, and the validation of clinical decision support systems and artificial intelligence applications in clinical studies.

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Authors' Contributions

RB and NO drafted the manuscript. RB developed the software architecture and conducted the statistical analyses. NO was responsible for the formulation of the overarching research goal and aims, the study design, conception, development of the methodology, management and coordination responsibility for the research activity planning and execution, data acquisition and design, creation of data models, and data analysis. NO and MD acquired financial support for the conduction of this study. MS supported programming and the implementation of computer code. All authors contributed to the interpretation of data. All authors critically reviewed and substantially revised the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Beck Depression Inventory documentation form created with Single-source Metadata ARchitecture Transformation.
[PNG File , 37 KB - mental_v8i6e26681_app1.png]

Multimedia Appendix 2
Symptom Checklist-90 Somatization Scale documentation form created with Single-source Metadata ARchitecture Transformation.
[PNG File , 119 KB - mental_v8i6e26681_app2.png]

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Abbreviations

CDISC: Clinical Data Interchange Standards Consortium
EHR: electronic health record
FHIR: Fast Healthcare Interoperability Resources
HL7: Health Level 7
MoPat: Mobile Patient Survey
ODM: operational data model
SMA:T: Single-source Metadata ARchitecture Transformation

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Review

Ethics and Law in Research on Algorithmic and Data-Driven Technology in Mental Health Care: Scoping Review

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Abstract

Background: Uncertainty surrounds the ethical and legal implications of algorithmic and data-driven technologies in the mental health context, including technologies characterized as artificial intelligence, machine learning, deep learning, and other forms of automation.

Objective: This study aims to survey empirical scholarly literature on the application of algorithmic and data-driven technologies in mental health initiatives to identify the legal and ethical issues that have been raised.

Methods: We searched for peer-reviewed empirical studies on the application of algorithmic technologies in mental health care in the Scopus, Embase, and Association for Computing Machinery databases. A total of 1078 relevant peer-reviewed applied studies were identified, which were narrowed to 132 empirical research papers for review based on selection criteria. Conventional content analysis was undertaken to address our aims, and this was supplemented by a keyword-in-context analysis.

Results: We grouped the findings into the following five categories of technology: social media (53/132, 40.1%), smartphones (37/132, 28%), sensing technology (20/132, 15.1%), chatbots (5/132, 3.8%), and miscellaneous (17/132, 12.9%). Most initiatives were directed toward detection and diagnosis. Most papers discussed privacy, mainly in terms of respecting the privacy of research participants. There was relatively little discussion of privacy in this context. A small number of studies discussed ethics directly (10/132, 7.6%) and indirectly (10/132, 7.6%). Legal issues were not substantively discussed in any studies, although some legal issues were discussed in passing (7/132, 5.3%), such as the rights of user subjects and privacy law compliance.

Conclusions: Ethical and legal issues tend to not be explicitly addressed in empirical studies on algorithmic and data-driven technologies in mental health initiatives. Scholars may have considered ethical or legal matters at the ethics committee or institutional review board stage. If so, this consideration seldom appears in published materials in applied research in any detail. The form itself of peer-reviewed papers that detail applied research in this field may well preclude a substantial focus on ethics and law. Regardless, we identified several concerns, including the near-complete lack of involvement of mental health service users, the scant consideration of algorithmic accountability, and the potential for overmedicalization and techno-solutionism. Most papers were published in the computer science field at the pilot or exploratory stages. Thus, these technologies could be appropriated into practice in rarely acknowledged ways, with serious legal and ethical implications.

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KEYWORDS

digital psychiatry; digital mental health; machine learning; algorithmic technology; data-driven technology; artificial intelligence; ethics; regulation; law; mobile phone

Introduction

Background

Data-driven technologies for mental health have expanded in recent years [1,2]. The COVID-19 pandemic has accelerated this shift, with physical distancing measures fast-tracking the digitization and virtualization of health and social services [3,4]. These initiatives extend from hospital- to community-based services for people with mental health conditions and psychosocial disabilities (the term *mental health conditions and psychosocial disabilities* is used to refer to the broad range of mental health conditions and the associated disability; the term is used by the World Health Organization [5]). Government agencies, private technology firms, service user groups, service providers, pharmaceutical companies, professional associations, corporate services, and academic researchers are among the actors involved [5-7]. The technologies they create serve various functions, including information sharing, communication, clinical decision support, digital therapies, patient or service user and population monitoring, bioinformatics and personalized medicine, and service user health informatics [1]. Only some of these broader digital technologies will use algorithmic technologies to which this paper will turn.

Throughout this paper, we use the term algorithmic and data-driven technologies to describe various technologies that rely on complex information processing to analyze large amounts of personal data and other information deemed useful to making decisions [6]. The term is used here to encompass technologies variously referred to as artificial intelligence, machine learning, deep learning, natural language processing, robotics, speech processing, and similar automation technologies. The paper is premised on the view that the term *algorithmic and data-driven technologies* offers a useful category for the purposes of this review, although important conceptual and practical differences exist between technologies within this broad category (eg, between artificial intelligence and machine learning).

In the mental health context, algorithmic and data-driven technologies are generally used to make inferences, predictions, recommendations, or decisions about individuals and populations. Predictive analysis is largely aimed at assessing a person's health conditions. Data collection may occur in a range of settings, from services concerning mental health, suicide prevention, or addiction support. Collection may also occur beyond these typical domains. For example, web-based platforms can draw on users' posts or purchasing habits to flag their potential risk of suicide [7]. CCTV systems with machine learning sensors in *suicide hotspots* can be programmed to assess bodily movements that may precipitate a person's suicide attempt [8]. Education institutions may flag students who appear to be in distress based on attendance records, social media use, and physiometric monitoring [9]. There are also examples of algorithmic technologies being used in forensic mental health settings [10] and other criminal justice settings [11], including databases that combine noncriminal mental health data with user-generated social media content for the apparent purpose of preventive policing [12].

Some prominent mental health professionals have argued that digital technologies, including algorithmic and data-driven technologies, hold the potential to bridge the "global mental health treatment gap" [13] by "reach[ing] billions of people" worldwide [14]. A 2019 *Lancet Psychiatry* editorial describes a "general agreement that big data and algorithms will help optimize performance in psychiatry" [15]. Others have described "widespread agreement by health care providers, medical associations, industry, and governments that automation using digital technology could improve the delivery and quality of care in psychiatry, and reduce costs" [16]. Indeed, governments and some private sector actors appear enthusiastic [1]. For people who use mental health services and their representative organizations, views on algorithmic technology in mental health care appear more ambivalent, although research by service user researchers, advocates, and their representative organizations comprises only a very small part of scholarship and commentary in the field [17-19].

This study set out to identify to what extent and on what matters legal and ethical issues were considered in the empirical research literature on algorithmic and data-driven technologies in mental health care. *Empirical research* refers simply to scholarship that seeks to use algorithmic and data-driven technology in an applied way in the mental health context.

Ethics and Law

Ethics refer to guiding principles, whereas laws, which may be based on ethical or moral principles, are enforceable rules and regulations with penalties for those who violate them. Scholarship on the ethical and legal dimensions of algorithmic and data-driven technologies in mental health care is relatively scant but growing [20-26]. Existing research generally draws together two strands of research: first, the ethicolegal issues involved in algorithmic and data-driven technological mental health initiatives [25-27] and, second, a broader scholarship concerning algorithmic and data-driven technologies [28-30]. We briefly discuss each of these strands of research.

According to Lederman et al [25], most web-based mental health interventions have not been subject to ethical scrutiny, particularly those that go beyond one-to-one web-based or phone-based counseling, such as mental health apps and moderated web-based forums. Lederman et al [25] suggest using the classic health ethics framework, with its four principles of nonmaleficence, beneficence, respect for autonomy, and justice, particularly given its widespread use and acceptance among the health professions [26]. However, given the emergence of digital mental health initiatives in nonclinical settings (eg, in education, work settings, social media, and financial services), other ethical frameworks and practices may be required [7,31]. Nonhealth settings are not governed by the same entrenched bioethical principles, norms of conduct, or regulatory frameworks as formal health care systems [31]. Burr et al [31] pointed out that the transfer of responsibility from traditional health care providers to institutions, organizations (both private and public), and individuals who are creating web-based mental health initiatives gives rise to new ethical considerations. These include the duty to intervene in emergencies, competency to address people's support needs, and ensuring the decisional capacity and health literacy of consumers of commercialized products [31]. This expanded scope is a sign that the ethical literature concerning digital technology in the mental health context is growing [20,24,32-34], even if ethical analyses may not occur in most applied initiatives, as suggested by Lederman et al [25]. Legal scholarship on digital technology in mental health care is sparse [1] but tends to focus on the regulatory frameworks applicable to digital health, privacy, confidentiality, cybersecurity, and software as medical devices [35-39].

The broader ethical and legal dimensions of algorithmic technologies have been the subject of a much larger scholarship [28-30,40,41]. Scholars in this field are typically concerned with issues of fairness, accountability, transparency, privacy, security, reliability, inclusivity, and safety, which are examined in contexts as diverse as criminal law, consumer transactions, health, public administration, migration, and employment. Legal scholars have tended to call for technological due process (involving fair, accountable, and transparent adjudications and rulemaking), net neutrality (broadly, equal treatment of web-based content by providers of internet access services) [42], and nondiscrimination principles [43]. Early legal and ethical scholarship focused on efforts to ensure basic standards of algorithmic transparency and auditing, but a more recent movement of scholars, regulators, and activists has begun to ask more fundamental questions, including whether algorithmic systems should be used at all in certain circumstances, and if so, who gets to govern them [44].

Methods

Design

This study adapted a scoping review methodology to undertake a broad exploration of the literature. Scoping reviews are particularly useful for surveying a potentially large and interdisciplinary field that has not yet been comprehensively reviewed and for which clarification of concepts is required [45], a characterization that appears apt for the use of algorithmic and data-driven technologies in mental health care. The scoping review method was also considered the most appropriate approach because it could capture the literature from several sources and disciplines with varying terminology and conceptual boundaries.

We adapted the Arksey and O’Malley framework for scoping reviews [46]. The framework involves the following five steps or framework stages: (1) identifying the research question; (2) identifying relevant studies; (3) selecting studies; (4) charting results; and (5) collating, summarizing, and reporting results.

A description of each step is outlined below.

We drew on elements of the Joanna Briggs Institute scoping review methodology [47] and PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) extension for scoping reviews [48] to support the rigor of our methods. Study selection included all study types, and the overall aim was to chart data according to key issues, themes, and gaps [46]. Materials were analyzed using conventional content analysis supplemented with keyword-in-context analysis (discussed below).

Identifying the Research Question (Step 1)

We sought to identify all studies within a selective sampling frame [49] that answered the following research questions:

- In what ways are algorithmic and data-driven technologies being used in the mental health context?
- How and to what extent are issues of law and ethics being addressed in these studies?

These questions were chosen to maintain a wide approach to generate the breadth of coverage [46].

Identifying Relevant Studies (Step 2)

A rapid or streamlined literature search was conducted. We started with a search string that emerged from our initial literature review (noted in the *Background* section). However, the search string was updated as we surveyed the literature, and new terms and ideas from other disciplines and practices were considered. We also undertook a hand search of relevant reference lists of included papers to identify other papers for inclusion. The search was not exhaustive because of the breadth of the topic area, but it aimed to be inclusive of diverse disciplines and varying conceptualizations of the topic.

The following search strings emerged through an iterative process (Textbox 1). They were applied in keyword fields or abstract and title fields (where available in each database).

Textbox 1. Iteratively developed search string.

Scopus

- (TITLE-ABS-KEY ('mental (health OR ill* OR disability OR impair*)' OR 'psychiatr*' OR 'psycholog*' OR 'beahvioral health') AND TITLE-ABS-KEY ('algorithm*' OR 'artificial intelligence' OR 'machine learning') AND TITLE-ABS-KEY ('internet' OR 'social media' OR 'chatbot' OR 'smartphone' OR 'tracking'))

Embase Ovid

- ('mental (health OR ill* OR disability OR impair*)' or 'psychiatr*' or 'beahvioral health').mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
- “mental illness”.mp. or mental disease/
- algorithm/ or machine learning/ or artificial intelligence/
- ('algorithm*' or 'artificial intelligence' or 'machine learning').mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
- Internet/ or “web-based”.mp.
- ('internet' or 'social media' or 'chatbot' or 'smartphone' or 'tracking').mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
- The above search strings were applied in various combinations.

Association for Computing Machinery

- ('mental health' OR 'mental ill*' OR 'psychiatr*' OR 'behavio* health') AND ('algorithm*' OR 'artificial intelligence' OR 'machine learning') AND ('internet' OR 'social media' OR 'chatbot' OR 'smartphone' OR 'tracking')

No date limit was placed, although the search was conducted between August 2019 and February 2020 iteratively. A language filter was applied to focus on English-language results, which was applied for pragmatic reasons to reduce the search scope and complexity (for more on limitations, including terms we appear to have overlooked, see the *Discussion* section).

After an extensive search, 1078 relevant peer-reviewed research studies were identified in the study selection stage. From these, papers that were not available in English, duplicates, and papers not available in the full text were excluded.

Study Selection (Step 3)

The process of identifying relevant studies among the 1078 papers was iterative, involving several discussions between coauthors. Unlike systematic reviews, where inclusion and exclusion criteria for studies are established at the outset, this study developed these criteria during the search process (Textbox 2) [46]. The purpose of deciding on criteria post hoc is to avoid barring studies that might not align with current understandings of the issue or topic [46]. This was especially important when including computer science databases in the search strategy because of the heterogeneity of studies broadly related to mental health.

Textbox 2. Inclusion and exclusion criteria.

Inclusion criteria

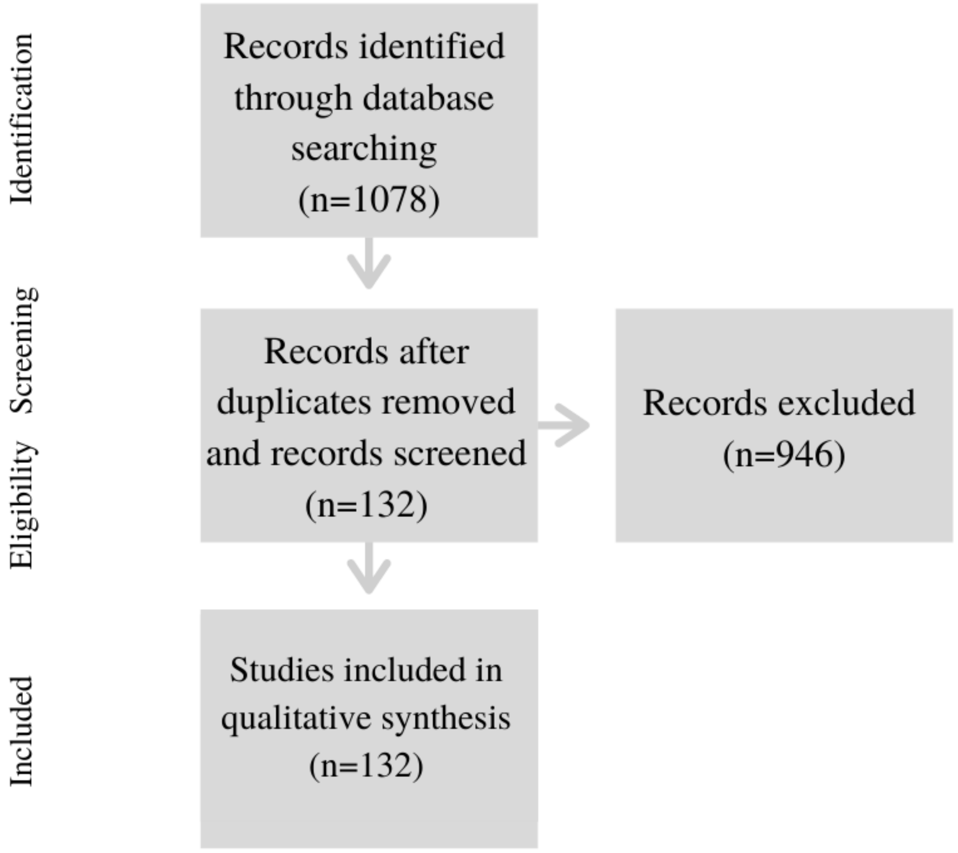
- Study undertaken in a mental health context or with application to a mental health context
- Text available in English
- Study related broadly to the use of big data, internet technology, artificial intelligence, sensors, smart technology, and other contemporary algorithmic technologies

Exclusion criteria

- Commentary pieces
- Studies focused on other health conditions
- Application of data science methods to clinical data collected via clinical technologies (eg, application of data science methods to magnetic resonance imaging data)
- Data science methods paper with no specific real-world application or objective
- Application of data science methods to psychiatric research in general
- Studies applied to animals or animal models

Owing to the large number of studies identified at step 2, we did not undertake a full-text review. Instead, we reviewed only the abstract and title according to our inclusion criteria. According to the PRISMA criteria described by Moher et al [50], systematic reviews would include a full-text review after duplicates were removed to assess all articles for eligibility. We did not take this step, as the screening and eligibility phases of the review could take place by reviewing the abstracts or titles (after all, we were simply looking for applied mental health research that used algorithmic and data-driven technologies—Figure 1).

Figure 1. Study selection for review.



This adaptation enabled us to review a large body of work in a rapidly expanding field. Our broad inclusion approach was also chosen to prevent the exclusion of studies from disciplines that do not conform to traditionally appropriate research designs, which might preclude them from reviews with stricter inclusion and exclusion criteria (eg, using an insufficient study design description as an exclusion criterion). For example, we found that many computer science papers were published in conference journals [51] and did not always include in-depth methods or an explicit statement of the research aim or objectives.

This process resulted in 132 empirical research papers included in the review. Figure 1 provides a PRISMA diagram that sets out the process of exclusion for our adapted study.

Charting Results (Step 4)

Through initial deductive analysis of the abstracts and discussions between the researchers, we identified several key issues and themes through which to consider the broad research field. We settled on a typology that considered both the form of technology used in the study (eg, social media, sensors, or smartphones) and the stated purpose for the mental health initiative (eg, detection and diagnosis, prognosis, treatment, and support).

The second step involved analyzing the data to determine how legal and ethical issues were discussed. The material was analyzed using the computer software package NVivo 12 (QSR International) [52]. Conventional content analysis was undertaken, supplemented by keyword-in-context analysis [52]. We used the following terms, drawn from themes and keywords arising in the literature noted in the *Ethics and Law* section, which are typically associated with legal and ethical matters arising in the use of digital technologies in mental health: *law** or *legal**; *ethic**; *human rights*; *transparen**; *oversight*; *accountab**; *bias*; *fairness*; *privacy*; *trust*; *regulat**

We sought a uniform approach to the 132 studies included in this review. However, in practice, it was often impossible to extract all the information required where research reports used varying terminology and concepts and potentially failed to include relevant material.

Collating, Summarizing, and Reporting Results (Step 5)

Several typologies can be used to categorize the algorithmic and data-driven technologies identified in these studies. As noted, we integrate two here: (1) the primary *forms* of technology and (2) their stated *purpose*. Such distinctions can help to highlight the predominant areas of technological inquiry and differentiate relevant ethical and legal concerns for the various categories.

Results

Typology: Form and Stated Purpose

Overview

We derived five major categories of technology (Textbox 3): (1) social media (53/132, 40.1%), (2) smartphones (37/132, 28%), (3) sensing technology (20/132, 15.1%), (4) chatbots (5/132, 3.8%), and (5) miscellaneous (17/132, 12.9%). We have discussed these categories in detail in the following sections. We further evaluated the papers according to the stated purpose of the technology using a typology created by Shatte et al [53]. They categorized papers into the following four categories: (1) detection and diagnosis; (2) prognosis, treatment, and support; (3) public health; and (4) research and clinical administration.

Textbox 3. Categorization of articles by the form and stated purpose of technology.

Social media

- Detection and diagnosis (26/132, 19.7%) [54-79]
- Prognosis treatment and support (4/132, 3%) [80-83]
- Public health (22/132, 16.7%) [84-105]
- Research and clinical administration (1/132, 0.7%) [106]

Smartphones

- Detection and diagnosis (17/132, 12.9%) [107-123]
- Prognosis treatment and support (20/132, 15.1%) [124-143]
- Public health (0/132, 0%)
- Research and clinical administration (0/132, 0%)

Sensing technology

- Detection and diagnosis (6/132, 4.5%) [144-149]
- Prognosis treatment and support (12/132, 9.1%) [150-161]
- Public health (2/132, 1.5%) [162,163]
- Research and clinical administration (0/132, 0%)

Chatbots

- Detection and diagnosis (0/132, 0%)
- Prognosis treatment and support (5/132, 3.8%) [164-168]
- Public health (0/132, 0%)
- Research and clinical administration (0/132, 0%)

Miscellaneous

- Detection and diagnosis (8/132, 6.1%) [169-176]
- Prognosis treatment and support (8/132, 6.1%) [177-184]
- Public health (1/132, 0.7%) [185]
- Research and clinical administration (0/132, 0%)

Neat distinctions were not always possible. For example, Nambisan et al [95] sought to validate a method of detecting depression among social media users in a large-scale data set (a common aim in the social media category). At first glance, their study might appear to fall within the *detection and diagnosis* category. However, the ultimate aim of the study was to improve public health informatics, which improves the accuracy of population-wide prevalence analysis. Hence, we placed this study in the public health category (defined in the following sections).

The four categories by Shatte et al [53] offer clinical or medical framing, which broadly matches the clinical orientation of the scholarship (as a counterview, some researchers have called for the demedicalization of digital platforms designed to help people in mental distress [186], a point to which we will return in our discussion). Shatte et al [53] found that most studies in their scoping review on machine learning in mental health research focused on detection and diagnosis—this is indeed reflected in our own findings. We found that 43.2% (57/132) of the studies broadly concerned detection and diagnosis.

We determined that 37.1% (49/132) of the studies broadly concerned technology aimed primarily at prognosis, treatment, and support, which includes initiatives for personalized or tailored treatment and technologies used in services where treatment is provided. Examples include the use of smartphone apps to provide personalized education to someone based on psychometric data generated by the app.

A total of 18.9% (25/132) of studies were on public health. Public health papers used large epidemiological or public data sets (eg, social media data and usage data from Wi-Fi infrastructure) to monitor or respond to persons who appear to be experiencing or self-disclosing an experience of distress, mental health crisis, or treatment. However, we struggled in applying this category, as many were borderline cases in the detection and diagnosis category. This ambiguity may be because many studies were based in the field of computer science and were contemplated at a higher level of generality, with limited discussion of the specific setting in which they might be used (eg, a social media analytical tool could be used in population-wide prevalence studies or to identify and direct support to specific users of a particular web-based platform).

Our search uncovered only 1 study related to research and clinical administration; this particular study focused on the triage of patients in health care settings.

Finally, it is noteworthy that despite the reasonably large volume of studies, all but a few were at an exploratory and piloting stage. This is not surprising given the predominance in our survey of scholarship from computer science journals in databases such as ACM. A key issue in this area of inquiry is the large context gap between the design of these technological innovations and the context of implementation. In many papers from the computer science discipline, the authors made assumptions or guesses as to how their innovations could be implemented, with seemingly little input from end users. This is not a critique of individual researchers; instead, as we shall discuss later, it reflects the need for interdisciplinary and consultative forms of research at the early stages of ideation and piloting. This matter also raises questions as to whether there is a strong enough signal or feedback loop from practice settings back to designers and computer scientists in terms of what *needs* they should be responding to and why.

Social Media

We found 53 studies concerning social media, in which data were collected through social media platforms. Two major platform types were identified: mass social media, including mainstream platforms such as Facebook, Twitter, and Reddit; and specialized social media, comprising platforms focused on documenting health or mental health experiences. Both forms of social media involve the collection of textual data shared by users and self-reported mental health conditions, and sometimes expert opinion on diagnoses attributable to users (identified through information shared on the web). For example, researchers may examine whether the content of posts shared correlates with, and can therefore help predict, people's self-reported mental health diagnosis. Most studies concerned mass social media platforms (Twitter: 17/53, 32%; Reddit: 14/53, 26%; Facebook: 6/53, 11%), with a small number concerning specialized social media (*PatientsLikeMe*: 1/53, 2%; *Psycho-babble*:1/53, 2%; *Reachout*: 1/53, 2%).

The largest sub-category in the social media group (26/53, 49%) have focused on predicting or detecting depression, with some concerning other diagnostic categories. Some studies attempted to capture multiple diagnostic categories or aimed to detect broad signs of mental ill-health.

Mobile Apps

In total, 38 studies concerned mobile apps used to collect and process data from participants, of which two main subcategories emerged. The first included apps that required active data input by participants (27/38, 71%), which either took the form of validated surveys (eg, Patient Health Questionnaire-9) or an experience sampling method; the second included those that passively collected data from inbuilt smartphone sensors (15/38, 39%). Some papers were counted twice as they had methods that covered both subcategories. Contemporary smartphones include a range of sensors related to sleep patterns, activity (movement), location data (GPS, Wi-Fi, and Bluetooth), communication or in-person human interaction (microphones), web-based activity (phone or text logs and app usage), and psychomotor data (typing and screen taps).

Apps that draw on these data sources can be considered passive sensing because the individual generally does not have to input data actively. Data collection generally requires participants to install an app that collects data from smartphone sensors and sends it to the researchers.

Sensing Technology

In total, 20 studies focused on broader sensor technology designed to continuously collect data on a person's activity or environment. We differentiated this category from smartphone passive sensing, although there is a clear crossover with some personal wearables that fall under the sensing technology category. As we use it here, *sensing technology* includes a range of both wearables and environmental sensing technology (our search strings included variations on this theme, including *tracking*, *biometric monitoring*, and *behavioral sensing*). Many wearables were off-the-shelf personal wearables such as Fitbits, although there were several others, such as radio-frequency identification tags. Environmental sensors refer to technologies that collect data within the environment or about the environment but are not personal wearables, such as smart-home devices.

The list of sensing technologies includes personal wearables (9/20, 45%), smart-home sensors, automated home devices, internet of things (3/20, 15%), Microsoft Kinect (a software developer kit that includes computer vision, speech models, and algorithmic sensors; 1/20, 5%), skin conductance technology (1/20, 5%), portable electroencephalogram (1/20, 5%), radio-frequency identification tags (2/20, 10%), the use of Wi-Fi metadata (2/20, 10%), and data collected via care robots (eg, Paro Robot; 1/20, 5%).

Some studies have examined sensor systems for use in psychiatric settings. For example, Cheng et al [159] used a wireless monitoring system to monitor the location and heartrate of psychiatric inpatients. Other studies have used sensors in everyday settings. For example, Dickerson et al [158] sought to create a "real-time depression monitoring system for the home" for which data are collected that are "multi-modal, spanning a number of different behavioral domains including sleep, weight, activities of daily living, and speech prosody"

Chatbots

The fourth group of studies explored the use of chatbots and conversational agents in web-based mental health contexts, of which 5 studies appeared. This group includes studies focused on chatbots being used by both people experiencing mental health conditions or psychosocial disabilities and those who provide them with care or support. For example, D'Alfonso et al [83] studied the development of a "moderated online social therapy" web application, which provides an interactive social media-based platform for youth recovering from psychosis.

Miscellaneous

This final group (17/132, 12.9%) included a range of studies that did not fit the previous categories. This category included the collection of data from video games and data sources where there was no explicit outline of how such data would be collected in practice (eg, facial expression data). We included the video game data in this *miscellaneous* category, although it could also possibly sit in the social media category.

Law and Ethics

Law

As noted, we conducted a thematic analysis supplemented by keyword-in-context analysis to identify themes related to law and ethics, as discussed in the *Background* section of this paper. There was little explicit discussion of legal issues, although issues such as privacy, which have precise legal dimensions, were discussed. However, privacy has rarely been discussed in terms of the law in the literature surveyed. We will return to the issue of privacy shortly. The term *law* appeared in just 1 study with reference to the legal implications of the particular algorithmic and data-driven technology being considered [187]. The term *legal* appeared in passing in three papers [92,99], among which the most substantial statement, by Faurholt-Jepson et al [133], referred to legal concerns as one of several considerations in different national contexts:

> *Using smartphones to collect large amounts of data on personal behavioral aspects leads to possible issues on privacy, security, storage of data, safety, legal and cultural differences between nations that all should be considered, addressed and reported accordingly.* [133]

A passing reference was made to the rights of user subjects in some studies (eg, Manikonda and De Choudhury [98] asked, "[h]ow...automated approaches, that are themselves prone to errors, [could] be made to act fairly, as well as secure one's privacy, their rights on the platforms, and their freedom of speech?"). Other studies referred very briefly to compliance with the relevant regulatory or legislative frameworks under which the algorithmic and data-driven technologies were tested, such as the Health Insurance Portability and Accountability Act of 1996 (United States) [73,108,155].

Ethics

In terms of explicit reference to ethics, 10 studies included a specific section on the ethical issues raised by their work [64,73,80,87,92,98,99,105,163,187] and 10 others included a broad reference to key ethical issues [64,70,122,124,126,133,140,152,184]. The latter material varied from one or two sentences to a paragraph or more. Although we searched for several ethical and legal themes (eg, privacy, security, safety, transparency, autonomy, and justice), the theme of privacy was dominant.

Privacy

Privacy was discussed in several ways across all the included studies but was primarily addressed as part of the research method rather than in the real-world implementation of the technology. Approximately 19.7% (26/132) of papers sought to address user privacy through anonymization, deidentification, or paraphrasing of personal information. For example, Li et al [93] stated, "to protect Weibo users' privacy, personally identifiable information (eg, names, usernames) were excluded from any research outputs."

The second major approach concerns what we have referred to as *privacy protocols*. This included aligning processes to legal requirements [73,108,155,187] but for the most part concerned some kind of process for data management, such as ensuring the consent of and providing notice to user subjects. For example, Manikonda and De Choudhury [98] proposed "guidelines to be incorporated in the design and deployment of [their] interventions and tools," which sought "voluntary consent from the population being studied and those likely to benefit from the technologies." However, unlike Manikonda and De Choudhury [98], very few studies have discussed the issue of consent at the implementation stage of their proposed technology. Instead, most authors discussed consent in terms of how their research was conducted. In some cases, mainly regarding social media, the authors argued that consent was not needed given the public nature of user-generated content on social media (a topic to which we will return).

A collection of privacy engineering approaches was taken, including hashing and encryption and managing the data processing location. There were a variety of approaches around when and where data were processed and how this aligned with ideas about privacy. Some studies have used encryption before sending data to servers for processing, whereas others have analyzed data locally on the smartphone or did not store specific data postprocessing. Wang et al [141], for example, noted, "we do not record any speech on the phone or upload to the cloud and all audio signal processing and feature extraction is based on privacy preserving algorithms."

Some authors referred to the tension between privacy and data quality—framed, for example, as "[p]rivacy versus lives saved" [92]. This framing was seen within specific methods and technological approaches, such as the data and privacy-preserving qualities of sensor data, compared with Wi-Fi infrastructure data. For example, Ware et al [162] argued that whereas Wi-Fi infrastructure data could be considered more privacy-preserving than collecting data from smartphones, it may also be less accurate. Ji et al [66] discussed how a method they tested "has an advantage over data protection methods because it trains on the entire dataset, but it also violates user privacy and breaks the data protection setting," and ultimately argued that their chosen "method achieves a balance between preserving privacy and accurate detection."

The final point in the privacy theme was expectations. Very few studies have considered the expectations people may have about how their data are used. This led to an acknowledgment that the use of data from sources such as social media or video games to make predictions about people's mental health changes the meaning of these data and could have unintended consequences. Eichstaedt et al [68], for example, noted that social media data used for health reasons might change how people perceive that data and thus the type of data they report. De Choudhury et al [99], in their analysis of *mental health content* in social media, warned that an unhelpful outcome could include "chilling effects in participation in the community, or suicide ideation moving on to fringe or peripheral platforms where such populations might be difficult to extend help to."

Discussion

Principal Findings

Overview

To summarize, we identified five major types of technology—social media, mobile apps, sensing technology, chatbots, and others—in which algorithmic and data-driven technologies were applied in the mental health context. The primary stated purpose of these technologies was broadly to detect and diagnose mental health conditions (approximately 57/132, 43.2% of studies). Only 15.1% (20/132) of papers discussed ethical implications, with a primary focus on the individual privacy of research participants.

Privacy

As noted, the privacy of participants was addressed in the studies primarily with reference to engineering methods and, in some instances, concerning regulatory compliance. In the smartphone group, notice and consent combined with engineering methods were used to address user-subject privacy concerns. In the social media group, privacy was discussed in terms of how data were managed and the technical elements of the algorithms used, including privacy-preserving algorithms [96] and limiting the use of identifiable information [87]. In the sensor group, privacy was addressed in several ways, particularly by collecting low-fidelity data [150] and anonymization [148].

Questions may be raised about how privacy is (or should be) conceptualized and how the technologies will fare in real-world settings. Taking a strictly legal approach to privacy, for example, may not necessarily confer a social license to operate. An example of a failure to align law and social license is the United Kingdom's proposed *care.data* scheme, where secondary data from general practitioners were to be collected for research purposes [188]. Although this scheme aligned, and in some cases, went further than legal requirements, it still faced a public backlash and was ultimately shut down.

Privacy as a concept exists as an expression of claims to dignity and self-determination. These more expansive concerns of dignity and autonomy were not the subject of explicit consideration in the studies examined in this review. This point raises the issue of possible gaps in the literature.

Gaps

Overview

It is difficult to discuss what did *not* appear in the literature, as such observations are necessarily subjective and will differ based on a person's disciplinary background, interests, and priorities. For our part, we noted four interconnected matters that we believe are important and which arise in the literature noted in the *Background* section. They are the paucity of ethical inquiry and consideration of algorithmic accountability, the near-complete lack of service user or subject input, and concerns with a medico-technological framing.

Gaps in Ethical Enquiry

Notwithstanding the common interest in matters of privacy across almost all papers, there was a relatively low engagement with broader ethical dimensions of the algorithmic and data-driven technology in question—a finding that appears to support the view of some scholars in the field [25].

However, an important distinction should be made between empirical studies designed to validate or explore a particular technology and (as we discussed in the *Background* section) the literature concerned *specifically* with ethical and legal issues arising from algorithmic technology. The very form of journal articles that examine applied research concerning algorithmic and data-driven technologies in mental health care may tend to preclude a focus on the ethical and legal issues that arise (although some authors clearly felt it worth noting pressing issues in their papers). Some disciplines, including computer science, appear to have traditionally separated ethics or legal articles from publications concerned with findings or validation regarding emerging technologies, although this tradition is somewhat challenged in the literature on ethics in design [189,190].

Furthermore, the gap between applied research, on the one hand, and research that is specifically focused on ethics, on the other hand, does not appear to be unique to the mental health context. For example, Hübner et al [191] point out that "ethical values have not yet found their firm place in empirically rigorous health technology evaluation studies" more generally. This dynamic “sets the stage for further research at the junction of clinical information systems and ethics” [191]. Indeed, others have sought to create frameworks to meet the new ethical and regulatory challenges of health care in the digital age [32].

A minority of the studies in our review discussed these challenges. Birnbaum et al [54], for example, discussed the limits of contemporary ethical standards for research on social media in the mental health context, noting that “[e]xisting ethical principles do not sufficiently guide researchers” and new technological approaches to “illness identification and symptom tracking will likely result in a redefinition of existing clinical rules and regulations.” However, many other studies have not discussed or alluded to these challenges. In one study, web-based videogame players were recruited to conduct a web-based survey asking for "sociodemographic and gaming information" and feedback concerning psychometric indicators to develop machine learning to predict psychological disorders. The researchers requested electronic consent from participants to take part in the study but “did not apply for, or receive, any approval from any board or committee for this research as this was a techno-behavioral general study which was non-medicinal, non-intrusive, and non-clinical in nature” [169]. Furthermore, the authors noted, “[we] are affiliated to a technology university which has no internal committee related to research on human subjects” [169].

New critical questions are required. For example, several studies in the social media category, the largest group of studies, eschewed institutional review board approval based on claims that their data sets were *publicly available*, raising ethical and legal concerns surrounding emergent, inferred, or indirect data concerning mental health and the potential appropriation of detection and screening tools in unethical (and potentially even illegal) ways. Such claims are being increasingly challenged, particularly following concerns about the creation of inferred data about unsuspecting and nonconsenting users in the health context generally [192] and the mental health context in particular [193]. Arguably, the likelihood of these risks being overlooked in research is exacerbated by the near-complete exclusion of persons with experience of mental health service use as active contributors to knowledge production in this field, whether as co- or lead investigators or even as advisors.

Lack of Service User Involvement

Very few studies (4/132, 3%) in this survey appear to have included people who have used mental health services, those who have experienced mental health conditions or psychosocial disability, or even those who were envisaged as end-beneficiaries of the particular algorithmic and data-driven technology, in the design, evaluation, or implementation of the proposals in any substantive way (except as research participants). In studies where service users were involved, this tended to comprise of research participants being involved in the co-design of content or codeveloping user-interfaces. D’Alfonso et al [83], for example, noted, “[t]he creation of therapy content [in their web-based platform]...was driven by feedback from users and expert youth mental health clinicians through iterative prototyping and participatory design.” With very few exceptions, however, the survey indicated a near-complete exclusion of service users in the conceptualization or development of algorithmic and data-driven technologies and their application to mental health initiatives. It is also noteworthy that even mental health practitioners, who may well be end users envisaged by technologists, were involved in relatively few studies.

The active involvement of mental health service users and representative groups for persons with psychosocial disabilities has become a prominent ethos in mental health and disability policies worldwide [194] and is imperative in international human rights law [195]. A study in our survey included an acknowledgment of the limitations of not working with affected populations [105]. However, the authors referred to study populations as research subjects rather than active contributors to technological development. Manikonda and De Choudhury [98] did recommend the “[a]doption of user centered design approaches in intervention and technology development, to investigate specific needs and constraints of the target users, as well as their acceptability, utility, and interpretability.” Similarly, Ernala et al [73] noted that the field could benefit extensively from cross-disciplinary partnerships and partnerships between “computational and clinical researchers, and patients.” They also recommended “[p]articipatory research efforts such as the Connected and Open Research Ethics (CORE) initiative [for use] to develop dynamic and relevant ethical practices to guide and navigate the social and ethical complexities of patient data collection” [32,73].

From a pragmatic perspective alone, the involvement of service users and others with psychosocial disabilities is generally agreed to increase the likelihood of “viable and effective—rather than disruptive and short-lived—advances” in digital technologies in the mental health context [14].

Of the scant commentary and research in the field by persons with psychosocial disabilities and service users, commentators have raised concerns about: the potential need for a *right to explanation* concerning algorithmic decision making for individuals (not only the right of an individual to understand how a decision about them was made but also to query the values that go into a particular algorithmic decision system) [196]; the risk of discrimination or harm where sensitive personal information is leaked, stolen, sold, or scraped from social media [197]; and the deployment of data-driven technologies in coercive psychiatric interventions and policing [19,196]. Keyword searches along these lines did not yield any relevant results. Emerencia et al [184] prioritized the ethical imperative of shared decision making (“an approach in which patient and clinician are equal participants in deciding the treatment plan”) in their study on algorithmic technologies that might generate "personalized advice for schizophrenia patients", and Saha et al [87] highlighted the potential harms caused by the use of social media data to examine “psychopathological effects subject to self-reported usage of psychiatric medication.” However, these were unusual considerations among the studies reviewed and were noted in passing.

Concerns With Algorithmic Accountability

As discussed in the *Background* section, ethical and legal scholars on algorithmic and data-driven technologies have begun to raise fundamental concerns about whether algorithmic systems should be used at all for certain purposes and, if so, who should govern them [44]. Pasquale [44] illustrates the evolution of these concerns with reference to mental health apps:

> *For some researchers who are developing mental health apps, the first-wave algorithmic accountability concerns will focus on whether a linguistic corpus of stimuli and responses adequately covers diverse communities with distinct accents and modes of self-presentation. Second-wave critics...may bring in a more law and political economy approach, questioning whether the apps are prematurely disrupting markets for (and the profession of) mental health care in order to accelerate the substitution of cheap (if limited) software for more expensive, expert, and empathetic professionals.*

Second-wave concerns give rise to questions as to who is benefiting from (and burdened by) data collection, analysis, and use [44]. Such concerns are spurred by questions about which systems deserve to be built, which problems most need to be addressed, and who is best placed to build and monitor them [198]. Scholarship on algorithmic and data-driven technologies in mental health services appears to have seldom asked such questions, at least explicitly ([196]; notable exceptions include [17] and [23]). The debate about algorithmic accountability in mental health care is likely to accelerate in the coming years amid broader calls for algorithmic decision systems to be subject to contest, account, and redress to citizens and representatives of the public interest.

Overmedicalization and Concerns of Techno-Solutionism

The issues the studies aimed to address were presented in medical terms and framed as problems that are amenable to digital technological solutions. This is not surprising. However, some scholars have raised concerns regarding this framing. In their survey of the messaging of mental health apps, Parker et al [186] argued that prominent apps tend to overmedicalize states of distress and may overemphasize "individual responsibility for mental well-being." There may be legitimate reasons to demedicalize some approaches to supporting people in distress via digital initiatives and remain cautious about framing the matters as medical problems amenable to digital technological solutions [193,199]. Rose [194] argues that:

> *most forms of mental distress are inextricably linked to problems of poverty, precarity, violence, exclusion, and other forms of adversity in people's personal and social experiences, and are best addressed not by medicalization, but by low intensity but committed and durable social interventions guided by outcomes that are not measured in terms of symptom reduction, but by the capacities that people themselves desire in their everyday lives.*

This argument raises broader questions about the politics of mental health, for which it would be unrealistic to expect empirical studies of algorithmic and data-driven technologies in mental health care to resolve. Nevertheless, there is an argument that such political considerations and value choices are currently overlooked, with an overwhelming emphasis on scientific methods and measurements of risk and benefit.

Comparison With Previous Work

Reviews such as those conducted by Shatte et al [53] and Tai et al [200] applied systematic literature search methods to identify the use of machine learning and artificial intelligence in modifying therapeutics and prevention strategies in psychiatry, and Doorn et al [201] performed a scoping review on its role in psychotherapy. However, to the best of our knowledge, no studies have surveyed the field to identify how ethical and legal issues are incorporated into applied research.

Limitations

A disadvantage of using a rapid scoping review method is the difficulty in reproducing the results, given the use of numerous search strings in multiple combinations. This is exacerbated by our aim to cover multiple technology types across several cross-disciplinary databases (resulting in 1078 potential studies reduced manually to 132). There are trade-offs in this broad, exploratory approach. In addition to the challenges of replicability, we cannot claim to have achieved an exhaustive review, as may be possible in systematic reviews of specific technologies or subtypes (such as machine learning). Furthermore, the wide range of new and emerging technologies in our scope poses terminological challenges; hence, we undoubtedly missed studies that used terms overlooked in our search strings (as a peer reviewer pointed out, we did not use the term *recommender system*). This is exacerbated by the intrinsic challenge of pinning down terms and concepts in any area of rapid technological change [202].

Despite these limitations, a survey of empirical studies offers valuable information. The principal strength of a scoping review is its *breadth*. Our broad and cross-disciplinary approach enabled us to identify cross-cutting trends in the literature as a whole, and the trends we identified are striking, that is, roughly 15.1% (20/132) of the studies in the survey contained even a brief consideration of ethical issues, and only 3% (4/132) of studies appeared to involve mental health service users or affected populations. We argue that this is a significant finding that warrants our chosen method and research design.

Conclusions

Our findings suggest that the disciplines undertaking applied research in this field do not generally prioritize *explicit* consideration of ethical and legal issues in their studies—and, perhaps more broadly, "the moral, political, social and policy issues at stake" [203]. Research institutions tend to focus strongly on protecting human participants involved in research, as they should, which is generally reflected in the studies in our survey (although not always). However, other important considerations, such as participatory and community-engaged research, which is an increasingly accepted requirement of mental health research, policy and practice, as well as broader ethicolegal issues in the field appear to be overlooked. This situation may have several explanations warranting further investigation, including editorial requirements for scholarly papers, the workings of institutional review mechanisms, funding arrangements, and prevailing evidentiary and epistemological cultures. However, with an increase in adverse effects involving flows of data concerning mental health [1], the situation must surely change.

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Conflicts of Interest

None declared.

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Abbreviations

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses

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Original Paper

Preliminary Outcomes of an Ecological Momentary Intervention for Social Functioning in Schizophrenia: Pre-Post Study of the Motivation and Skills Support App

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Abstract

Background: People with schizophrenia and other serious mental illnesses often lack access to evidence-based interventions, particularly interventions that target meaningful recovery outcomes such as social functioning and quality of life. Mobile technologies, including smartphone apps, have the potential to provide scalable support that places elements of evidence-based interventions at the palm of patients' hands.

Objective: We aim to develop a smartphone app—called Motivation and Skills Support—to provide targeted social goal support (eg, making new friends and improving existing relationships) for people with schizophrenia enrolled in a stand-alone open trial.

Methods: In this paper, we presented preliminary outcomes of 31 participants who used the Motivation and Skills Support app for 8 weeks, including social functioning pre- to postintervention, and momentary reports of treatment targets (eg, social motivation and appraisals) during the intervention.

Results: The findings suggest that the intervention improved self-reported social functioning from baseline to treatment termination, particularly in female participants. Gains were not maintained at the 3-month follow-up. Furthermore, increased social functioning was predicted by momentary reports of social appraisals, including perceived social competence and the extent to which social interactions were worth the effort.

Conclusions: The implications of these findings and future directions for addressing social functioning in schizophrenia using mobile technology have been discussed.

Trial Registration: ClinicalTrials.gov NCT03404219; https://clinicaltrials.gov/ct2/show/NCT03404219

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KEYWORDS

schizophrenia; psychosis; social functioning; social skills; motivation; mHealth; smartphone; mobile phone

Introduction

Background

For people with schizophrenia and other serious mental illnesses, psychosocial interventions demonstrate efficacy in improving important recovery outcomes, including occupational and social functioning [1]. In particular, negative symptoms such as low drive can improve through individual and group-based behavioral approaches such as social skills training (SST) and cognitive behavioral therapy for psychosis (CBTp) [2-4]. Although antipsychotic medications are the first line of treatment for both acute psychotic symptoms and prevention of relapses in schizophrenia [5], evidence-based psychosocial approaches can effectively address impairments in functioning that persist despite adequate pharmacological treatment [6,7].

Despite the demonstrated efficacy of psychosocial approaches to care, most individuals with schizophrenia experience long-standing challenges with social impairment [8]. Limited access to evidence-based care and the need for regular support beyond the time-limited nature of existing treatment for people with resource limitations contribute to poor long-term outcomes for these patients [9,10]. Effects of CBTp on functioning, for example, often do not persist far beyond treatment termination [11]. Recent mobile approaches to psychosocial support, such as smartphone apps, can help increase access to evidence-based, ongoing support. This is particularly important now, given increasing smartphone ownership among those with serious mental illnesses [12,13].

App-based interventions also have other advantages beyond in-person treatment. Apps can support real-time self-management outside of the therapy office, which may be particularly useful for addressing the dynamic nature of concerns that can arise during social interactions. Recently developed app-based interventions have shown promise in addressing psychosocial outcomes in a mobile format. For example, the FOCUS smartphone app is a multifaceted mobile intervention that targets auditory hallucinations, mood, sleep, functioning, and medication adherence [14]. FOCUS has demonstrated similar efficacy to standard in-person psychosocial approaches to care for people with schizophrenia, including in reducing symptoms and improving broadly defined recovery outcomes [15]. Other smartphone apps have been designed to address motivational impairment more directly, including in patients with early psychosis [16]. Text message–based approaches incorporating goal setting and other cognitive behavioral elements have also been used to target motivational negative symptoms [17,18]. Granholm et al [19] also recently developed a mobile app called CBT2go to supplement in-person CBTp.

Although existing mobile interventions address the broad needs of individuals with psychotic disorders in a comprehensive approach—including in combination with ongoing face-to-face care—they were not designed to directly target the multifaceted social needs of people with psychotic disorders, often described as the most critical need among patients themselves [20]. Indeed, only one of the reviewed studies showed improvements in social functioning, an effect that did not persist beyond treatment termination [19]. Thus, there remains a need for mobile approaches to directly target the complex, multifaceted nature of impaired social functioning in psychotic disorders.

Objectives

To address this need, we aim to develop the Motivation and Skills Support (MASS) smartphone app. Our primary aims are to (1) develop an ecological momentary intervention (EMI) that integrates evidence-based psychosocial treatment approaches with insights from basic affective, motivational, and cognitive science to target key contributors to impaired social functioning in schizophrenia (namely, social motivation); (2) translate elements of SST and CBTp to allow for real-time support of social goal attainment in people's daily lives; (3) systematically enhance social motivation by providing feedback of information about prior affective social experiences related to individuals' social goals; and (4) incorporate stakeholder input (people with schizophrenia and expert clinicians) in the design of the intervention to assess attitudes regarding mobile technology and include content relevant to the everyday social needs of people with schizophrenia (see Fulford et al [21] for a more detailed description of app development, including data on usability and acceptability).

In this paper, we describe the preliminary outcomes of the MASS app in an open pilot trial. We report changes in clinical outcomes from baseline to treatment termination and 3-month follow-up. We also report changes in key intervention targets (ie, social motivation, associated behavior, and appraisals) during the intervention, as reported by ecological momentary assessment (EMA). We hypothesized that social functioning would increase and positive and negative symptoms would decrease during the intervention and that changes would be maintained at follow-up. We also predicted significant improvements in EMA-reported treatment targets throughout the intervention and that these targets would be associated with improvements in clinical outcomes from baseline to termination.

Methods

Study Procedures

This was a two-site, open pilot intervention study that took place in the Boston and San Francisco Bay areas (registered clinical trial NCT03404219). Clinical and outcome data were collected on three occasions: baseline (preintervention), at the end of the 8-week intervention (treatment termination), and 3 months following treatment termination (follow-up). Participants were first screened over the phone; those who met the screening criteria were invited to complete a baseline session that started with informed consent, followed by an assessment of eligibility and clinical measures. This was followed by an intervention period. At the end of each assessment (baseline, termination, and follow-up), participants were reimbursed for their time with cash payments.

Participants

We recruited people with schizophrenia using fliers and word-of-mouth at community treatment and rehabilitation centers that serve people with serious mental illness. The inclusion criteria were a diagnosis of schizophrenia between the ages of 18 and 65 years, receiving current pharmacological treatment, psychotherapy, or both and fluency in English. Exclusion criteria were current (past 6 months) substance use disorder, self-reported current suicidal ideation (via structured diagnostic interview), or self-reported diagnosis of a neurological disorder. Although the study was advertised as potentially of interest to those who wished to improve their social lives, social impairment or interest in improving social functioning were not formal inclusion criteria.

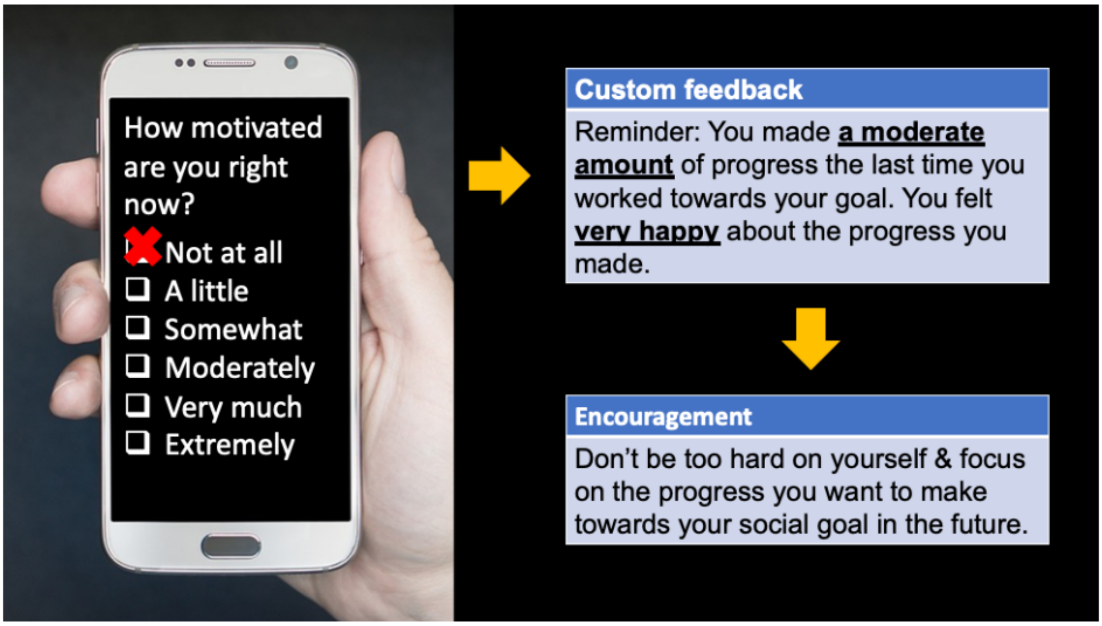
Intervention: MASS Mobile App

At the baseline assessment, participants worked with a research assistant to collaboratively select a social goal they wanted to work on, which should be feasible to achieve during the intervention. This social goal was programmed into the app by the research assistant, and then participants were introduced to the smartphone and the app, and they were asked to demonstrate basic phone and app functions to ensure comprehension and identify any potential challenges. Participants were provided with these smartphones to keep (Samsung Galaxy S8), and prepaid data and call and text plans were provided during the intervention period. Participants could access the app at any time during the intervention and could also access the SST video content beyond the study through links on the phone’s home screen.

Intervention content was delivered twice daily, 7 days a week for 60 days, via automatic push notifications in concert with the EMA surveys—one in the morning and one in the evening, using semirandom administrations (ie, within blocks of 2.5 hours). We did not reimburse participants to respond to surveys and encouraged the use of the app on an as-needed basis for social goal support. During the intervention period, research assistants attempted to contact participants once weekly (or less frequently if the participant preferred) through brief check-in phone calls to address any technical issues or other questions regarding the intervention. When these check-ins occurred, they were generally no longer than 10 minutes and focused exclusively on technical support for the phone or app, given that some participants did not have a history of smartphone ownership or experience with apps.

Broadly, the intervention was developed as a targeted approach for addressing social functioning (primary outcome) in people with schizophrenia in a scalable mobile format. We used the Ethica Data mobile platform to deliver the intervention content through a native Android operating system app. The key elements included SST to address social skill challenges as they relate to goal progress in daily life and structured social goal support and feedback to address social motivation impairments that interfere with forming and maintaining social bonds, which were the primary targets of the intervention. Elements of cognitive behavioral therapy—including self-monitoring of progress toward social goals and social appraisals (ie, perceptions of social competence in recent interactions), and then feedback based on participants’ own ratings from previous EMA instances—were incorporated to address these social motivation impairments. For example, when participants reported low motivation to work toward their social goal, the app would remind them of positive social experiences that occurred in earlier interactions (Figure 1). These components were informed by models of motivational impairment that suggest challenges in accessing memories of prior positive experiences can interfere with the drive to attain goals [22-24]. The app also provides validating and encouraging statements to increase anticipatory pleasure for future social experiences, consistent with the temporal experience of the pleasure model of impairment in schizophrenia [25]. Details on the iterative development process and theoretical framework for the MASS app are provided in a recent paper by our team [21].

Figure 1. Motivation and Skills Support app content: feedback and validation and encouragement to address social motivation impairment.



How motivated are you right now?

☒ Not at all
☐ A little
☐ Somewhat
☐ Moderately
☐ Very much
☐ Extremely

Custom feedback

Reminder: You made **a moderate amount** of progress the last time you worked towards your goal. You felt **very happy** about the progress you made.

Encouragement

Don’t be too hard on yourself & focus on the progress you want to make towards your social goal in the future.

The format of the MASS app was an EMI, which consisted of push notifications via a smartphone that linked the user to app content related to social goal support and feedback. SST content included social goal support, including a list of specific steps the user could choose from and video content designed to provide modeling of effective communication in real-world contexts. The videos included two pairs of actors (1 man and 1 woman in each) demonstrating eight primary social skills (eg, active listening, sharing pleasant or unpleasant feelings), mirroring those covered in SST (links to SST videos are provided in Multimedia Appendix 1) [26]. All skills were demonstrated in a full-length video that included narratives. Participants were instructed to watch the full-length video on their own time during the first week of the intervention; full-length videos were accessible on the smartphone's home screen. The video narratives included two stories: one involved 2 old friends reconnecting after several years apart, and the other included 2 acquaintances working toward developing a stronger connection. Although not explicitly stated for all characters, the subtext was that each narrative included a character with a history of mental health challenges; as such, disclosing mental health needs was one demonstrated skill. During the intervention, SST videos were delivered in short clips embedded within the EMI content, structured based on which skills were displayed.

The MASS app was personalized during an orientation meeting with the participant so that the goal support was specific to each participant's identified social goal selected from a list of available goals curated by the research team. For example, if the participant chose to *make a new friend by going to events* as their desired goal at the baseline assessment**,** during the intervention period, the app would provide a list of steps required to attain that specific goal from which the participant could select (eg, "Identify an event that interests you by searching online or in a newspaper/publication," "Find transportation to an event [eg, ask a relative to drive you, or look up the train, subway, or bus schedule]," or "Introduce yourself to someone at an event and start a conversation by saying hello"). This content is provided in the context of EMI delivered via notifications twice daily throughout the intervention period. Each step included the option to view additional information about how to complete the step and provided specific examples when appropriate (eg, if a participant selected "Identify an event that interests you," the app offered specific websites as suggestions). After being reminded of their primary social goal, the participant had the option of selecting one of the available steps to work on during the next several hours. If the participant elected to work on one of the suggested steps at that time, the EMI would query the participant as to how motivated they were to work toward that step and how much progress they anticipated making on the step (Figure 1). In the final section of the survey, the participant had the opportunity to view SST content videos, with guidance as to which videos would be most relevant, given which step the participant chose to work on related to their goal. In the abovementioned example, the participant could select SST video clips that demonstrated effective ways of using active listening and/or finding common interests.

For instances in which participants either elected to not work on their social goal or when they elected to work on their goal but reported low motivation and/or anticipated progress, they were provided a statement of validation (eg, "Everyone has difficulties working towards their goals sometimes") and encouragement (eg, "We find that the best way to think of social goals and social skills is that you are building a bridge, brick by brick, day by day. This takes time and effort") randomly administered by the app from a set of 31 potential statements (16 validation and 15 encouragement). These statements were generated by our research team, which includes 4 clinical psychologists with extensive experience working with people with schizophrenia. The participants also had the opportunity to view SST content videos at any time, regardless of whether they wanted to work on their social goals at that time.

Measures

Primary Outcome: Social Functioning

The primary outcome measures for this study were the Social Functioning Scale (SFS [27]) and the Heinrichs Quality of Life Scale–Interpersonal Relations (QLS-IR [28]) subscale. The SFS is a self-report instrument designed to capture a wide range of socially relevant behaviors and activities and is the most widely used scale for assessing social functioning in schizophrenia [29]. The 79-item scale includes assessment of social competence and performance across seven domains: withdrawal (social isolation), interpersonal functioning (social contacts and interpersonal competence), prosocial activities (social recreation activities), recreation (solitary recreation activities), independence - competence (social abilities), independence - performance (actual performance of social skills), and employment. Standard scores were calculated, with a mean of 100 (SD 15) across all domains, and the total score was computed based on the mean of all domains. Lower scores represent more impairment in social functioning. The QLS-IR is an interview-rated measure that includes items designed to address social functioning across a range of social contacts and relationships throughout the past 30 days.

The QLS-IR (along with other domains assessed by the QLS, including role functioning and motivation) was originally designed to measure impairments reflective of the deficit syndrome (ie, persistent, primary negative symptoms), but the scale has been used extensively as an outcome measure in intervention studies [30]. Although the SFS captures more subjective qualities of interpersonal functioning (ie, satisfaction and perceived competence), the QLS-IR assesses both the quantity and quality of social functioning as ascertained by a trained interviewer. As such, we included both assessments as primary outcome measures to gather data on the extent to which the MASS app intervention addressed the broad spectrum of social functioning.

Secondary Outcomes: Positive and Negative Symptoms

We used the Brief Psychiatric Rating Scale [31] as our measure of positive symptoms. We administered the following items: somatic concern, grandiosity, suspiciousness, hallucinations, unusual thought content, bizarre behavior, disorientation, and conceptual disorganization [32,33]. For negative symptoms, we used the Clinical Assessment Interview for Negative Symptoms (CAINS) [34]. The CAINS assesses experiential (motivation and pleasure [MAP]) and expressive deficits. We only present findings for the MAP items here, given that we did not expect the intervention to improve expressive deficits. Trained interviewers conducted these symptom assessments.

Treatment Target: Social Motivation (Desire, Behavior, and Interaction Appraisals)

EMA items addressed multiple components of social motivation, including the desire for social contact, the number of recent social interactions, and appraisals of the outcomes of these interactions. The desire for social contact was assessed with the following question: “How much would you like to talk to or interact with someone right now?” with response options ranging from 1 (not at all) to 5 (extremely). When participants elected to work on their social goal, they were asked, “How motivated are you to work on this step?” with response options ranging from 1 (not at all motivated) to 5 (as motivated as possible). The number of interactions was assessed with the following question: “How many conversations did you have online, by phone/text, or in person, since the last time you filled out a survey?” Response options included *none*, *1*, *2*, or *3 or more*.

We asked participants to rate their appraisals of the outcomes of recent interactions after instances in which they reported having a recent conversation. These included items that addressed perceived social skills (“How well do you think you communicated in those conversations?” with response options ranging from 1 [I did not communicate well at all] to 4 [I communicated very well]), the extent to which interactions were worth the effort (“To what extent were those interactions worth the effort?” with response options ranging from 1 [not worth the effort at all] to 4 [definitely worth the effort]), and how likable they perceived themselves to be (“What do you think other people thought of you in those conversations?” with response options ranging from 1 [very unlikable] to 4 [very likable]).

Analyses

We first examined distributions of the outcome measures to assess normality. We also ran bivariate correlations between the sample characteristics and clinical assessments to examine potential confounding factors. Assuming normal distributions, we ran separate repeated measures general linear models with each outcome variable as the dependent variable across the three time points (baseline, termination, and follow-up), including relevant covariates. We present tests of linear change and include effect size estimates (partial eta squared) for each outcome. We followed up general linear models with two-tailed paired-samples *t* tests to identify changes from baseline to treatment termination and present Cohen *d* effect sizes to estimate the magnitude of the short-term treatment effect.

For EMA data, we first examined the distributions of the variables of interest. For normally distributed variables, we ran mixed-effects linear models to examine developmental changes in each variable during the 8-week intervention period in separate models. We included the time point as a predictor of each EMA variable.

We also examined the extent to which the intervention target (ie, EMA-reported social motivation) predicted changes in social functioning from baseline to treatment termination. We included any EMA-reported variables that demonstrated a linear change during treatment and used the covariate method to demonstrate changes in social functioning via regression models, with the aggregated EMA variables as predictors, baseline clinical measures as covariates, and termination measures as outcomes [35]. We also included gender as a covariate in analyses of social functioning, given well-documented gender differences in social skills and other social outcomes in schizophrenia [36].

Results

Overview

In total, 7 participants completed the study prematurely. Reasons for discontinued participation included no longer being interested in the study after initially enrolling, encountering technical difficulties with the mobile app, or being lost to follow up (Figure 2). This left 31 participants who completed the entire study. The sample characteristics are listed in Table 1. The final sample ranged in age from 22 to 65 years (median 48 years). The sample consisted of roughly half men, half schizophrenia, and half schizoaffective disorder and was racially diverse (17/31, 55% non-White). Most of the sample was unemployed, currently receiving disability payments, noncollege graduates, and never married.

Participants selected a broad range of social goals, including friends, family, and romantic relationships (see Table 2 for the selected goals). After treatment termination, we conducted an exit interview and, of the 28 participants, 19 (68%) reported completing some (10/28, 36%) or all (9/28, 32%) of their social goals (we did not collect these data for our first 3 participants). As one goal in particular—*practice conversation skills with an existing friend*—was potentially easier to achieve than the remaining goals, we tested whether goal attainment rates were higher for this goal than the others. Of the 5 participants who selected this goal, 4 (80%) met at least a part of their goal. Of the 23 participants who selected one of the remaining goals, 15 (65%) reported meeting at least part of their goals. These proportions were not significantly different (X^2_1=0.3; *P*=.60).

Participants responded to 42.5% (51/120) of push notifications on average, which was acceptable given the nature of the study (ie, the app was designed to be used on an as-needed basis for social goal support). There was a wide range of engagement in SST video content. One participant never watched the SST videos, whereas, on the other extreme, one participant viewed the videos 422 times. After removing this outlier, participants viewed the videos an average of 13.5 (SD 14.52) times during the 60-day intervention period (median 10).

Figure 2. CONSORT (Consolidated Standards of Reporting Trials) chart for the Motivation and Skills Support app open pilot.

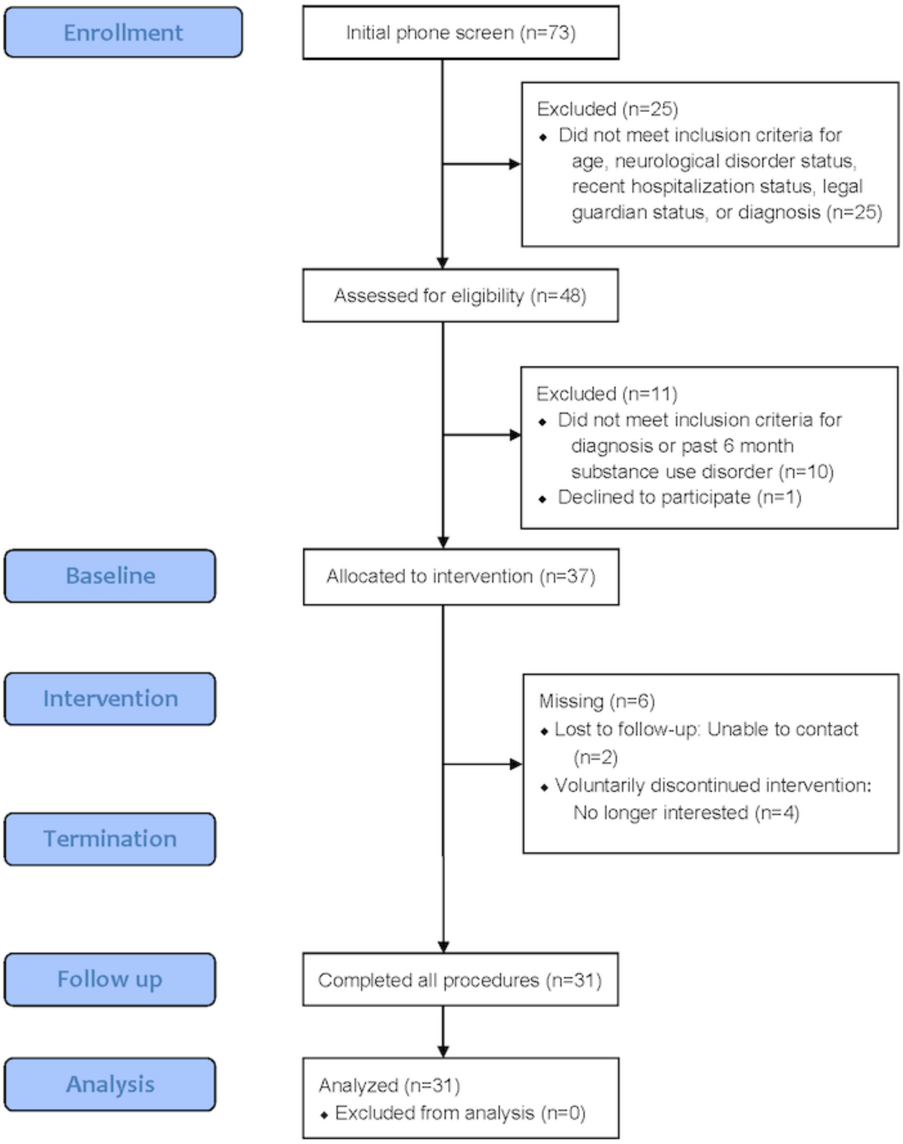


Table 1. Participant demographics and sample characteristics (n=31).

Variable	Values
Diagnosis, n (%)	
Schizophrenia	17 (55)
Schizoaffective disorder	14 (45)
Race, n (%)	
Asian American	9 (29)
Black or African American	5 (16)
White	14 (45)
Multiracial	3 (10)
Hispanic or Latinx ethnicity	1 (3)
Age (years), mean (SD)	46 (11)
Illness duration (years), mean (SD)	23.03 (12.52)
Gender (men), n (%)	16 (52)
Antipsychotic medication, n (%)	26 (87)
Marital status (married, cohabitating, or divorced), n (%)	4 (13)
Education (college graduate), n (%)	9 (29)
Employed (full- or part-time), n (%)	11 (36)
Disability (receive disability payments), n (%)	21 (75)
Smartphone history, n (%)	26 (87)

Table 2. Social goals selected and number completed (consider putting goals in order of most to least common; n=31).

Social goal	Participant, n (%)
Make a new friend by going to events	7 (23)
Make a new friend at work	1 (3)
Practice conversation skills with an existing friend	5 (16)
Reconnect with an old friend	2 (7)
Improve an existing friendship with regular activity	1 (3)
Improve relationship with family member you don’t live with or see regularly	7 (23)
Improve relationship with family member you live with or see regularly	3 (10)
Start a romantic relationship with someone you already know	1 (3)
Start a romantic relationship through a dating website	4 (13)
Participants who completed part or all of social goal	19 (68)[a]

[a] n=28 participants with data on goal attainment.

Clinical Outcomes

Before analyzing clinical treatment outcomes, we examined potential differences in changes in social functioning (SFS and QLS-IR) from baseline to treatment termination based on sample characteristics, including gender (all but 1 participant identified as a man or a woman), age, race or ethnicity, and employment status (because the vast majority were never married, we did not examine this variable). There was only one difference among these variables: women demonstrated significantly greater improvement in SFS scores from baseline to treatment termination than men (t_{30}=−2.19; P=.04; Cohen d=0.8).

Primary Outcome: Social Functioning

The intervention outcomes are shown in Table 3. The mean SFS scores showed a moderate increase from baseline (107.99, SD=7.13) to treatment termination (110.13, SD 7.95; t_{30}=−2.52; P=.02; Cohen d=0.44), but then decreased at follow-up (108.23, SD 7.29; overall F_2=2.56; P=.09; partial η^2=0.08). In an analysis of covariance model with gender as a between-subjects factor, the time by gender interaction effect was significant (F_2=3.26; P=.046; partial η^2=0.1). Women showed increases in SFS scores from baseline to termination, which then decreased from termination to follow-up. On the other hand, men showed relatively little change in SFS scores across the 3-time points (Figure 3). This time by gender interaction was best represented by a quadratic term (F_1=7.55; *P*=.01; partial η^2=0.21). The mean QLS-IR scores showed a small increase from baseline (2.60) to treatment termination (2.90; t_{30}=−1.33; *P*=.19; Cohen *d*=0.24), and then a decrease at follow-up (2.70; overall F_2=1.13; *P*=.33; partial η^2=0.04).

Table 3. Intervention outcomes: social functioning, positive symptoms, and motivation and pleasure negative symptoms.

Measure	Baseline, mean (SD)	Treatment termination, mean (SD)	3-month follow-up, mean (SD)	Baseline to follow-up		Baseline to termination		Cohen *d*
				F test (*df*)	*P* value	Post hoc *t* test (*df*)	*P* value	
SFS[a] total	108.00 (7.13)	110.13 (7.95)	108.23 (7.29)	2.56 (2)	.09	−2.52 (30)	.02	0.44
QLS-IR[b]	2.60 (1.36)	2.90 (1.15)	2.70 (1.25)	1.13 (2)	.33	−1.33 (30)	.19	0.24
BPRS[c] positive symptoms	2.44 (0.70)	2.22 (0.78)	2.14 (0.76)	3.74 (2)	.03	2.49 (30)	.02	0.45
CAINS-MAP[d]	1.64 (0.70)	1.71 (0.60)	1.71 (0.77)	0.19 (2)	.83	−0.65 (30)	.52	0.12

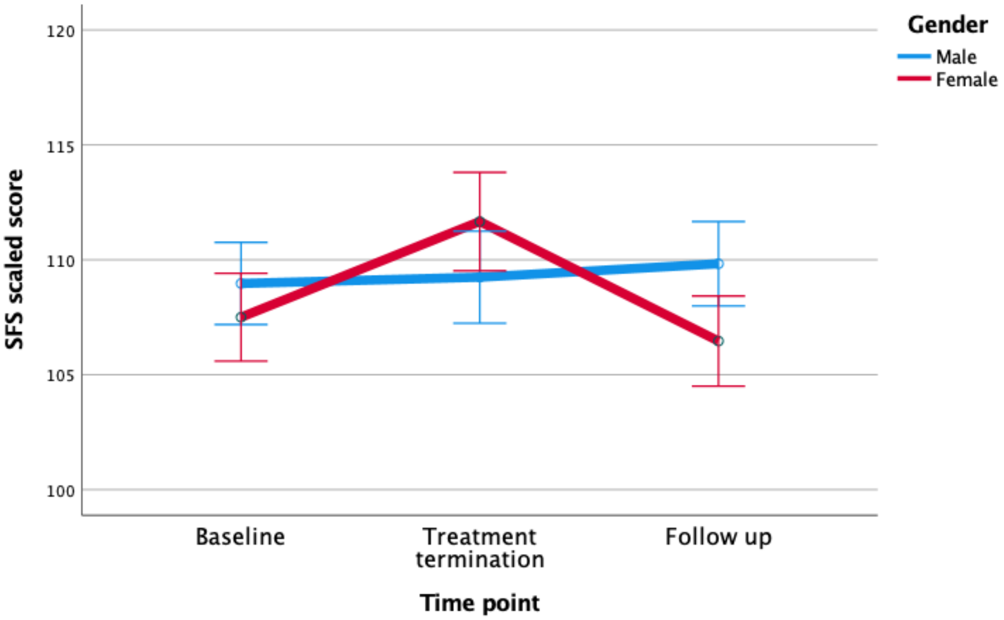
[a] SFS: Social Functioning Scale.

[b] QLS-IR: Quality of Life Scale–Interpersonal Relations.

[c] BPRS: Brief Psychiatric Rating Scale.

[d] CAINS-MAP: Clinical Assessment Interview for Negative Symptoms-Motivation and Pleasure.

Figure 3. SFS by gender. SFS scores significantly differed from baseline to treatment termination among female participants (*P*=.04). SFS: social functioning outcomes.



Positive and Negative Symptoms

Brief Psychiatric Rating Scale positive symptoms decreased significantly across the 3 time points (overall, *F*=3.74; *P*=.03; partial η^2=0.11). Post hoc tests revealed a moderate decrease from baseline to follow-up (t_{30}=2.49; *P*=.02; Cohen *d*=0.45), and a small decrease from baseline to termination (t_{30}=1.65; *P*=.11; Cohen *d*=0.30) and from termination to follow-up (t_{30}=1.04; *P*=.31; Cohen *d*=0.19). CAINS-MAP scores did not change across the 3 time points (overall, *F*=0.19; *P*=.83; partial η^2=0.01).

Change in Momentary Treatment Targets and Associations With Social Functioning

As reported earlier, the missing data for the EMA surveys were 55%. Missing EMA data were unrelated to sample characteristics (eg, gender, age, or diagnosis) or clinical variables at baseline (eg, social functioning and negative symptoms) nor did it change over time (*b*=−0.002, SE 0.003; X^2_1=0.5; *P*=.50). Thus, the findings included all the participants in the study.

General desire to interact with others (*b*=−0.04, SE 0.05) and motivation to work on steps toward social goals (*b*=0.02, SE 0.08) did not change during the intervention (see Multimedia

Appendix 1 for outputs). The number of interactions reported via EMA decreased across the 8-week intervention period ($b=-0.11$, SE 0.05; $t_{30}=-2.18$; $P=.03$; 95% CI −0.20 to −0.01). The number of interactions reported showed a small, negative association with the number of missing surveys ($r=-0.33$; $P=.09$), suggesting that the decline in reported interactions could have reflected survey burden, or simply that those with fewer interactions were less likely to engage with the app.

A preliminary analysis revealed that the three items assessing social appraisals of recent interactions (how likable they were, how well they communicated, and how much these interactions were worth the effort) were all highly correlated with each other ($r>0.80$). As such, we calculated a composite social appraisal variable, which was the average of these three items (α=.95). This social appraisal composite increased significantly in the intervention period ($b=0.11$, SE 0.05; $t_{30}=2.23$; $P=.03$; 95% CI 0.01 to 0.19; Figure 4).

We then examined the degree to which aggregated EMA-reported social appraisals predicted changes in social functioning (SFS and QLS-IR) from baseline to treatment termination using linear regression. We included gender as a covariate in these models. EMA measures of social appraisals predicted significant increases in SFS scores from baseline to treatment termination. Social appraisals were not associated with changes in QLS-IR scores (Table 4).

Figure 4. Changes in ecological momentary assessment-reported social appraisals during the intervention period.

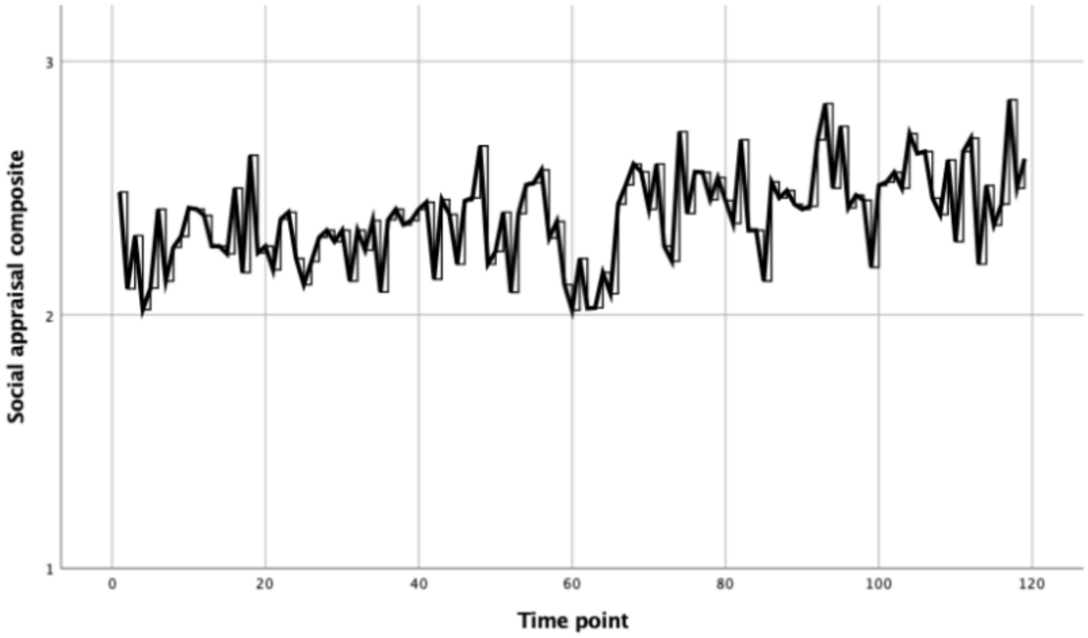


Table 4. Changes in social functioning (Social Functioning Scale and Quality of Life Scale–Interpersonal Relations) from baseline to treatment termination as predicted by ecological momentary assessment-reported social appraisals.

Social functioning	b (SE)	*t* test (*df*)	*P* value	R^2	R^2 change
SFS[a] termination					
SFS baseline	0.848 (0.124)	6.820 (30)	<.001	0.594	N/A[b]
Gender	3.540 (1.701)	2.081 (30)	.047	0.650	0.056
Social appraisal composite	2.810 (1.362)	2.063 (30)	.049	0.700	0.049
QLS-IR[c] termination					
QLS-IR baseline	0.465 (0.135)	3.447 (30)	.002	0.321	N/A
Gender	0.461 (0.356)	1.295 (30)	.21	0.362	0.041
Social appraisal composite	0.031 (0.288)	0.108 (30)	.92	0.363	0.001

[a] SFS: Social Functioning Scale.

[b] N/A: not applicable.

[c] QLS-IR: Quality of Life Scale–Interpersonal Relations.

Discussion

Principal Findings

This paper presented the preliminary outcomes of an open pilot trial of the MASS smartphone app in 31 outpatients diagnosed with schizophrenia or schizoaffective disorder. Low study attrition and high levels of engagement in the app suggest that this stand-alone mobile intervention was feasible. In addition, the MASS mobile intervention demonstrated promise for addressing social needs in people with schizophrenia, with significant increases in our primary outcome, self-reported social functioning, as measured by the SFS, from baseline to treatment termination. This is the first study to demonstrate that a stand-alone mobile intervention can be effective at improving social functioning in schizophrenia, making these preliminary findings an important step forward in this important area of high need.

The significant improvement in self-reported social functioning may reflect increased satisfaction with and perceived competence in social interactions. This is evidenced by changes in key intervention targets reported by EMA in the 8-week intervention period. Participants reported significant increases in positive social appraisals, including perceptions of how well they thought they communicated with others, how likable they were, and the degree to which these interactions were worth the effort. Furthermore, the mean levels of these positive social appraisals were associated with significant increases in social functioning from baseline to treatment termination, suggesting that these appraisals show promise as key intervention targets.

Increases in positive social appraisals could have resulted from several components of the MASS app intervention. For example, SST video content and associated opportunities to practice skills could have increased participants' confidence in their social abilities, leading to increased perceptions of effective communication skills. This content could also have led to more effective communication and the associated natural positive consequences of those skills. Perceptions of effective communication could also have resulted from support for social goals, such as regular reminders of specific steps required to attain desired social goals; feedback on goal progress (ie, completing such a step) could have provided concrete evidence of competence. This would be consistent with theories of goal pursuit, including those that form the foundation for organizing goals in ways that make them specific, measurable, attainable, realistic, and time-limited [37,38]. One way the MASS app could have been effective in improving perceived social effectiveness is by serving as a tool to structure larger social goals in ways that make them more attainable, thus increasing confidence in the ability to ultimately reach them.

A potential challenge for people with schizophrenia spectrum disorders is navigating the complexity of social interactions; such complexity may increase the perceived effort required for a successful interaction [39,40]. Thus, increased positive social appraisals could have also led to reductions in perceived effort required to communicate effectively or simply could have enhanced the extent to which these interactions were perceived as enjoyable. More work is needed to disentangle the specific mechanisms involved in modifying these appraisals.

It is also possible that features of the study other than MASS app content could have served to increase positive social appraisals and social functioning. Although the MASS app was delivered as a stand-alone mobile intervention, our research team did have contact with participants through check-ins over the phone (eg, troubleshooting technical issues and/or discussing any challenges with the intervention app). These check-ins could have had a positive effect on positive social appraisals, an unintended consequence reported in previous EMA work in schizophrenia [41]. It will be helpful to quantify the degree of social contact provided by research staff in future work examining the efficacy of digital interventions to better understand the extent to which this serves as an active intervention ingredient [9]. It is also possible that increased awareness of social activity associated with completing EMA surveys could have served to improve social functioning. For example, repeated monitoring and reporting of social contacts could have primed participants to reach out to others and increase communication, further increasing social functioning by the end of the intervention. However, the impact of awareness alone on overall social functioning was likely to be small relative to the active intervention components.

Improvements in self-reported social functioning were not maintained at the 3-month follow-up. The lack of sustained improvement indicates that ongoing support (or support for a longer period) may be needed to maintain positive social outcomes in people with schizophrenia, especially concerning attaining long-term goals (eg, making a new friend). This is not surprising given longitudinal work demonstrating significant stability in social impairment in this population throughout long periods [8,42] and work showing limited long-term gains in social functioning in the context of time-limited evidence-based interventions (eg, cognitive behavioral therapy) [11]. Important follow-up work should examine adequate dosing and/or the need for the long-term stability of support in social functioning outcomes.

Significant reductions in positive symptoms, particularly suspiciousness, hostility, and unusual thought content, suggest the promise of the MASS intervention in addressing auxiliary experiences associated with social functioning. Active intervention components, such as social goal support, could have served to reduce the potential for ambiguity in social interactions through increased structure and predictability. This structured support could have further reduced feelings of suspiciousness, given the higher likelihood of interpretation biases in ambiguous situations among people who experience paranoia [43]. To better understand this possibility, future work could incorporate momentary measures of interpretation biases (ie, perceiving others as threatening) to examine the extent to which these may have decreased in the intervention. In addition, given the lack of a control group in this study, it is possible that reductions in positive symptoms were because of the passage of time alone and not specific to the intervention. Although we did not recruit participants during a period of heightened symptoms (most were at the low end of the spectrum), it is still possible that those interested in participating were experiencing more distress than usual and that this dissipated naturally over time. However, it is important to note that nearly all participants were on a stable dose of antipsychotic medication at study entry.

There were differences in social functioning outcomes by gender: for women, SFS scores increased significantly from baseline to treatment termination but then returned to baseline levels at the 3-month follow-up assessment). For men, the SFS scores remained relatively unchanged across the three time points. Women with schizophrenia typically have better social functioning than men [44,45]. For example, women show better social skills [36,46] and are more likely to marry [47,48] than men with schizophrenia. However, differences observed in this study did not appear to be related to baseline levels of social functioning, as mean values were not significantly different between genders at baseline. Differences also did not appear to be related to adherence to the intervention (men and women did not differ in EMA surveys completed). Another possibility is that social functioning outcomes are related to the types of social goals selected. There was a noticeable difference in goals selected between genders: 5 men chose to work toward improving a relationship with a family member whom they did not live with or regularly see, whereas only 1 woman chose this goal. It is possible that this goal was more challenging than others; however, given the small sample size, we cannot definitely test this assumption. Nonetheless, in future work, it will be important to collect additional data on the extent to which goals vary in difficulty and how variance in difficulty might influence outcomes.

The lack of a positive impact of the MASS app on interview-rated social functioning (QLS-IR) or the number of social contacts (reported via EMA) suggests that although the intervention improved a broad range of perceived social outcomes (as assessed by the SFS), it did not impact specific markers of social functioning, such as the number of contacts or social network size. Scores on the QLS-IR reflect increases in social network size and degree of contact with relatives and acquaintances, among other objective outcomes, similar to EMA-reported interactions. These and other outcomes, including negative symptoms, may be particularly challenging to improve in a brief, remotely delivered intervention and may require additional support that cannot be delivered in such a platform. As such, a way to improve the effectiveness of the MASS app (as with other mobile interventions) would be as a supplemental, augmentative intervention to be used alongside standard evidence-based interventions delivered in standard, in-person contexts [9]. This approach was recently tested by Granholm et al [19], in which participants received up to 24 weeks of combined weekly group therapy and mobile intervention. Improvements in key targets, including defeatist attitudes and negative symptoms, have been reported. Similar to this study, the authors demonstrated improvements in social functioning, but only from baseline to treatment termination (not over follow-up). Another way to improve the effectiveness of the MASS app, as mentioned earlier, would be to increase the length of the *active* intervention period, providing support for a sufficient amount of time for participants to achieve their desired social goals fully.

Conclusions

As reported earlier, the findings are limited to the uncontrolled nature of this pilot study. As such, we cannot rule out the possibility that outcomes could be owing simply to the passage of time. Furthermore, our sample was relatively small, and we may have been underpowered to detect the small effects of the intervention. Another potential limitation of this study is that we provided mobile devices and data plans to all participants, making it unclear whether this intervention approach would be scalable to individuals who lack the resources needed for sustained ownership of personal smartphones. Despite these limitations, the MASS app demonstrates promise as a stand-alone mobile intervention and is ultimately used as a supplemental intervention designed to address social functioning needs in people with schizophrenia.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Motivation and Skills Support app social skills training video content.
[PDF File (Adobe PDF File), 98 KB - mental_v8i6e27475_app1.pdf]

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Abbreviations

CAINS: Clinical Assessment Interview for Negative Symptoms
CBTp: cognitive behavioral therapy for psychosis

EMA: ecological momentary assessment
EMI: ecological momentary intervention
MAP: motivation and pleasure
MASS: Motivation and Skills Support
QLS-IR: Quality of Life Scale–Interpersonal Relations
SFS: Social Functioning Scale
SST: social skills training

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Original Paper

Needs and Experiences of Users of Digital Navigation Tools for Mental Health Treatment and Supportive Services: Survey Study

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Abstract

Background: Despite a recent proliferation in web-based and digital resources that are designed to assist users in finding appropriate mental health treatment and supportive services, it can be overwhelming, confusing, and difficult for an individual or family member to access and use an appropriate navigation tool. As digital resources are increasingly sought after, there is an urgent need for a clearer understanding of digital navigation tools in order to help link individuals with the tool that is best suited to their needs.

Objective: The objective of this study was to determine the needs of individuals seeking mental health treatment and supportive services and to quantify their experiences and satisfaction with available digital navigation tools.

Methods: A survey was offered via an email newsletter and social media posting throughout the extended membership of the National Alliance on Mental Illness, which includes both individuals with a mental health condition and their family members and support networks. A 13-item anonymous survey, which consisted of multiple-choice and open response options, was developed to measure participants' past use of and experiences with web-based, mobile, and phone-based navigation tools. The survey was available from April 9 through May 21, 2020.

Results: A total of 478 respondents completed the survey; the majority of respondents were female (397/478, 83.1%) and aged ≥35 years (411/478, 86%). Younger respondents were more likely to report seeking mental health services for themselves, while older respondents were more likely to be searching for such services on behalf of a family member. The majority of respondents seeking such services on behalf of a family member (113/194, 58.2%) required a combination of mental health treatment and supportive services. Furthermore, two-thirds of respondents (322/478, 67.4%) used a navigation tool to find treatment or services. The majority of respondents who provided feedback about their experiences with navigation tools (224/280, 80%) reported difficulties, with data availability and accuracy being the most commonly reported issues.

Conclusions: The survey results suggest that issues with data availability and accuracy in available navigation tools remain a major barrier for locating timely and appropriate mental health treatment and supportive services within the population of individuals seeking such services. Particularly for individuals seeking care on behalf of a family member, improving the accuracy of and users' experiences with navigation tools could have a major impact on effectively connecting people to treatment and support services.

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KEYWORDS

mental health; supportive services; perception; quality; satisfaction; needs; digital tools; directories; navigation

Introduction

Approximately 1 in 5 adults and 1 in 7 adolescents in the United States experience a mental health condition each year [1,2]. Although there has been significant progress in reducing the stigma around seeking care, ensuring parity in insurance coverage, and developing new therapeutic models, many individuals continue to struggle in isolation when attempting to enter and navigate a complex and fractured care system. Each of the over 60 million people with a mental health condition has a unique set of experiences and needs that do not always fit neatly into the array of services that are available to them. Beyond talk therapy, which has become increasingly accessible through advances in telehealth [3], and medication, which can often be prescribed by a primary care physician [4], many people are in immediate need of specialized services, such as crisis care or partial hospitalization programs [5,6]. Additionally, coordinated care for chronic physical health issues [7], housing and legal support, or straightforward guidance and reassurance may be needed as people navigate their overall health care path [8].

In the context of the global COVID-19 pandemic, historic protests against systemic racism and injustice and significantly heightened political tensions, rates of anxiety, depression, and trauma-related stress have skyrocketed [9]. These overlapping crises have brought to light the flaws in our current systems of care. For many individuals, treatment can be inaccessible, unaffordable, and unsuited to their specific needs [1,10,11]. In 2019, approximately 43% of US adults with a mental illness who did not receive needed services stated that they could not afford the cost of treatment, 33% did not know where to go for help, and 20% simply could not afford to invest the necessary time for finding and receiving treatment [1]. For researchers and providers who are invested in reducing this disparity and increasing access to and the appropriate use of mental health services, it is critical to understand how people currently seek out and access treatment and support options.

Health care–focused technology solutions have proliferated in recent years. A recent study of downloadable apps for personal mental health management and support reported more than 1400 individual products in the Google Play and iTunes stores [12]. Insurance providers who offer Affordable Care Act marketplace and Medicare Advantage plans are required to publish provider directories [13,14], and many insurers and health systems offer web-based provider search and appointment scheduling tools. However, successfully connecting to appropriate services can be challenging, even with the aid of a directory or search tool. Users may be unsure about what service is the most appropriate for their specific needs and how to parse information on the internet about a diversity of specialties and treatment modalities with overly technical names and descriptors [15]. Provider directories are prone to inaccurate or out-of-date information [16]. Mental health providers are less likely to participate in insurance network plans and, consequently, may change their offerings and availability at will [17]. Amid a flood of information, users who are likely already experiencing considerable stress may be overwhelmed and left without clear guidance.

Current efforts for simplifying this search process and supporting user decision making include the development of e-hubs—web-based directories of local resources and community services that enable users to efficiently search for and organize potential treatment and support options. With the recent rise in web-based mental health tools, more comprehensive e-hubs have emerged to support access to web-based resources such as web-based forums, self-help videos, and support groups [18,19]. It is particularly relevant that these web-based navigation resources and e-hubs have been community [19] and expert driven [18]. Although the availability and complexity of these navigation tools has increased, no single e-hub is recognized as a gold-standard model.

The COVID-19 pandemic has highlighted the importance of accessible mental health services [20] and has resulted in a surge in the demand for web-based treatment options. Despite the clear potential that digital navigation tools have for improving accessibility to both web-based and in-person resources, research on this topic is sparse and often limited to the experiences of younger adults [21]. Continued progress requires a more complete understanding of how people search for mental health treatment and related services and how satisfied they are with their experiences of using different tools. Thus, in this survey study, we aimed to assess how people seeking mental health resources use and perceive technology-based navigation resources. As we were aware of prior research suggesting that information on interventions is the most important [22] and that older adults are becoming increasingly comfortable with operating web-based platforms [23], we hypothesized that overall satisfaction with digital navigation tools would be high. However, given the diversity of the needs and experiences of users and the difficulty of maintaining accurate informational resources across a variety of platforms, quantifying the actual experience of users is critical.

Methods

The National Alliance on Mental Illness (NAMI) is a nonprofit, national advocacy group based in the United States. By using a nationwide network of state and local community–based affiliates, NAMI provides education, awareness, and advocacy programs to support the mission of empowering individuals with mental illness and their family members to lead productive and fulfilling lives. An integral part of this work is the operation of the NAMI HelpLine—an information and support center that is staffed by individuals with lived experiences of mental illness. The HelpLine served over 150,000 individuals in 2019 through phone calls, emails, social media interactions, web-based resources, and letters [24]. Throughout the first half of 2020, the HelpLine received a record number of inquiries and requests, which were in large part due to concerns about COVID-19 and stress-related mental health concerns.

In order to better serve the needs of the community and improve service delivery, NAMI conducted a web-based, anonymous survey to assess individuals' needs and experiences when searching for mental health resources. This voluntary survey was promoted through NAMI's national leadership email newsletter and the NAMI Facebook and Twitter accounts. The survey was available from April 9 through May 21, 2020. The eligibility requirements included any adult (aged ≥18 years) located in the United States who had searched for mental health treatment or services for themselves or someone else via the internet.

The survey consisted of 13 questions, including demographic questions, questions abouts the types of mental health services sought, questions about the types of tools used, and questions about prior experience with navigation tools. Multimedia Appendix 1 outlines the questions that were asked in the survey as well as the type of responses available.

Results

A total of 520 individuals completed the survey, and 478 individuals met the eligibility requirements. A large portion of respondents (397/478, 83.1%) were female, 14.6% (70/478) were male, and 1.5% (7/478) were gender nonbinary or self-described their gender identity. Half of the respondents were aged ≥55 years (242/478, 50.6%), 35.4% (169/478) of individuals were aged 35-54 years, and 13.4% (64/478) of participants reported that they were between the ages of 18 and 34 years. Most participants (403/478, 84.3%) self-identified as White or Caucasian, 6.3% (30/478) of participants self-identified as Black or African American, 2.5% (12/478) reported a self-described identity, 2.1% (10/478) self-identified as mixed or multiracial, 1.7% (8/478) self-identified as Asian or Pacific Islander, and 1% (5/478) self-identified as Native American or Alaska Native. Demographics are detailed in Table 1.

Table 1. Demographic characteristics of participants.

Characteristics of survey respondents	Values, n (%)
Gender	
Female	397 (83.1)
Male	70 (14.6)
Nonbinary or self-described	7 (1.5)
Unreported	4 (0.8)
Race and ethnicity	
Asian or Pacific Islander	8 (1.7)
Black or African American	30 (6.3)
Native American or Alaska Native	5 (1)
White or Caucasian	403 (84.3)
Mixed or multiracial	10 (2.1)
Self-described	12 (2.5)
Unreported	10 (2.1)
Age category (years)	
18-34	64 (13.4)
35-54	169 (35.4)
≥55	242 (50.6)
Unreported	3 (0.6)

A total of 67.4% (322/428) of respondents reported that they used a web-based platform, phone-based directory, or mobile app to find mental health services. Older adults were less likely to use navigation tools compared to younger adults, with 37.2% (90/242) of those aged ≥55 years reporting that they had never used a web-based platform, phone-based directory, or mobile app to find mental health services, as shown in Table 2. Younger respondents (aged 18-34 years) were less likely to seek support by using the phone-based HelpLine or a phone-based directory compared to middle- and older-aged individuals. While 21.9% (90/411) of respondents aged ≥35 years reported seeking resources by using the phone-based HelpLine or a phone-based directory, only 7.8% (5/64) of younger participants used a phone-based directory, and 12.5% (8/64) of younger participants used a mobile app to seek resources. Younger respondents (55/64, 85.9%) and middle-aged respondents (aged 35-54 years; 115/169, 68%) were more likely to report searching for resources for themselves, while older individuals (aged ≥55 years) were more likely to report searching for resources on behalf of a family member or another individual who required support (131/242, 54.1%).

Table 2. Use of navigation tools by age.

Responses	All respondents	Respondents aged 18-34 years	Respondents aged 35-54 years	Respondents aged ≥55 years
Tool sought and used, n (%)				
Web-based search platform	289 (60.4)	45 (70.3)	112 (66.3)	131 (54.1)
Mobile app	48 (10)	8 (12.5)	18 (10.7)	22 (9.1)
Phone-based HelpLine or directory	97 (20.3)	5 (7.8)	38 (22.5)	52 (21.5)
No tool used, n (%)	156 (32.6)	17 (26.6)	48 (28.4)	90 (37.2)
Seeking on behalf of self, n (%)	281 (58.8)	55 (85.9)	115 (68)	111 (45.9)
Seeking on behalf of another, n (%)	197 (41.2)	9 (14.1)	54 (32)	131 (54.1)
Total responses, n	478	64	169	242

In total, 48.2% (228/473) of respondents reported only seeking resources that were related to treatment (talk therapy, outpatient psychiatry, inpatient care, or crisis care), while 49.9% (236/473) reported seeking a combination of treatment and support resources (social worker or community resource officer, housing, and legal or financial assistance). Across all age groups, those who were seeking resources on behalf of someone else were the most likely to be seeking a combination of treatment and supportive services (113/194, 58.2%; Table 3). The top three resources that respondents reported seeking were talk therapy (362/473, 76.5%), outpatient psychiatry (361/473, 76.3%), and crisis care (250/473, 52.9%), as depicted in Figure 1. The highest rated concern reported was whether a service was covered by their insurance. The lowest rated concerns, which are illustrated in Figure 2, included transportation, cultural considerations, and respect for gender identity.

Table 3. Type of service sought among individuals seeking services on behalf of themselves versus those seeking services on behalf of another.

Responses	All respondents	Seeking on behalf of self	Seeking on behalf of another
Total responses, n	473	279	194
Treatment only, n (%)	228 (48.2)	151 (54.1)	77 (39.7)
Support service only, n (%)	9 (1.9)	5 (1.8)	4 (2)
Combination of treatment and support services, n (%)	236 (49.9)	123 (44)	113 (58.2)

Figure 1. The most common services sought by survey respondents.

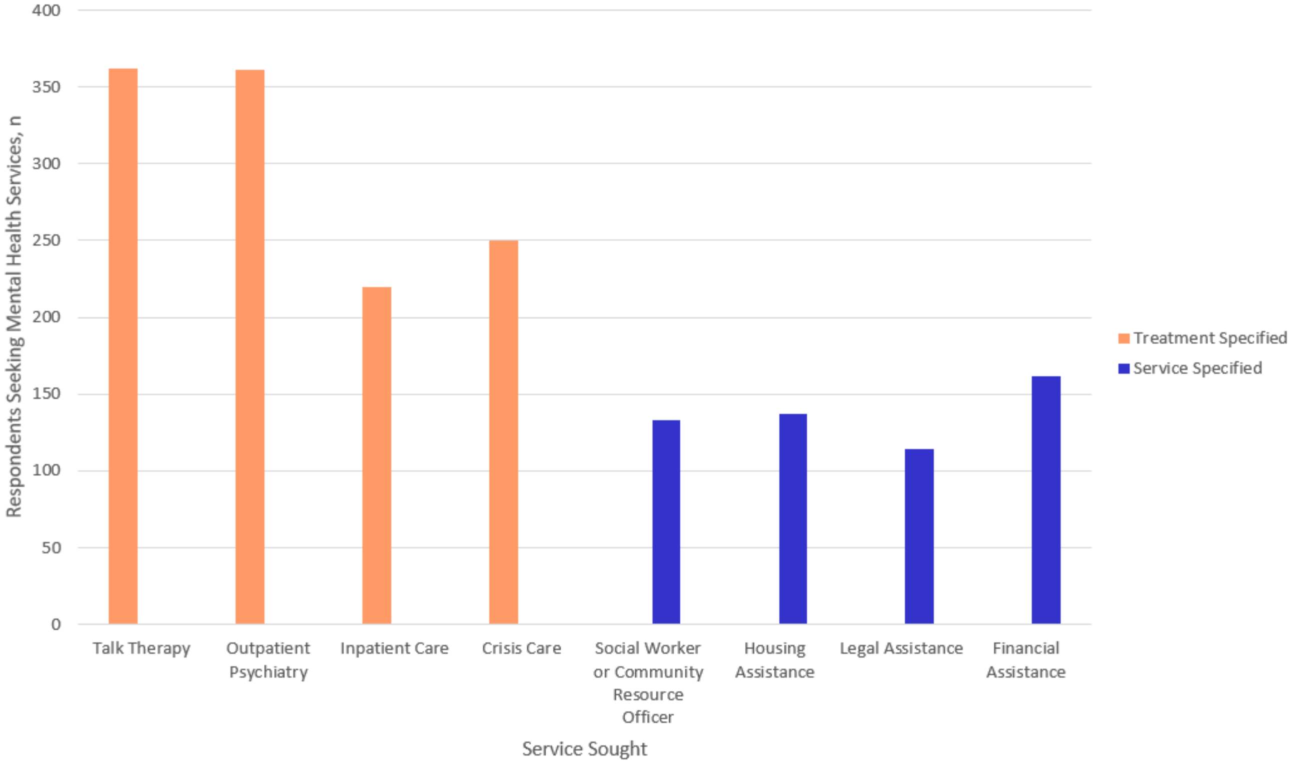
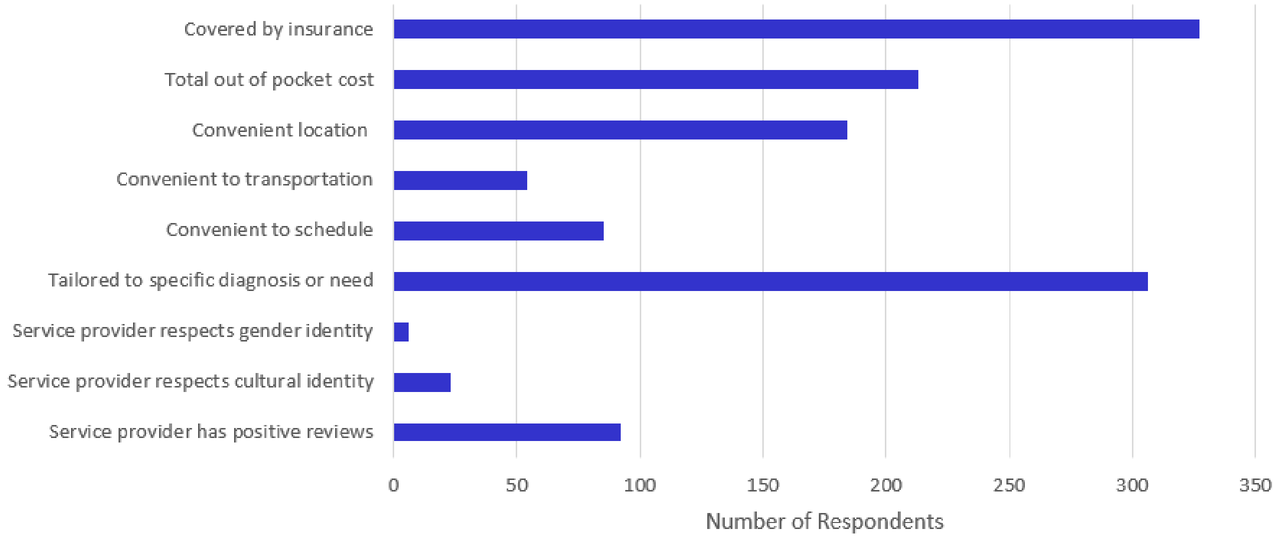


Figure 2. The most common concerns among survey respondents.



Of the 280 survey respondents who provided details about their experiences with navigation tools, 224 (80%) indicated that they had experienced frustration or difficulty. The most commonly reported difficulties were about data availability and quality; approximately half of respondents who reported experiencing issues with navigation tools indicated that their search results did not contain enough information (118/280, 42.1%) or that the information provided was incorrect or out of date (132/280, 47.1%), as detailed in Table 4. Older adults who reported using navigation tools (103/132, 78%) were not significantly more likely than younger age groups (31/42, 74%) to report difficulties (*P*=.57), but participants who were seeking services on behalf of a family member or someone else (89/106, 84%) were somewhat more likely to experience issues compared to those seeking services for themselves (135/174, 77.6%; Table 5). However, the difference was not statistically significant (*P*=.20). For individuals playing caregiver roles, the availability of comprehensive and user-friendly navigation tools is especially relevant, as the services that are needed tend to be more complex in nature.

Table 4. Difficulties with navigation tools by age.

Responses	All respondents	Respondents aged 18-34 years	Respondents aged 35-54 years	Respondents aged ≥55 years
Provided details about the use of a navigation tool, n	280	42	104	132
Any difficulty, n (%)	224 (80)	31 (73.8)	88 (84.6)	103 (78)
Tool was confusing	50 (17.9)	8 (19)	21 (20.2)	21 (15.9)
Specific need was not covered	95 (33.9)	14 (33.3)	37 (35.6)	43 (32.6)
Geographic area was not covered	53 (18.9)	7 (16.7)	21 (20.2)	24 (18.2)
Not enough information provided	118 (42.1)	22 (52.4)	45 (43.3)	51 (38.6)
Information provided was incorrect or out of date	132 (47.1)	25 (59.5)	47 (45.2)	59 (44.7)
No difficulty, n (%)	56 (20)	11 (26.2)	16 (15.4)	29 (22)

Table 5. Difficulties with navigation tools among individuals seeking services on behalf of themselves versus those seeking services on behalf of another.

Responses	Seeking on behalf of self	Seeking on behalf of another
Provided details about the use of a navigation tool, n	174	106
Any difficulty, n (%)	135 (77.6)	89 (84)
Tool was confusing	32 (18.4)	18 (17)
Specific need was not covered	54 (31)	41 (38.7)
Geographic area was not covered	31 (17.8)	22 (20.8)
Not enough information provided	72 (41.4)	46 (43.4)
Information provided was incorrect or out of date	81 (46.6)	51 (48.1)
No difficulty, n (%)	39 (22.4)	17 (16)

Discussion

The results from our web-based survey showed that two-thirds (322/478, 67.4%) of adults seeking mental health treatment or support services used web-based, phone, and app-based tools to find resources and information, but the majority (224/280, 80%) experienced difficulties and dissatisfaction largely due to out-of-date and incorrect information. The use of these tools varied with age, with younger people being more likely to use navigation tools, especially web-based platforms or mobile apps, and more likely to seek mental health services for themselves as opposed to seeking such services for someone else.

The survey results suggest that existing digital navigation resources do not meet the demands of users. Although widespread internet access and increased comfort with web-based tools has resulted in the increased visibility of web-based mental health resources, a lack of reliable curation has led to an accumulation of out-of-date and incorrect information. These results suggest that a focus on the quality of content may be the most important next step in this research area. Offering some degree of personalization in insurance coverage matching services also appears to be a crucial factor—one that is not commonly available to date. Furthermore, web-based resources must account for the different needs and priorities within user populations. For instance, a previous study suggested that older adults (aged ≥65 years) were more willing to engage with digital tools after receiving digital skills training and a demonstration of a tool's value [25]. However, an alternative study found significant variance in older individuals' (aged ≥65 years) use and perceptions of the benefits of digital tools; the differences were more aligned with racial identity and socioeconomic status than with age [26]. The results from the survey conducted in our study did not show a meaningful difference in the percentages of older adults who found that navigation tools were confusing to use.

The primary limitation of this study lies in the generalizability of the results. As the survey was conducted via a web-based platform and promoted through digital communication channels, it can be assumed that all participants had reliable internet access and at least a moderate level of comfort with using the internet. Participants with a connection to NAMI may have been more likely than the general population to have past experiences with seeking mental health services and support, and many (eg, those seeking inpatient treatment) were likely to be individuals or family members of an individual with a serious mental illness. Our findings may consequently have limited generalizability to individuals seeking services and support for less intensive and more common mental health conditions. The participant population was heavily weighted toward older White females, indicating that issues affecting members of minority communities are underrepresented. The survey did not collect information on socioeconomic status or geographic location, of which both are factors that may significantly influence users' needs for and experiences with seeking services. Finally, this study was conducted from April to May 2020 (ie, early stage of the COVID-19 pandemic), and we expect that the concerns and experiences of those seeking mental health care may have changed, as the pressures and constraints of the ongoing pandemic have continued to affect both mental health needs and the accessibility of related services. Finally, this study was only offered in English; therefore, it is not representative of many patients and families who read in other languages.

In summary, there remains a need for improved digital navigation resources and e-hubs, as existing services do not meet the needs and expectations of users. As more mental health resources move to web-based platforms, ensuring that services remain easily searchable and accessible will only become more important.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Finding mental health services: Survey on experiences and needs.

[DOC File , 81 KB - mental_v8i6e27022_app1.doc]

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Abbreviations

NAMI: National Alliance on Mental Illness

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Original Paper

Impact of Jointly Using an e–Mental Health Resource (Self-Management And Recovery Technology) on Interactions Between Service Users Experiencing Severe Mental Illness and Community Mental Health Workers: Grounded Theory Study

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Abstract

Background: e–Mental health resources are increasingly available for people who experience severe mental illness, including those who are users of community mental health services. However, the potential for service users (SUs) living with severe mental illness to use e–mental health resources together with their community mental health workers (MHWs) has received little attention.

Objective: This study aims to identify how jointly using an interactive website called *Self-Management And Recovery Technology* (SMART) in a community mental health context influenced therapeutic processes and interactions between SUs and MHWs from their perspective.

Methods: We conducted a qualitative study using a constructivist grounded theory methodology. Data were collected through individual semistructured interviews with 37 SUs and 15 MHWs who used the SMART website together for 2 to 6 months. Data analysis involved iterative phases of coding, constant comparison, memo writing, theoretical sampling, and consultation with stakeholders to support the study's credibility.

Results: A substantive grounded theory, *discovering ways to keep life on track*, was developed, which portrays a shared discovery process arising from the SU-worker-SMART website interactions. The discovery process included choosing to use the website, revealing SUs' experiences, exploring these experiences, and gaining new perspectives on how SUs did and could keep their lives on track. SUs and MHWs perceived that their three-way interactions were enjoyable, beneficial, and recovery focused when using the website together. They experienced the shared discovery process as relationship building—their interactions when using the website together were more engaging and equal.

Conclusions: Jointly using an e–mental health resource elicited recovery-oriented interactions and processes between SUs and MHWs that strengthened their therapeutic relationship in real-world community mental health services. Further work to develop and integrate this novel use of e–mental health in community mental health practice is warranted.

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KEYWORDS

digital mental health; tablet computers; therapeutic relationship; recovery narratives; lived experience video; personal recovery; schizophrenia; mobile phone

Introduction

Background

People experiencing severe mental illnesses are increasingly using digital technologies and are willing to consider using web-based information and interventions. These include web-based and mobile-based interventions collectively defined as *e–mental health* [1]. Several systematic reviews have demonstrated the feasibility and acceptability of e–mental health for this population [2-5]. Features that people who experience severe mental illness value in e–mental health resources include interactivity, access to web-based peer support, and remote human support [2]. However, engagement in and completion of structured e–mental health interventions can be mixed [6,7]. Thomas et al [8] canvassed community mental health service users (SUs) about their views on using e–mental health resources. They found that most respondents used websites and video streaming when seeking information about mental health on the web and were positive about accessing these types of resources with their mental health workers (MHWs). Providing human support also increases the effectiveness of e–mental health interventions that are otherwise often didactic and informational [9]. Making e–mental health resources available to mental health SUs who experience severe mental illness and MHWs to use together thus appears to be worth pursuing and further understanding.

Therapeutic Relationships and e–Mental Health

The influence that jointly using an e–mental health resource may have on interactions between a SU and MHW, including the potential impact on the nature and quality of their therapeutic relationship, is important to understand. The therapeutic relationship in community mental health has been defined "as an appraisal of the connection and interaction between service users and clinicians that is defined through the delivery of mental health treatment" [10]. Qualities including trust, hope, empathy, and encouragement are argued to be at least as important as any therapeutic technique in mental health [11] and community mental health specifically [12]. The quality of relationships in interventions involving augmentative use of technology is reported to be comparable with those in interventions delivered face-to-face without a technology component [13], although research with people experiencing severe mental illness is rather limited [14].

Therapeutic relationships occurring in the context of technological interventions have also been considered using the associated term *therapeutic alliance*. Dixon et al [15] defined a therapeutic alliance as a component of the therapeutic relationship, specifically "the dynamic ability to work together in the interest of problem solving." Although there are various conceptualizations of the therapeutic alliance [16], three elements have long been considered the foundations of a strong alliance in interventions delivered face-to-face [14,17]. These are establishing an interpersonal bond, agreeing on the goals, and agreeing on the tasks for working together (as originally outlined by Bordin [18]). Berger [19] explored the therapeutic alliance in psychological internet interventions ranging from internet-based, guided self-help to real-time videoconferencing. He concluded that in all modalities, the client-rated therapeutic alliance was similar to the alliance in face-to-face therapies. Despite these claims, Henson et al [20] were surprised to find insufficient research to draw conclusions about the therapeutic alliance in their narrative review focused on smartphone apps for people living with severe mental illness. The dimensions of the alliance in digital environments may also differ from those in face-to-face relationships for people living with severe mental illness [14]. Overall, our understanding of the therapeutic alliance in e–mental health for people living with severe mental illness is limited and focused on two-way interactions between a SU and an e–mental health resource in the absence of human support. In contrast, three-way interactions named a "triangle of alliance" [13]—that is, the interactions involving an SU, e–mental health resource, and a human supporter that arise when technology is blended with face-to-face therapy—have received less attention.

Recovery-Oriented Interactions and e–Mental Health

There is another way to understand interactions between SUs and MHWs that may inform the development of e–mental health resources for joint use. Interactions between SUs and MHWs can also be defined in relation to personal recovery, that is, an SU's active, individual, and personal process of constructing a meaningful life in the context of living with a mental illness [21-23]. Supporting personal recovery by providing recovery-oriented practices has become a mandate for community mental health services [21,23]. Recovery-oriented practice includes the nature of the relationship between a worker and SU and the working practices or focus of the interactions that occur within the relationship [24]. Working relationships that support personal recovery share similarities with common relationship-building factors [12]. For example, collaborative, open, respectful, and empathetic relationships that elicit a person's unique goals and active participation are commonly cited as supporting personal recovery [25-27]. Slade et al [24] proposed three working practices that support personal recovery: identifying SU values, amplifying SU strengths, and supporting SUs to strive to achieve their goals. Despite this growing understanding of how to support personal recovery, such interactions can be challenging to achieve in community mental health [24-26], where factors such as the need to interact with several workers at different intensities, ambiguity regarding goals, or involuntary treatments can negatively impact interactions between SUs and workers [10]. In this context, bringing e–mental health resources designed to promote personal recovery into community mental health practice may be helpful.

Emerging research indicates that SUs and MHWs using e–mental health resources together can elicit interactions that support personal recovery. In a scoping review of six jointly used e–mental health resources, Strand et al [28] found that using these resources to create and follow-up personal goals and access peer support was consistent with recovery-oriented practice. Similarly, Williams et al [29] identified that jointly used e–mental health resources could support recovery-oriented practice when the resources included components such as information and education, self-management tools, communication channels with workers and peers, and shared decision-making tools. However, both reviews concluded that using the e–mental health resource together could also negatively influence interactions between SUs and their workers, resulting in communication misunderstandings and mistrust [28,29]. Given these mixed findings, further research to understand the nature of interactions occurring when SUs and MHWs use recovery-oriented e–mental health resources together is warranted.

Self-Management And Recovery Technology Research Program

This qualitative study addresses this research gap by exploring interactions between SUs and MHWs when they jointly used a website known as *Self-Management And Recovery Technology* (SMART). Websites that include illness self-management, psychoeducation, and peer-support resources are a common form of feasible and acceptable e–mental health resources for people living with severe mental illness [1,5,6]. The SMART website was codeveloped with people with lived experience of severe mental illness for use in community mental health practice as part of a funded research program [30,31]. The SMART research program was conducted in mental health services in the community, including clinical (government-operated services that employ psychiatrists and an interdisciplinary health care workforce) and community-managed services (nongovernment agencies employing community MHWs and other health professionals). Service locations included urban and regional sites in Victoria, Australia.

Study Aim

As the SMART website was a novel development, the overarching aim of this qualitative research was to explore the experiences of SUs and MHWs who used it in practice within community mental health services. This study specifically aims to identify how jointly using the SMART e–mental health resource in a community mental health context influenced therapeutic processes and interactions between SUs and MHWs from their perspectives.

Methods

Overview

A constructivist grounded theory (CGT) methodology was used because it focuses on studying actions and social processes in areas where little is known [32]. This methodology was appropriate to investigate the experience of jointly using an e–mental health resource, which is fundamentally a social and interactive process that is not currently well understood [28,29]. CGT aims to develop an interpretive understanding or theory of an experience in context and to capture the essence of and variations in a social process [32]. Grounded theory methods are well suited to research in mental health contexts [33] and have been used to explore experiences of recovery from an SU [34] and MHW [35] perspective and web-based support among people experiencing mental ill-health [36,37].

Ethical approval for this study was obtained from a metropolitan health service with coordinating ethical authority, Alfred Health (Project 208/15), and accepted by participating universities and mental health services.

Participant Recruitment

SUs and MHWs who had used the SMART website were eligible to participate in this study. Those people who had agreed to receive invitations for further SMART-related research were sent a flyer that provided information about this qualitative study. Participants were informed that the qualitative study was connected to the first author's PhD project.

The initial purposive sampling of SUs and MHWs who had used the SMART website was followed by theoretical sampling. Theoretical sampling techniques are central to the CGT and aim to select participants who are likely to have experiences relevant to emerging issues and categories in the data [32,38]. Theoretical sampling included selecting 6 information-rich participants for a second interview and recruiting MHW participants who had varied experiences using the website. These participants provided data related to the conditions that influenced joint website use.

Study Context: SMART Website Design, Content, and Use

The SMART website was designed to support self-management and personal recovery. It was based on the CHIME (Connectedness, Hope, Identity, Meaning, and Empowerment) conceptual framework [21], which posits recovery as a personal journey involving the processes of being connected with others, having hope for the future, forming an identity beyond illness, finding meaning in life, and being empowered in one's life [21]. SUs and MHWs had a personal and private log-in to access the website. SUs could use the website in meetings with workers using a tablet device supplied to workers and any other time they chose using their smartphone or computer [30].

The website comprised seven topics: recovery, managing stress, health, me, relationships, empowerment, and life [30]. The key contents for each topic are shown in Textbox 1. A core feature of the website was that each topic included embedded videos, where 11 peers shared their lived experiences. SUs' experiences of watching peer videos have been described elsewhere [39]. Each topic also included a summary text providing topic information and reflective exercises that SUs could complete and save on the website. Examples of the reflective exercises included questions following videos, charts for monitoring different aspects of one's health, and worksheets to identify factors influencing well-being, including strengths, stressors, and coping strategies.

Textbox 1. Self-Management And Recovery Technology website content.

Recovery (5 Sections)

- Introduction to the concept of recovery
- Recommended starting point and use guidance

Managing Stress (6 Sections)

- Relationship between stress and mental health
- Common stressors and coping strategies

Health (9 Sections)

- Relationship between physical and mental health
- Self-management, including diet, exercise, sleep, and medication

Me (11 Sections)

- Identity, including effects of stigma
- Personal growth through lived experience, focusing on strengths

Relationships (7 Sections)

- Interactions between relationships and mental health
- Nurturing existing relationships and fostering new connections

Empowerment (8 Sections)

- Empowerment in interactions with mental health service providers
- Getting the most out of services; rights and advocacy

Life (9 Sections)

- Developing new meaning in life
- Personal values and identifying related goals

The SMART research program included 2 different studies that influenced the way SUs and MHWs used the website. In SMART Therapy, a randomized controlled trial (NCT02474524), SUs used the SMART website with a trained worker for up to 8×50-minute sessions. These sessions were usually held once a week and were in addition to the SUs receiving their usual community mental health services [30]. The second study, SMART Service, investigated SMART website use in routine practice. The participants in this study were SUs and their current community MHWs. These pairs used the website together in their usual meetings as they chose (eg, session frequency and length of use were optional) for up to 6 months [31].

Participant Characteristics

In total, 52 participants were recruited from responses to the study flyer and follow-up contact (Table 1). Participants were recruited from 3 clinical and 5 community-managed mental health services. All participants received a detailed participant information form and provided their informed consent. Reasons for nonparticipation included not responding to the invitation, no longer being connected to the mental health service, not having time, or not being interested.

Table 1. Participant recruitment (N=52).

Participants–SMART[a] study	Clinical services, n (%)	Community-managed services, n (%)	Total, n (%)
Service user			
SMART Therapy			
Female	4 (8)	15 (29)	19 (36)
Male	2 (4)	5 (9)	7 (13)
SMART Service			
Female	1 (2)	4 (8)	5 (10)
Male	2 (4)	4 (8)	6 (12)
MHW[b]			
Both studies			
Female	3 (5)	8 (15)	11 (21)
Male	2 (4)	2 (4)	4 (8)
Total	14 (27)	38 (73)	52 (100)

[a] SMART: Self-Management And Recovery Technology.

[b] MHW: mental health worker.

SU participants (n=37) were predominantly women aged between 18 and 64 years, and all of them had a diagnosis of a schizophrenia-related disorder or either bipolar disorder or major depression with psychotic features present in the last 2 years [31]. None of them were employed full-time and 95% (35/37) received financial support from the government. Nearly all SUs (36/37, 97%) used the internet, and more than half owned at least 2 devices to access the internet, including a mobile phone, computer, or tablet device. Most SUs used SMART with a trained MHW in SMART Therapy, whereas 30% (11/37) used the website with their usual MHW in SMART Service (Table 1). More than half of the SU participants (24/37, 65%) used the SMART website in their own time and with their worker.

MHW participants (n=15) were predominantly women aged between 23 and 60 years (Table 1). Most had worked in mental health services for <5 years. They all had access to computers in the workplace; however, less than half used a tablet device at work before the SMART study. This paper focuses on the experience of 12 workers who used SMART with SUs from once a week to approximately once every 2 months with each SU. Workers in SMART Service used SMART in their usual work with 1 to 3 SUs, whereas those in SMART Therapy used SMART with multiple SUs. In total, 3 worker participants joined the SMART Service study but did not use the website in their work despite offering the website to eligible SUs.

Data Collection and Analysis

Data collection and analysis occurred systematically, iteratively, and concurrently, as recommended by Charmaz [32]. Data were collected through individual semistructured interviews conducted in mental health services or by telephone from 2015 to 2017. SU and MHW interview guides were developed in consultation with members of the project reference group and are available in Multimedia Appendix 1. The interviewer (first author), an occupational therapist and academic with previous qualitative research and mental health work experience, had no prior relationship with participants other than having met 2 workers briefly through the SMART project. SU interviews lasted for an average of 40 (SD 13; range 18-65) minutes, and worker interviews lasted for an average of 36 (SD 13; range 22-73) minutes. Interviews were audiorecorded with permission and transcribed for data analysis, or handwritten notes were taken by request for 15% (8/52) of participants. Researcher reflections were recorded immediately after each interview. SU participants were reimbursed with a Aus $30 (US $23) gift voucher. Workers were interviewed during their paid work hours. In total, 6 SU participants agreed to the second follow-up interview to explore their use of the website over time. Written interview records were provided to all participants who opted to receive this information.

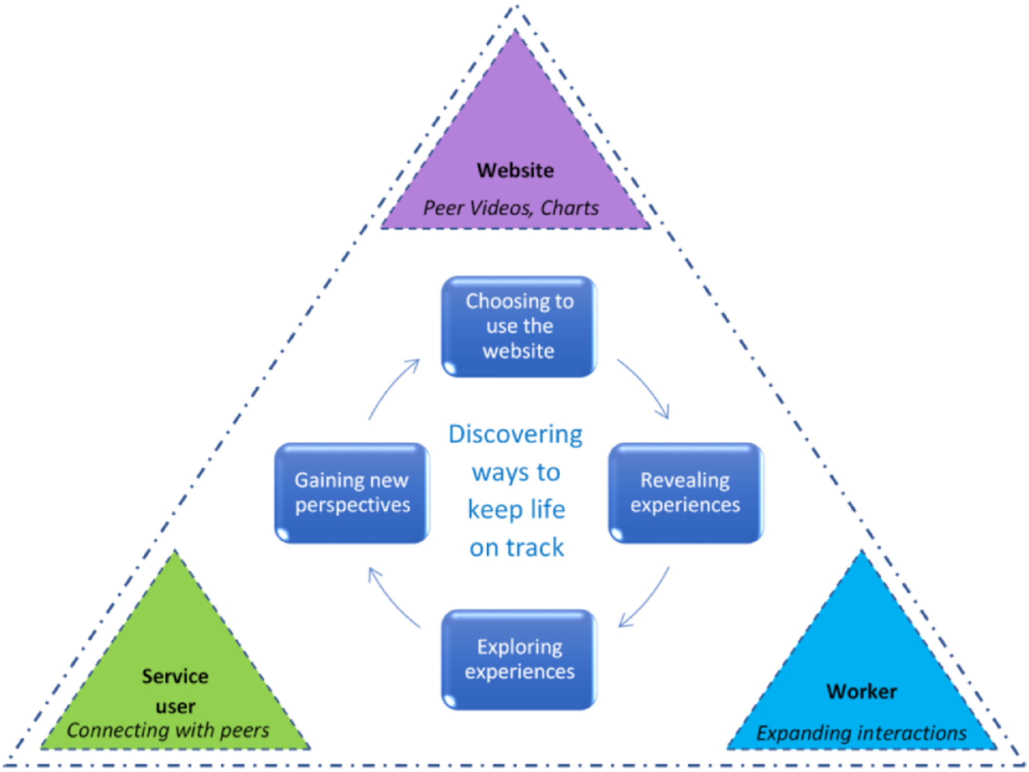
Data analysis conducted by the first author included initial paper-based coding on the transcripts to label and summarize the data for SU participants and separately for MHW participants. A constant comparative analysis was used to identify the analytic leads [32]. The transcripts were then uploaded to NVivo 11 (QSR International) qualitative data analysis software for focused coding. In this stage of computer-based coding, the analyst condenses and clusters the initial codes into more abstract conceptualizations [32,38,40]. Memo writing, reflective journaling to note researcher responses, freewriting, and diagramming of developing ideas were used to capture thoughts, develop analytical ideas, and identify gaps where more information is needed [32]. The final analytical phase involved reviewing memos, new focused computer-based coding, and considering different explanations of the data using abductive reasoning, as described by Charmaz [32]. This phase unified the data concerning the impact using the SMART website had on SU-MHW interactions from the perspective of all participants. Data collection and analysis continued until a point of conceptual density was reached [41], which is when the developing analytical categories are robust, with well-defined properties, and relationships between categories have been specified [32]. Credibility was enhanced by sharing three newsletters with participants and services that conveyed the evolving analysis, and through meetings with a lived-experience advisory panel, with a lived-experience consultant employed in the SMART research program in the final analytical phase, and regularly with all authors.

Results

Substantive Grounded Theory: Discovering Ways to Keep Life on Track

This CGT study aimed to develop an understanding of the therapeutic processes and interactions that arose when SUs and MHWs jointly used an e–mental health resource in community mental health contexts. The substantive grounded theory, *discovering ways to keep life on track*, was identified. This core interactive process unfolded when SUs and workers used the website together, as illustrated in Figure 1. Getting life back on track and keeping it heading toward a personally desired future was an overarching concern for SUs. They had spent time and effort working toward keeping their lives on track and were willing to try using a new website that might support this endeavor. Workers wanted to support SUs in getting their lives back on track by addressing topics that mattered to SUs beyond their illness symptoms and treatment. Previously, these interactions were sometimes elusive, whereas using the SMART website together involved three-way interactions that facilitated meaningful discussions and a shared focus on keeping life on track. Participants perceived that these SU-worker-website interactions were enjoyable, beneficial, and recovery focused and that using the website together was relationship building. The subprocesses that made up the overarching discovery process are outlined as follows.

Figure 1. Summary of the process of discovering ways to keep life on track.

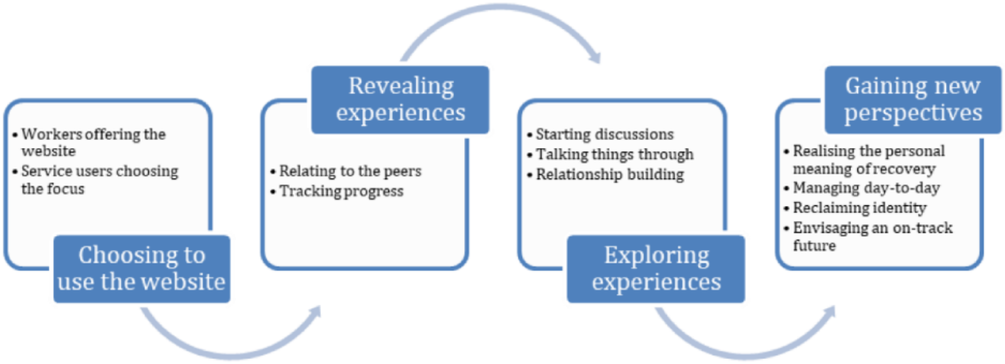


Subprocesses Contributing to the Discovery Process

Overview

The discovery process involved key interrelated subprocesses: choosing to use the website, revealing experiences of keeping life on track, exploring personal experiences of keeping life on track, and gaining new perspectives on keeping life on track (Figure 2). These subprocesses are expanded below using anonymized participant quotes attributed to an SU or MHW to illustrate the discovery process in action.

Figure 2. Subprocesses contributing to discovering ways to keep life on track.



Choosing to Use the Website

The discovery process was initiated by SUs having choice and control over their website use, both when they began using the SMART website together and over time. This is encapsulated in the subprocess *choosing to use the website*. Initially, MHWs *offering the website* gave SUs a choice about whether to use the website and which topics to explore. Being able to offer a choice was important to workers as they were reluctant to take action that might be perceived as *forcing* use:

> *It's also nice to think, to be able to give someone an option that you 're not forcing down their throat and that he could turn around and say, "No, I can do that if I want, but I'm going to say no."* [Madeleine, MHW]

Workers *offering the website* was also important to SUs as it provided them with support if they were unfamiliar with technology and invited them to explore topics of interest in the website without obligation:

> *She said to me, "you're free to do this and lead these sessions. If you do just want to talk for a while and not even use this website, I'm happy to do so."* [Amy, SU]

Exploring the website together led to SUs *choosing the focus* of the interaction. SUs initially chose topics that they felt were safe to discuss. Erin, an MHW who used SMART with several SUs, noted that the topics of health or managing stress could be easier topics for SUs to start with, as other topics could be "a bit too abstract." SUs could also decline to use the website. This was the case for SU Liam, who explained that despite some initial interest, he doubted the credibility of information on the internet, and his use of the website in meetings "went cold after a few months."

Revealing Experiences of Keeping Life on Track

The next subprocess involved *revealing experiences of keeping life on track*. The process of exploring self-selected topics on the SMART website led to SUs sharing new personal information with MHWs. Sharing personal information was facilitated by SUs *relating to the peers* in the videos and discovering that they shared experiences with and felt the same as their peers:

> *Well, with them, like, it (watching the videos) made me feel like I know I'm not the only person that's what's happened to me has happened to. It made me feel like I wasn't the only one...[Enigma, SU]*

SUs could express that they shared experiences with their peers in the videos rather than finding the words themselves. A variation on *relating to the peers* in the videos occurred for some SUs who perceived that their experiences were different from the peers. The contrast enabled them to highlight their own experiences and thus also revealed their experiences with the worker. Others expressed that they lost interest in using the website if the experiences that the peers shared were too different from their own. This could occur when a SU perceived that they were at a different stage of living with mental illness from the people in the videos.

In addition to the peer videos, *tracking progress* using the charts and tools on the website also revealed experiences. Using the charts provided concrete information about SUs' day-to-day experiences, including their stress, sleep, mood, diet, and exercise, which could be tracked over time:

> *I found that the charts were helpful to see a baseline of how I had been that week. I was able to look at the charts from week to week (in the meetings), to look back at a chart and then use it again.* [Harley, SU]

MHWs also noted that using the charts on the website helped reveal an SU's experiences:

> *It (SMART) was also useful because we talked about some of his warning signs, him becoming unwell again, and some of these match up with what is in SMART, so you can identify it...I know he was using the charts, especially for keeping the sleep patterns and eating patterns and how he was feeling on those days.* [Simon, MHW]

Exploring Personal Experiences of Keeping Life on Track

Revealed experiences next became the focus of discussions in the subprocess *exploring personal experiences of keeping life on track*. Participants particularly valued the way in which jointly using the SMART website was *starting discussions* about keeping life on track:

> *It's a really good communication tool, like it's a really good way to open-up conversations about specific topics...opening them up and kind of reading through them and watching those videos...it opened-up for him to be talking about his own lived experience for specific things, and what he used for self-care for instance.* [Leona, MHW]

Using the website together to start discussions was especially helpful for workers when their past efforts to communicate had been a struggle. For example, when an SU was "not someone who likes to talk that much" (Madeleine, MHW) or "really reticent, very anxious and had a lot of difficulty producing his own information" (Donna, MHW). Similarly, for Bruce, an SU, the website was a "good framework to start that discussion," after which using the website with a worker was helpful as the worker could "probe...just making you think."

Discussions next shifted to involve *talking things through*, where deeper reflections on the SU's personal experiences of keeping life on track were elicited. This joint discussion and reflection made the experience of using the website highly meaningful to SUs:

> *It's meant that rather than just going in and reading the material on the site, I actually had the option to discuss that and how it affected me and what it meant to me, and that's just as beneficial as the site itself. It was as important I think as just going through the material on my own, it had far more meaning I think having someone to talk about it with.* [Pam, SU]

Joint website use enabled MHWs to support SUs to "talk things through" by noticing how they responded to the website and encouraging them to reflect on the information. This was helpful for SUs who had difficulty concentrating on the written content on the website or who found some of the content challenging:

> *It really helped to have her (MHW) sit there and talk things through with me, especially when I didn't understand something or you know, went into a, like sometimes I'd be triggered by something that they were talking about or something like that and just to have her to bring me back down, or bring me back into reality.* [Reese, SU]

Exploring personal experiences built relationships between SUs and MHWs. SUs and workers who used the SMART website together over time indicated that they were experiencing new ways of interacting that were more open and equal, contributing to *relationship building*. SUs Kali and Shirley perceived that their usual workers got to know them better by using the website together. For MHW Phoebe, conversations were "richer" and "more in-depth." MHW Erin described using the website as very useful "in that relationship building between a worker and the person, for those trust issues, opening that up and helping to understand their point of view and their unique experience." Greater equality in interactions was suggested by Aimee when she described why her experience using the website was "unique" and "the most helpful type of thing I've ever received":

> *Even though other professionals its based mainly on me, it's just more like I felt really comfortable with the surrounding, it wasn't uncomfortable, like I didn't have the sense that the person with me was like, higher up than me if that makes any sense. I just felt like this person's like a friend of mine and just teaching me these things, whereas other professionals I don't have that sense, they didn't make me feel comfortable with the situation.* [Aimee, SU]

MHWs suggested that using the website shifted their interactions to a more equal footing with SUs by making them more natural:

> *It was also very natural, instead of kind of trying to do these activities where the client had to just straight away start talking, we were able to use peer support (via peer videos) really beautifully to kind of say compare and contrast what was happening.* [Donna, MHW]

Gaining New Perspectives on Keeping Life on Track

The final subprocess in the discovery process involved SUs *gaining new perspectives on keeping life on track* in four areas. These included *realizing the personal meaning of recovery*, *discovering new perspectives on managing day-to-day*, *reclaiming identity*, and *envisaging an on-track future*. MHWs gained a new and deeper understanding of the meaning of each of these new perspectives to the SU.

The participants' quotes demonstrate these new perspectives. First, "realizing the personal meaning of recovery" by engaging with the website and the worker transformed SUs' perspective on recovery:

> *I was crying and just found it a lot of relief. I'd gone along years thinking recovery was...you know, more than a doing word. Thinking that recovery was something...that you could strive for and actually cure yourself, and it wasn't that at all, it was different ways of actually coping.* [Sylvester, SU]

Second, SUs discovered new perspectives on *managing day-to-day*, such as having a routine, having good relationships, keeping up with appointments, and coping with stress:

> *I learnt how to um, manage myself, my stress, I learnt how to be able to connect with people. I tried to reconnect with old people, new people, it was just...mainly connection with people really. Communication-wise and stuff like that I didn't understand it before and I got some understanding of it because of this, and it's just really great to have.* [Aimee, SU]

Third, using the website with an MHW facilitated a process of *reclaiming identity* as SUs reflected on the challenges of losing their sense of self and self-esteem and were more able to recognize their feelings, identify their strengths and values, and grapple with their feelings of stigma and shame. SU Zara related how talking with a worker changed her perspective on disclosing her experience of mental illness to others:

> *I don't feel it has to handicap me anymore. I don't feel it's something I have to feel ashamed about, which is a very important point...Because I said to her, "If I was with a group of people I sort of half*

> *knew and we were having a sort of social chat, I've never revealed that I have a history of mental illness." And she said, "Oh you wouldn't?" And then I thought to myself why the heck wouldn't I? You know like it really brought me to the fact that I am covering up; why am I covering up? It must be because I feel ashamed; why should I feel ashamed? It's not my problem of shame, it's their problem if they're going to be judgmental.* [Zara, SU]

Finally, SUs and MHWs described how using the website together led to *envisaging an on-track future*. For example, Zara (SU) described how she had gained confidence: "I'm on the right track and that I can go full speed ahead." Similarly, Reese (SU) said, "I'm feeling a lot more positive about me being able to be recovered, be in recovery." Phoebe (MHW) explained that using the website together had enabled the SU she worked with to "at the end to be able to see, oh we've been answering all these questions, this is how they might fit in for me in a plan for the future."

Discussion

Principal Findings

Mohr et al [9] argue that there is a need to understand how digital technology can "fit into the context of mental health services." This CGT study provides an example of this fit: SUs and MHWs using a self-management and recovery-oriented website together. The in-depth focus on participants' experiences identified that using the website together elicited a process of discovering ways to keep life on track where SUs and workers gained a deeper understanding of the SU's life. SUs and workers who worked together before the SMART study and who used the website flexibly as part of their regular meetings found the discovery process beneficial. So too, did SUs and trained workers who met with the sole purpose of using the website together. Using the website together over time built relationships with the qualities of engagement and equality between SUs and workers. The experience of using an e–mental health resource for SUs and the interactions between an SU and MHW were both enhanced. Thus, this study indicates that e–mental health can be integrated into community mental health with benefits arising from the ensuing three-way interactions. These principal findings are next discussed in relation to personal recovery and therapeutic relationships and compared with existing related research.

Recovery-Oriented Interactions in the Discovery Process

Interactions between SUs and MHWs when using the SMART website together aligned with processes and practices that support personal recovery. First, the subprocess *choosing to use the website* enabled the important recovery-oriented way of working where SUs are given choices, and self-direction is encouraged [23,25]. This flexible way of using the SMART website appeared to influence its uptake. When choosing to use the website, workers supported those who experienced attention issues or who were unfamiliar with technology, thus overcoming issues that can impact SU engagement with e–mental health [2,6]. Second, the lived-experience videos on the website validated SUs' experiences, creating a sense of connection with peers and triggering the subprocess of *revealing experiences*. SUs' actions to manage challenges in their lives were revealed, thus making their strengths apparent. Third, the subprocess of *exploring experiences* started discussions about what SUs valued in their lives and their goals for the future. Exploring experiences together also provided a safe space for SUs to discuss the emotional responses that can arise from recovery narratives [42]. Fourth, the subprocess of *gaining new perspectives* involved a discussion about the SU's goals in which workers encouraged SUs to try out new strategies to work toward these goals, thus supporting goal striving. Discussions that explored a SU's identity and the personal meaning of recovery developed a shared vision of the SU as someone with an evolving identity and a positive future. This reflects an important recovery-oriented process that Soundy et al [43] suggest MHWs should pay attention to: "supporting clients to understand and experience the self as a fluid process that is not fixed." In summary, interactions occurring in the discovery process are consistent with recovery-oriented processes [21] and with the recovery-oriented working practices proposed by Slade et al [24]: identifying values, amplifying strengths, and supporting goal striving.

Therapeutic Relationships in the Discovery Process

Trusting and respectful relationships can be difficult to achieve in community mental health [10]. In this context, it is notable that using the SMART website together built relationships between SUs and MHWs. SU-worker relationships were perceived to be more engaging and more equal when using the website together. Equality and engagement are characteristics that contribute to relationships that SUs value—relationships that are hope-inspiring, empathic, and encouraging [11] and power-balanced [44], which "consist jointly of equality and collaboration" [45]. The subprocess *choosing to use the website* contributed to the sense of equality, as SUs were given control of the digital device and the topics to explore. Overall, the discovery process was engaging as the topics were relevant, and the lived-experience videos and charts stimulated discussions and reflections that were taken further by using the website together.

Using the website together also influenced the bond, task, and goal agreement that underpin therapeutic alliances [14,17,18]. A trusting bond between a SU and an MHW was developed that enabled the exploration of sensitive topics in the discovery process. This bond was supplemented by SUs identifying with their peers in the lived-experience videos. Hearing lived experiences from peers provided an additional source of relatedness, positive regard, and hope [39]. The SMART website, accessed on a digital device, provided an engaging and collaborative activity, which initiated or strengthened a shared focus on the goal of personal recovery. Kidd et al [12] argue that effective working alliances develop through a gradual and patient approach based on flexible ways of engaging. This study indicates that jointly using an e–mental health resource may provide such a flexible way of engaging, with the potential to create a strong *triangle of alliance* between an SU, a worker, and an e–mental health resource [13].

Comparison With Other Research Into Jointly Using e–Mental Health Resources

This study demonstrates similarities with Norwegian research, where a recovery-oriented e–mental health resource, ReConnect, was integrated into community mental health practice [46]. Using ReConnect facilitated different and positive communication between SUs and MHWs, particularly when expectations about using the resource were matched and the resource was integrated into working together. Strand et al [46] refer to these positive influences as *new relational avenues* that enrich working relationships. Unlike this study, some ReConnect participants also reported feelings of mistrust and disappointment arising in the SU-worker relationship. Asynchronous web-based communication led to *waiting for the other* and workers *feeling overwhelmed* because of increased communication demands [46]. The SMART website was only used together in face-to-face meetings, which avoided a similar issue. The positive findings from this study, in combination with the Strand et al [46] findings, support the assertion by Torous and Hsin [47] that digital mental health tools should be reframed as tools that can strengthen and augment therapeutic relationships, provided there is a clear shared understanding about how and when they will be used. Further implications for using e–mental health tools in community mental health follow.

Implications for Using e–Mental Health in Community Mental Health

This study indicates that jointly using an e–mental health resource can facilitate recovery-oriented interactions and build therapeutic relationships in community mental health, making this way of using e–mental health worthy of further development and application. It is recommended that future e–mental health resources for people experiencing severe mental illness include lived-experience content, that tools designed to address personal recovery and self-management are incorporated, and that SUs and MHWs use such resources together collaboratively and synchronously. Further research in different settings and using different e–mental health resources is needed to build on these findings.

Limitations

This study has several limitations. Despite engagement with a lived-experience consultant and advisory panel, the study design may have been strengthened if a person with lived experience was more actively involved as a coresearcher, as has been recommended for studies that concern personal recovery [23] and e–mental health interventions [48]. Study participants were volunteers who were willing to try something new. This willingness has been identified as a limitation in e–mental health research, given the potential differences between willing volunteers and the broader population [9]. The qualitative findings are thus grounded in the study context and are not directly transferable to different mental health settings. Conducting interviews with pairs of SUs and MHWs who used the website together may have enabled a deeper examination of the impact of using the website on their therapeutic relationship. This was not possible because of recruitment timing and the need to obtain independent consent. Finally, the findings reported here do not address the barriers that prevented some workers from using the SMART website with SUs. Further research that explores the barriers and facilitators to jointly use an e–mental health resource will support future implementation in community mental health practice.

Conclusions

This CGT study identified that when an SU experiencing severe mental illness and an MHW together used an e–mental health resource focused on recovery and self-management, recovery-oriented processes and interactions were elicited. Together, SUs and workers discovered ways that SUs did and could keep their lives on track when using the website became a regular part of their meetings. The tripartite alliance built positive working relationships between SUs and MHWs. Community mental health services seek ways to reorient their services so that they support SUs in their personal recovery. This qualitative study suggests that using an e–mental health resource together can elicit a discovery process that may make a valuable contribution toward this goal. Jointly using e–mental health resources in community mental health practice is therefore recommended as worthy of further development in research and practice.

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Authors' Contributions

All authors were affiliated with the SMART research project, which was led by NT and managed by FF. All authors collaborated on designing the qualitative research component of the project and have coauthored other related papers. AW implemented the qualitative research project with research supervision provided by EF and JF and project oversight provided by NT and FF. All authors contributed to the preparation of the manuscript and read and approved the final submission.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Qualitative interview guides.

[DOCX File , 29 KB - mental_v8i6e25998_app1.docx]

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Abbreviations

CGT: constructivist grounded theory
CHIME: Connectedness, Hope, Identity, Meaning, and Empowerment
MHW: mental health worker
SMART: Self-Management And Recovery Technology
SU: service user

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Original Paper

Twitter Users' Views on Mental Health Crisis Resolution Team Care Compared With Stakeholder Interviews and Focus Groups: Qualitative Analysis

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Abstract

Background: Analyzing Twitter posts enables rapid access to how issues and experiences are socially shared and constructed among communities of health service users and providers, in ways that traditional qualitative methods may not.

Objective: To enrich the understanding of mental health crisis care in the United Kingdom, this study explores views on crisis resolution teams (CRTs) expressed on Twitter. We aim to identify the similarities and differences among views expressed on Twitter compared with interviews and focus groups.

Methods: We used Twitter's advanced search function to retrieve public tweets on CRTs. A thematic analysis was conducted on 500 randomly selected tweets. The principles of refutational synthesis were applied to compare themes with those identified in a multicenter qualitative interview study.

Results: The most popular hashtag identified was *#CrisisTeamFail*, where posts were principally related to poor quality of care and access, particularly for people given a *personality disorder* diagnosis. Posts about CRTs giving unhelpful self-management advice were common, as were tweets about resource strains on mental health services. This was not identified in the research interviews. Although each source yielded unique themes, there were some overlaps with themes identified via interviews and focus groups, including the importance of rapid access to care. Views expressed on Twitter were generally more critical than those obtained via face-to-face methods.

Conclusions: Traditional qualitative studies may underrepresent the views of more critical stakeholders by collecting data from participants accessed via mental health services. Research on social media content can complement traditional or face-to-face methods and ensure that a broad spectrum of viewpoints can inform service development and policy.

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KEYWORDS

Twitter; social media; qualitative; crisis resolution team; home treatment team; mental health; acute care; severe mental illness

Introduction

Twitter in Mental Health Research

Twitter has emerged as a prominent social media platform that may be a valuable data source for researchers wanting to access stakeholders' views on many topics, including mental health services [1]. Results from a survey of mental health professionals suggest that psychiatrists and psychologists hold mixed views on using social media in their professional lives [2]. However, in recent years, researchers have used Twitter as a source of qualitative data to explore mental health by analyzing tweets from the general public regarding depression [3-7], schizophrenia [7,8], Alzheimer disease [9], suicide [10], stigma [11], and mental health professional conduct [1]. This research has found active communities of Twitter users discussing topics related to mental health and mental health care [5].

Twitter has its own methodological strengths and limitations as a source of secondary data for research. First, it offers researchers a quick and affordable way to access textual data that can be analyzed both qualitatively and quantitatively. For example, researchers have analyzed Twitter posts to provide rapid insights into the impact of the COVID-19 pandemic [12-14]. Twitter allows information to be collected in a naturalistic setting and therefore captures meaningful moments for Twitter users, which are less subject to the researcher's influence [4,15,16]. However, Twitter analysis clearly only accesses the views of those who use the internet and engage with this particular social media platform. Tweets are currently more likely to be from younger, more affluent sectors of the population [17,18]. Twitter users may sometimes tweet in a *reactive* way, conveying *in-the-moment* feelings and experiences [19] rather than more reflective views. Finally, short tweets can lack depth of content and context, making them harder to make inferences from when compared with rich and complex interview transcripts [5]. Similar to any data collection method, these strengths and limitations are important to consider when analyzing Twitter data in mental health research.

Research using Twitter or other social media data relies on the premise that the data reflect authentic experiences. Recently, commentators have attempted to evaluate the authenticity of Twitter posts [20-22]. Twitter has a public declarative function, which might influence the way people communicate on the platform and the content they share [23]. Social media platforms provide a forum for the construction and curation of social identities via a rapid exchange of personally, socially, and politically relevant information [23]. As such, data obtained via this medium need to be understood within the context of these multiple agendas [24,25]. Nonetheless, Twitter has been viewed as an extension of the real world [26,27]. Where Twitter posts are considered within their context, they can provide researchers with authentic knowledge of people's daily rituals, opinions, and experiences [23].

Traditional qualitative methods are usually labor-intensive and costly [28]. In research environments where resources are scarce and where rapid investigations of stakeholder views with direct clinical and policy relevance are needed, Twitter may be a readily accessible opportunity for data collection. Twitter may also provide novel perspectives on mental health service provision, as users posting on social media platforms may be different from those who agree to participate in research, especially research in which participants are recruited via mental health services. However, studies have not yet investigated how views on mental health care are expressed on Twitter compared with those identified through traditional qualitative data collection methods, and little is known about the unique contribution of a Twitter analysis.

Crisis Resolution Teams

Crisis resolution teams (CRTs; sometimes known as home treatment teams) were implemented nationally in the United Kingdom following policy directives in the National Health Service (NHS) in 2000 [29]. The remit of CRTs is to provide intensive community support to those experiencing a mental health crisis, with the aim of reducing the need for inpatient psychiatric hospital admission [30,31]. Research using electronic health record data indicates that most patients using CRT services are White, unmarried, middle-aged, and live in areas of high social deprivation [32]. Although research has shown that CRT support increases service user satisfaction with acute care in some circumstances [31,33,34], this is not consistent across services [35,36]. Furthermore, CRTs have not reduced admission rates nationwide to the degree anticipated [32,37]. Stakeholder perspectives of CRT care can inform initiatives to improve implementation, service user experiences, and outcomes [35,38]. The largest qualitative study on UK stakeholders' views of CRTs to date was conducted by Morant et al [38] as part of the work to develop a model of CRT good practices [39]. The thematic analysis found that staff continuity, carer involvement, and emotional and practical support are important components for CRT implementation [38].

Study Aims

Combining different sources for qualitative analyses is advocated to achieve a comprehensive understanding of a phenomenon [40,41]. Thus far, research on CRTs has relied on traditional qualitative methods. In this study, we aim to explore Twitter posts about CRTs and compare these posts with views obtained via interviews and focus groups. We seek to extend our understanding of the potential of Twitter as an easily accessible source of relevant stakeholder views, compare findings from Twitter with those from more traditional qualitative methods, and consider what this adds to our understanding of CRT implementation as experienced by stakeholders, including service users, family carers, service providers, and mental health practitioners.

A common methodological pitfall when comparing and combining different qualitative methods is to claim that one method is *better* than another [40]. By comparing Twitter posts with data collected via face-to-face methods, we do not wish to verify one data collection method or claim that one method is more trustworthy; rather, we are interested in comparing findings from these data sources to explore similarities and differences among views expressed regarding CRTs in both contexts.

Methods

Ethics Approval and Consent to Participate

This study was designed in accordance with guidelines on social media research published by the British Psychological Society [42] and the Association of Internet Researchers [43] and was approved by the University College London ethics chair (project ID: 1329/001). As this study only used publicly available tweets, there was no requirement for consent to participate. Twitter quotes used in this study have been paraphrased. Paraphrased quotes were tested through Twitter and Google search engines to ensure that the identity of the Twitter users was protected. Ethical approval for the Crisis Team Optimization and Relapse Prevention (CORE) study was obtained from the London Camden and Islington Research Ethics Committee (REC reference number 10/H0722/84), and written informed consent was obtained from all study participants.

Data Collection

Twitter

Twitter's advanced search function was used to retrieve public tweets relevant to CRTs. Search terms were chosen through informal explorations on Twitter and included known terminology relevant to CRTs (eg, *home treatment team*) and relevant *hashtags* (including *#crisisteamfail* and *#crisisteamsuccess*). A full list of search terms is presented in Table 1.

Table 1. Total number of tweets retrieved, excluded, and randomly selected for analysis by the search term[a].

Search term	Total retrieved tweets, n (%)	Date range of retrieved tweets	Excluded tweets[b], n (%)	Included tweets, n (%)	Tweets randomly selected for analysis, n (%)
#CRHTT[c]	16 (0.33)	August 23, 2012-September 5, 2017	0 (0)	16 (0.38)	1 (0.2)
#crisisteam	516 (10.65)	December 6, 2011-May 25, 2018	109 (17.03)	407 (9.68)	186 (37.2)
#crisisteamfail	934 (19.27)	November 20, 2014-May 12, 2018	4 (0.63)	930 (22.11)	127 (25.4)
#crisisteamsuccess	26 (0.54)	November 20, 2015-November 25, 2017	0 (0)	26 (0.62)	6 (1.2)
#dearcrisisteam	147 (3.03)	November 24, 2014-May 1, 2018	0 (0)	147 (3.5)	30 (6)
#hometreatmentteam	20 (0.41)	September 10, 2013-May 29, 2018	1 (0.16)	19 (0.45)	1 (0.2)
Crisis resolution team	132 (2.72)	September 22, 2010-June 1, 2018	21 (3.28)	111 (2.64)	10 (2)
Home treatment team	1714 (35.37)	July 12, 2010-June 1, 2018	37 (5.78)	1677 (39.87)	209 (41.8)
Crisis team	1255 (25.9)	November 1, 2017-November 30, 2017; February 1, 2018-February 28, 2018	465 (72.66)	790 (18.78)	90 (18)
Total	4846 (100)	July 12, 2010-June 1, 2018	640 (100)	4206 (100)	500 (100)

[a] Some tweets were captured by more than one search term.

[b] Reasons for exclusion: tweet not clearly relevant to UK mental health crisis resolution teams, tweet not in the English language, or tweet suspected to be from or about minors.

[c] CRHTT: Crisis Resolution Home Treatment Team.

We collected tweets posted between January 1, 2010, and June 1, 2018. While conducting the search, we found that the term *crisis team* produced many results. Most of these tweets were irrelevant to the study's focus on mental health CRTs. To ensure that the data set was manageable and relevant to the study, we collected 2 months of tweets for the *crisis team* search only. We assigned a number to each month in the overall period (January 1, 2010-June 1, 2018), then used a random number generator that randomly selected 2 months of tweets (November 2017 and February 2018) for the *crisis team* search. For all other search terms, we collected tweets posted between January 1, 2010, and June 1, 2018.

As tweets were extracted into an encrypted Microsoft Excel document, identifying features such as usernames and pictures were removed. Tweets were included if they were clearly relevant to UK mental health CRTs and excluded if they were not in the English language or were suspected to be from or about minors. The latter included tweets that either mentioned Child and Adolescent Mental Health Services or explicitly stated that their or someone else's age was below 16 years. We did not analyze the number of retweets or responses. Tweets citing external links were included, but these links were not accessed or analyzed.

CORE Interviews and Focus Groups

We used interview and focus group data from the CORE study for a comparison with the Twitter data. CORE was a research program that aimed to define and improve fidelity to good practice in mental health crisis teams [44]. A qualitative study was conducted as a part of this, aiming to explore stakeholders' experiences and views of CRTs and identify what they considered important for good CRT care. Semistructured interviews and focus groups were conducted with service users (n=41), carers (n=20), and CRT practitioners (n=137). Participants were recruited via CRT clinicians from 10 mental health catchment areas in England. The topics covered included experiences of CRT care, access to and discharge from CRTs, what is most important in CRT care, suggestions for best practices, and any barriers to or facilitators of achieving good practice. Questions were broad and open to allow respondents to bring up what they found important. Further details can be found in the previous study [38]. In this study, researchers had access to the full set of anonymized transcripts as a secondary data source.

Data Analysis

Twitter Analysis

Once all search outputs had been collated, tweets were selected for analysis using a random number generator. Tweets were selected and analyzed, 100 tweets at a time. Tweets were organized into basic descriptive categories following the principles of conventional content analysis [45] to provide an overview of the data set. If the tweet stated what kind of stakeholder was tweeting, for example, a service user or staff member, this was recorded as the tweet *relation*.

The main qualitative analysis of the Twitter data used thematic analysis, following the guidelines by Braun and Clarke [46,47]. We used an inductive approach to explore the data, although we were also guided by the awareness of findings from the previous CORE study. The lead researcher (NC) generated codes from the first 100 tweets to identify the initial themes. A second researcher (JW), who had lived experience of mental health service use, also conducted a thematic analysis on the first 100 tweets [48]. The 2 researchers discussed the tweets and combined their codes to collaboratively develop ideas on initial themes. The lead researcher then progressed through the data set of 100 tweets at a time, continuing with an inductive approach and transforming the coding frame as appropriate. One tweet could have multiple codes or contribute to multiple themes, although due to the short nature of tweets, this rarely occurred. The analysis was a collaborative and iterative process in which the wider research team met regularly to discuss the development of the coding frame and the clustering of codes into more abstract themes, and any uncertainties or disagreements between members of the team were resolved through discussion. The research team included various perspectives on the research topic, including lived experience, clinical roles, and academics working in CRT research. This iterative analysis process continued until thematic saturation was reached at 500 tweets. Changes or trends over time were not analyzed.

CORE Analysis

The CORE interviews and focus groups had already been analyzed using inductive thematic analysis by researchers in the original study [38]. The researchers in this study had access to the analyzed transcripts, notes, and coding frames on NVivo (QSR International). The lead researcher (NC) read this content to familiarize herself with the data and their interpretation in the original study. Other members of the research team worked on the original CORE study (NM, BLE, and SJ).

Comparative Analysis

The principles of refutational synthesis were used to compare the CORE qualitative interview data set to the Twitter data set. Refutational synthesis is a form of meta-ethnography that involves exploring and explaining contradictions among qualitative studies, with a focus on contextual differences [49,50]. We created tables, to structure the refutational synthesis, in which codes and themes from both data sets were listed against one another if they had any relation or contrast. Discussions on these comparisons were held by the research team.

Results

Twitter Search Results

Table 1 shows the number of tweets retrieved and included per search term. In total, 4206 tweets were retrieved from nine search terms. The highest number of relevant tweets was collected using the search term *home treatment team*. Hashtags identified in the search process included trending topics such as *#crisisteamfail*, which was the most frequently tweeted hashtag search term.

Who Is Tweeting?

Owing to the search strategy and the nature of Twitter, we were unable to determine the precise demographics of our sample, such as age, location, or mental health diagnosis (if any) of *tweeters*. As the search was made from a computer in London, tweets are more likely (but not verifiably) to be from the United Kingdom. It was feasible to identify what kind of CRT stakeholder the Twitter user was with reasonable confidence for most analyzed tweets (381/500, 76.2%). Table 2 shows the total number and percentages of stakeholder groups for the 500 analyzed tweets. Service users were the most common group who tweeted about CRTs (239/500, 47.8%) with fewer tweets posted by job advertisers, staff, and family or friends. There was 87% agreement between the 2 coders for 100 tweet relations, indicating that it is feasible to identify who is tweeting consistently.

Table 2. Twitter user relation groups (who was tweeting) for analyzed tweets (N=500).

Relation group	Tweets, n (%)
Service user	239 (47.8)
Unknown	119 (23.7)
Job advertisers	60 (12)
Other	30 (6)
Family or friend	26 (5.2)
CRT[a] staff	26 (5.2)

[a] CRT: crisis resolution team.

What Do People Tweet About?

The content analysis for 500 tweets indicated that large proportion of tweets expressed negative views about CRTs (205/500, 41%), compared with a small proportion of posts about positive experiences (36/500, 7.2%). The remainder of tweets were more neutral, for example, personal updates. These personal updates involved the Twitter user sharing live updates on their whereabouts and activities, such as “I’m off to see the CRT.” Information sharing (80/500, 16%) was more common than information seeking (21/500, 4%). For example, Twitter users shared information on how to contact the CRT. A proportion of tweets included job advertisements to work in CRTs (62/500, 12.4%). Sometimes we could identify where *tweeters* were engaged in conversation with one another through the “@” symbol in their tweets (80/500, 16%), where they shared their experiences of CRT services and at times offered emotional support.

Thematic Analysis of Twitter Content

We identified principally critical Twitter content about experiences of accessing CRTs and the quality of care provided, comments on resource limitations, and a small number of more positively toned tweets by CRT staff members.

Accessing Crisis Team Care

Among the critical posts, some Twitter users reported having difficulty accessing CRT care for themselves or a family member or friend. Twitter users described barriers to access help, such as feeling prematurely *turned away* by the CRT. This was particularly the case in which Twitter users posted that they had been diagnosed with a *personality disorder*. Other mental health diagnoses were rarely mentioned and were not associated with this experience of rejection from the CRT. Twitter users also reported difficulties in contacting the CRT, particularly by phone:

> *When the CRT find out you have a diagnosis of BPD, they just ignore you.*
>
> *I’m lucky to have access to the crisis team—not everyone does just because of their diagnosis.*
>
> *Just tried to ring the crisis team, no-one answered, no answerphone.*

Although not all tweets discussing access to crisis care were negative, positive sentiments were sometimes tinged with surprise or sarcasm, suggesting a mixed landscape of experiences and a lack of consistent access to the CRT:

> *Crisis team staff came to see me the same day that I called them, what kind of parallel universe is this?*

Quality of Care

Twitter users expressed varying experiences of quality of care, although sentiments were once again weighted toward the negative. There were many tweets about CRT staff giving inappropriately basic self-management advice to service users, such as having a cup of tea or taking a bath. Service users tweeted that, as a consequence, they felt that services did not understand or appreciate the severity of their crisis and that their own self-management strategies may have already been exhausted. They expressed finding distraction or self-care advice to be patronizing and insensitive. Discussions on inappropriate self-management advice have been so widely circulated on Twitter that, at times, Twitter users interacted with each other in tones of sarcasm:

> *Crisis team, if I’m talking to you I’ve already tried drinking tea and doing mindfulness colouring whilst in the bath.*
>
> *A paramedic would never advise a patient to just go for a walk or watch TV, so why does the crisis team?*

Of the smaller number of service user tweets about positive experiences of CRTs, these were often attributed to CRT staff listening to service users and providing meaningful, appropriate advice. Interestingly, Twitter users tended to attribute *success stories* to individual staff members. In other words, *#crisisteamsuccess* depended on the expertise of individual staff members:

> *There are some really excellent CRT staff members out there, they are rare but real.*
>
> *The woman who visited from the crisis team this morning was so reassuring.*

Strain on Mental Health Services

There were recurrent mentions of NHS cuts, a lack of hospital beds, and the use of police and paramedics to cover what was felt to be a lack of mental health professionals in the community. Such frustrations with the *system* were expressed by service users, family, and friends alike but were not mentioned by any self-identified CRT staff members in this sample:

> *The mental health system is in meltdown, further cuts mean services can’t cope, no hospital beds, crisis team overwhelmed, they need more funds.*
>
> *My local CRT have no resources, no training, the system is broken.*

Working in a CRT

A small number of Twitter users (26/500, 5.2%) were identified as CRT staff members. Although there were some suggestions for long and unsociable working hours, there was a positive trend in these tweets in which staff members expressed gratitude to their team. Most of these tweets seemed to be from nursing or medical trainees on placements, reflecting that Twitter is often used by a younger age group who may be more open to talking about their work on social media [2]:

> *Am sad that my time working in the CRT is coming to an end, it is a v good team #rewarding*
>
> *Working on new years eve, yay for me! #mentalhealthcrisisteam*

Refutational Synthesis: Themes From Twitter Compared With Interviews and Focus Groups

Overview

The CORE study identified three domains that were important to stakeholders in CRT care: (1) the organization of CRT care (including easy and quick access to care and staff continuity), (2) the content of CRT work (including the staff being empathetic and providing emotional support), and (3) the role of CRTs in the wider system (eg, gatekeeping admissions). This was explored in detail in the original study publication, along with the demographics of the sample [38].

In the refutational synthesis, we found that the features identified as important for good access to and quality of CRT care in the CORE study aligned with the views of tweeters. However, there were differing views on how far this was currently being achieved in practice, with tweeters being generally more critical of CRT care. In Table 3, we list some of the comparisons among themes that highlight similarities and differences between the data sets. Here, we provide details on the areas of convergence and divergence in stakeholder views of the access and quality of CRT care. We also discuss the strain on mental health services as a theme that is unique to the Twitter data set.

Table 3. Results from the refutational synthesis examining similarities and differences among themes identified in the Twitter data set and the Crisis Team Optimization and Relapse Prevention interview and focus groups data sets, with code examples[a].

Theme	Twitter data set	Interviews and focus groups data sets
Accessing CRT[b] care		
	Importance of quick and easy access	*Importance of quick and easy access*
	Reports of difficulty accessing the CRT, for example, via the phone	—[c]
	Diagnosis of a "personality disorder" as a barrier to accessing CRT care	—
Quality of CRT care		
	Importance of empathetic staff members	*Importance of empathetic staff members*
	Feeling dismissed by inappropriate distraction or self-care self-management advice	—
	—	*Holistic models of care*
Strain on mental health services		
	Underresourced community crisis services	—
	Use of police or paramedics in mental health crises	—
CRT's role in the wider system		
	—	*Gatekeeping hospital admissions*
	—	*CRT as an alternative to hospital*

[a] Codes are indicated using italics.

[b] CRT: crisis resolution team.

[c] Not identified.

Accessing CRT Care

The importance of having readily accessible crisis care was evident in both the CORE interviews and the Twitter data set. However, the two data sets illustrated very different service user experiences. As discussed, service users on Twitter largely complained that the CRT was not readily available, for example, by not answering the phone or being too far away. Such tweets were often in real time, reporting contact (or a lack of contact) with the CRT as it happened:

> *No one will answer the phone during handover for an hour, what if it's an emergency?* [Twitter user]

In contrast to the largely negative views expressed on Twitter, CORE service users reported mixed experiences with access to care. Some service users reported that it was mostly quick and easy to contact the CRT by phone, and many appreciated that care was available during unsociable hours:

> *Overall, what matters most? I would say the fact that you can make contact with the Crisis team 24 hours, 24/7.* [CORE service user]

An important finding in the Twitter data set was that people who were diagnosed with a *personality disorder* felt that their diagnosis was a barrier to access care, and these Twitter users often felt that stigma against their diagnosis meant that they were denied care:

> *Crisis team said "CRT care for people with a diagnosis of BPD can make them worse, so we don't really visit them."* [Twitter user]

Issues regarding access to care for people with *personality disorders* did not arise in the CORE study. Among the small subset of service users in the CORE study with *personality disorder* diagnoses, the sense of rejection identified in the Twitter posts was not expressed. Conversely, these service users often reported positive service experiences and did not identify their diagnosis as a barrier to treatment. In focus groups with CRT staff members, there were diverging opinions regarding whether CRT support was appropriate for those with *personality disorder* diagnoses. Some staff expressed perceived difficulties in supporting people with these diagnoses, including difficulties in maintaining the boundaries of therapeutic relationships, difficulties with the time-limited nature of CRT support, and general pressures on mental health systems and teams:

> *More and more, we've got a lot of people on our books with borderline personality disorder...They*

> *refer to us because they [referrers] don't know what to do with them, which is fine, but neither do we.* [CORE CRT staff]

In summary, although both data sets show a mixed landscape of experiences, Twitter users often reported more difficulty accessing CRT care. This was particularly the case for Twitter users who were posting about *personality disorder*.

Quality of Care

Both service users and carers in the CORE study reported mixed experiences of the quality of care received from CRTs. In the CORE interviews, help with practical issues, emotional support, and relationship building were all described as important aspects of good quality care. Service users valued times when they received emotional support from staff who listened to them and came across as caring. There was a wish among some stakeholders for a more holistic approach to care, for example, more support with social issues. This was not observed in the Twitter sample:

> *They did listen to me. They did understand my predicament. They acknowledged my dilemma about taking a medication.* [CORE service user]
>
> *Crisis team advising me to take a walk in the park is probably the worst thing to say considering I make self-harm plans in the park* [Twitter user]

Importantly, a significant aspect of care quality that was frequently discussed by service users on Twitter was receiving unhelpful self-management advice from the CRT. This was unique to Twitter: in the CORE data set, stakeholders did not report experiences of feeling dismissed by distraction or self-care advice.

Both data sets identified staff characteristics as a determinant of good quality treatment, with consensus that there is a wide variety of staff expertise within CRTs. As CRT staff work shifts, the extent to which consistent therapeutic relationships are established varies greatly, and continuity of care is a challenge. This was reflected in both data sets, where continuity of staffing was valued and seen as important in CRT care. Personal staff characteristics, such as empathy and compassion, were consistently described in both forms of data as critical ingredients in good CRT support:

> *He's had some good, really good staff come to see him, and he's had some damn awful, pretty diabolical people come to see him, as well.* [CORE carer]
>
> *Shocked by reading the hashtag #crisisteamfail, I have experienced this but I also think some CRT staff are great* [Twitter user]

Strain on Mental Health Services

In our sample, we found that people posted on Twitter about a strain on mental health services due to high demands and a lack of resources. This theme was unique to the Twitter data set and was not discussed in the CORE interviews and focus groups with service users, despite the broad semistructured nature of the interview questions. Some Twitter users directed tweets toward the Twitter accounts of the NHS and UK government. This theme reflects the political nature of Twitter as a social forum in comparison with interviews and focus groups that take place in a private space. This theme was distinct from the theme "the role of CRTs in the care system" in the CORE data set, which described the role of CRTs as gatekeepers for hospital admissions:

> *NHS mental health crisis services are being stretched to breaking point.* [Twitter user]
>
> *Police are helping people who are self-harming cos the conservatives slashed funding for CRTs.* [Twitter user]

Discussion

Principal Findings

Our findings suggest that the analysis of Twitter data can complement traditional qualitative research methods and expand our understanding of stakeholder views of mental health crisis care delivered by CRTs. Many of the same things feature in what service users and family caregivers describe as valuable components of good quality CRT care in both fora, particularly staff who listen and provide warmth and empathy. We accessed additional insights into the experiences of CRTs from Twitter. Twitter users posted that self-management strategies suggested by CRT staff were frequently experienced as unhelpful and expressed concern about the strain on mental health services. Twitter users with *personality disorder* diagnoses discussed their diagnosis as a barrier to accessing CRT care. More generally negative sentiments were expressed on Twitter compared with *traditional* face-to-face data collection methods. Therefore, it seems likely that more negative experiences of CRT service use and implementation may be missed by relying solely on face-to-face data collection methods.

Twitter differs from traditional qualitative methods in several respects. Interviews and focus groups are often set up as *spaces for reflection*. This is encouraged in numerous ways: at the time of data collection (usually after some time has elapsed since the experience), in the open nature of questioning, and in the way in which interviews are introduced as research where there are no *right* or *wrong* answers [51]. The interviews and focus groups were also structured to some degree by the researcher. Twitter, on the other hand, is an instant form of communication, where individuals often post using mobile phones in the *heat of the moment* [19,52]. Twitter posts also take place outside of research encounters. When considering these very different research contexts, this strengthens our confidence in the congruent themes in our analysis, as these are expressed both inside and outside of the *interview room*.

Twitter is set up as a social media forum, encouraging interactions between users [23,53,54]. There appeared to be a community of service users with similar negative experiences of CRTs in this study, who engaged and supported each other in the *Twittersphere*. For example, interactions about unhelpful self-management advice appear to have turned into a *running joke* in this Twitter community as part of the hashtag *#crisisteamfail*. This is a clear example of how views are constructed and reinforced in the social sphere of Twitter in a way that is very different from how views are expressed in individual face-to-face methods. Analyzing Twitter posts can therefore allow access to how issues and experiences are shared among socially mediated communities of health service users [23,55].

The participant recruitment processes for interviews and focus groups in the CORE study likely introduced some selection bias, as potential participants were identified via CRTs. This necessarily excludes people in mental health crises who could not or did not want to engage with CRTs. As the CRT staff contributed to identifying service users and their family members, they may have been more likely to identify service users who had engaged positively with CRT care (although CORE study researchers took steps to help avoid selection bias by the staff). For example, participants diagnosed with *personality disorders* in the CORE interviews had received a service from the CRT, so the sample was unlikely to include people who felt that they had been denied care. The Twitter analysis may therefore allow research to access a broader range of voices compared with face-to-face qualitative methods alone.

Individuals who are active on Twitter may differ from those who engage in traditional qualitative research and may differ from CRT service users as a whole. A significant proportion of mental health service users (and nonusers) are distrustful of services or may have had negative previous contacts with services, sometimes involving coercion. These individuals may be more inclined to engage in Twitter than in traditional research projects. In addition, given its broad social reach, people who use Twitter may be more likely to engage as advocates and activists, bringing this distinctive point of view to the table. Twitter can be viewed as a naturalistic public setting in which service users can have their voices heard [23], gaining power in this virtual space where they can choose to remain anonymous. Some people may feel more comfortable communicating through text, rather than face-to-face interactions. Twitter users tend to be from younger sectors of the population [18], whereas CRT service users as a whole tend to be middle-aged [32], which may explain some differences between themes identified in this study and highlights that Twitter may reflect younger service users' experiences of CRTs. By using interviews and focus groups alone, research on CRTs thus far may fail to access the views of less-engaged service users and more critical stakeholders.

Strengths and Limitations

This is the first study to compare views expressed on Twitter with data collected from interviews and focus groups in the field of mental health research. A broad range of search terms were used, both with and without *hashtags*, which link tweets together. By conducting the search directly from Twitter, we avoided bias that would have been introduced if we used software such as NCapture [56]. The benefits of including lived experience perspectives in analyzing qualitative data in mental health research to help provide a more complete understanding of the data [57] are equally relevant for research involving Twitter. Collaborative coding in this study enhanced the validity of qualitative analysis: the research team included key stakeholder perspectives and experiences of using, providing, and researching mental health services.

This study has some limitations. The search strategy meant that the demographics of tweeters could not be retrieved. Tweets were accessed through Twitter's advanced search function, which uses Twitter's application programming interface. This means that the search output is determined in part by Twitter's programming. Nevertheless, research suggests that the application programming interface method still retrieves a large proportion of tweets available in the public domain [58]. The search terms used in this study were inclusive, but there will inevitably be some relevant tweets that were missed. The study design meant that we were unable to conduct any causal analysis to explain the differences between the themes in both data sets. Finally, tweets are by nature short and may therefore lack the depth, nuance, or complexity of other narrative forms. There is some room for misinterpretation where there is a lack of context and a lack of opportunity to explore the meaning of tweets further [5]. Collaborative coding and meetings with a wider research team aimed to resolve the uncertainties as much as possible.

Implications for Clinical Practice and Future Research

The refutational synthesis found that there are some overall congruent messages about what is considered important in CRT practice; however, there were differing views about how far this is being achieved and some themes emerged from only one set of analyses. Our confidence in CORE study findings [38] regarding critical ingredients of good CRT implementation—including good access, responsiveness, and consistent and caring staff—is strengthened by the present findings. This is consistent with previous qualitative studies that identified similar critical ingredients of good CRT services [35]. To our knowledge, our study is the first to examine stakeholder perspectives of CRTs using social media data. The stark comparison between service user experiences accessed using Twitter or face-to-face methods shows that we should approach either data source with caution as a gauge of overall service user experience. This reinforces the need for better and more coordinated routine collection and analysis of patient-reported experience measures in mental health services and highlights the virtues of triangulating different sources in qualitative research [41].

Our analysis suggests that CRTs need to develop new approaches when supporting individuals with self-management advice and that CRT staff should avoid giving general self-care advice, such as going for walks. This is likely to apply to other clinical contexts in mental health care. Instead of self-care advice, self-management strategies should be tailored toward relapse prevention and recovery goals [59]. For example, a randomized controlled trial demonstrated the benefits of having a peer support worker promote self-management strategies for those recently discharged from a CRT [60]. Although research has shown that mental health professionals have mixed opinions about using Twitter in their professional life [2], we argue that Twitter may be a helpful source of viewpoints for service improvement initiatives [1,16]. However, future work is needed to investigate whether Twitter is representative enough to provide real-time feedback on mental health services.

Researchers may find it beneficial to engage proactively with Twitter to gain a broad range of perspectives. This is particularly the case when research questions seek to include those who have difficulty engaging or have disengaged from services or where studies have difficulty recruiting participants for lengthy interviews and focus groups. Future research using Twitter data may use natural language processing techniques to examine the broad content of Twitter posts. It would also be interesting to track trends and changes over time. A limitation of this study was that we could not conduct any causal analysis, and future research may explicitly ask CRT stakeholders to reflect on and explain differences between themes in the Twitter and interview data sets. The themes identified in this study demonstrate that more research is needed on how best to optimize crisis care for people who have been diagnosed with a *personality disorder*, as our Twitter analysis showed that this group often felt dismissed, neglected, and stigmatized by services. Further explorations are desirable to examine the potential of Twitter and other social media platforms in mental health research. We hope that there will be developments in evidence-based best practice for conducting qualitative research using Twitter data and for combining social media analysis with standard interviews.

Conclusions

Twitter users provided unique perspectives on CRT implementation, including the importance of the type of advice offered to help manage crises and the perceived limitations of CRT services. Research on social media content adds complexity to our understanding of phenomena and can complement traditional or face-to-face research methods in health care research by allowing the voices of people who may be more critical of services to be heard.

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Authors' Contributions

NC, NM, BLE, and SJ contributed to the study design and data collection. NC, JW, NM, SJ, and BLE contributed to the data analysis. BLE and SJ led the CORE program, and NM led the qualitative component of the CORE program. All authors contributed to the drafting of the manuscript, led by NC. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

CORE: Crisis Team Optimization and Relapse Prevention
CRT: crisis resolution team
NHS: National Health Service

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Original Paper

Trajectories of Change in an Open-access Internet-Based Cognitive Behavior Program for Childhood and Adolescent Anxiety: Open Trial

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Abstract

Background: Although evidence bolstering the efficacy of internet-based cognitive behavioral therapy (iCBT) for treating childhood anxiety has been growing continuously, there is scant empirical research investigating the timing of benefits made in iCBT programs (eg, early or delayed).

Objective: This study aims to examine the patterns of symptom trajectories (changes in anxiety) across an iCBT program for anxiety (BRAVE Self-Help).

Methods: This study's participants included 10,366 Australian youth aged 7 to 17 years (4140 children aged 7-12 years; 6226 adolescents aged 12-17 years) with elevated anxiety who registered for the BRAVE Self-Help program. Participants self-reported their anxiety symptoms at baseline or session 1 and then at the commencement of each subsequent session.

Results: The results show that young people completing the BRAVE Self-Help program tend to fall into two trajectory classes that can be reliably identified in terms of high versus moderate baseline levels of anxiety and subsequent reduction in symptoms. Both high and moderate anxiety severity trajectory classes showed significant reductions in anxiety, with the greatest level of change being achieved within the first six sessions for both classes. However, those in the moderate anxiety severity class tended to show reductions in anxiety symptoms to levels below the elevated range, whereas those in the high symptom group tended to remain in the elevated range despite improvements.

Conclusions: These findings suggest that those in the high severity group who do not respond well to iCBT on a self-help basis may benefit from the additional support provided alongside the program or a stepped-care approach where progress is monitored and support can be provided as necessary.

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KEYWORDS

iCBT; child; adolescent; anxiety; online; trajectories of change

Introduction

Anxiety is an increasingly common childhood mental health condition, with potentially significant life-long repercussions for those who do not access early treatment [1]. Internet-based or eHealth interventions are recommended for encouraging the primary prevention and early intervention for mental illness [2]. In particular, the evidence base for internet-based cognitive behavior therapy (iCBT) in the treatment of childhood anxiety has been growing continuously, with the best outcomes observed when delivered with therapist support [3-8]. More recently, research has demonstrated the feasibility of self-help iCBT for childhood anxiety as a means of achieving widespread service implementation in real-world clinical and community contexts [9]. Self-help iCBT, which does not rely on any therapist support, has the potential to offer evidence-based mental health assistance in a timely and effective manner and in a way that overcomes barriers to accessibility, cost, stigma, anonymity, and shortages of health care professionals [10]. Several successful iCBT platforms have been developed and validated internationally for children and young people (eg, BIP Anxiety [11,12] and SPARX [13]) and adults (eg, MindSpot Clinic [14], This Way Up [15], and Shuti [16,17]).

The BRAVE Self-Help program is the only widely disseminated iCBT program for childhood anxiety, which is made publicly available, free of charge, to all children and adolescents in Australia. Although the preliminary effects of this self-help iCBT program appear somewhat weaker than those found for the therapist-supported iCBT version [9], clinically meaningful improvements are still made by a large proportion of anxious youth who engage in and complete the program, further demonstrating its potential as a population-level, early intervention. Specifically, it was demonstrated that for those users who completed six or more self-help iCBT sessions, there was a moderate to large reduction in anxiety (Cohen d=0.81 and Cohen d=0.87 for adolescents and children, respectively [9]). Furthermore, for those who had completed nine sessions, approximately 57.7% (94/163) achieved recovery into nonelevated levels of anxiety and 54.6% (89/163) showed statistically reliable reductions in anxiety [9]. However, anxiety was not measured at every session, and the amount of change made from session to session was not explicitly tested. Therefore, it is unclear when reductions in anxiety actually occurred and for whom.

Very little research has been conducted on the timing of benefits made in iCBT programs (eg, early or delayed). March et al [9] demonstrated that users' anxiety was reduced after only three self-help iCBT sessions (Cohen d=0.59), suggesting that change may occur early and rapidly. Furthermore, in their examination of brief and full versions of a cognitive behavioral therapy (CBT) website (MoodGym) for adults with elevated depression, Christensen et al [18] found that a single module of CBT was insufficient to reduce depression symptoms, but extended CBT (approximately three sessions) was associated with greater improvements. Importantly, however, they also found that programs longer than three sessions were not necessarily associated with greater improvement [18]. There is also some evidence from face-to-face interventions that can provide potential insight into the ideal dosage and response trajectories. In one study of face-to-face CBT for anxious youth, a nonlinear symptom trajectory was reported, whereby a rapid response was evident over the first six sessions, with tapering anxiety reductions over the remainder of the intervention [19]. In another study examining the separate trajectories of anxiety and depressive symptoms over the course of a transdiagnostic treatment for adolescents, Queen et al [20] found that, on average, participants' total anxiety scores reduced steadily during treatment (by 4.76 units every 8 weeks) and then slowed during the follow-up period (reduced by only 1.48 units every 8 weeks). Together, the evidence to date suggests that a reduction in symptoms appears to commence after at least three sessions of iCBT [9,18]. However, a session-by-session trajectory across iCBT programs for children and adolescents has yet to be examined.

We examined patterns of symptom trajectories (changes in anxiety) across BRAVE Self-Help program sessions to determine whether BRAVE Self-Help produces a gradual and linear impact on anxiety symptoms or whether the greatest impacts are made early in treatment and to determine distinct trajectories of anxiety symptoms within BRAVE Self-Help participants. Such information will help in determining ideal doses of self-help iCBT and whether small doses of treatment are sufficient. Given that variability is likely to be present in how young people respond to self-help interventions, identifying factors associated with different trajectories may assist in understanding the mechanisms through which the program works and may inform targeting and tailoring of the program. Thus, we aim to identify subgroups of participants (including identifying common demographic and clinical characteristics of these subgroups) based on latent change trajectories in anxiety scores in response to BRAVE Self-Help. Previous studies have used this analytic approach to determine the trajectories of depressive symptoms and suicidal ideation in internet-based interventions [17,21], and in longitudinal studies examining trajectories of anxiety symptoms [22,23]; however, this approach is yet to be applied for examining responses to anxiety treatment in the context of a web-based program for young people. The identification of key demographic and clinical variables that predict subgroup membership has the potential to inform the effective delivery of supported interventions, tailored, or alternative treatments. In this way, the results will inform recommendations regarding the use of iCBT within the context of population-level models of care that are open to everyone and are typically not monitored by health care professionals.

Methods

Intervention

BRAVE Self-Help is an interactive internet-based iCBT program for preventing and treating anxiety among youth. The program, described extensively elsewhere [9,24], is offered as an open-access web-based program targeting young Australians aged 7 to 17 years. It comprises 10 sessions of 30 to 60 minutes each, with two additional booster sessions that can be completed as revision modules. Sessions include CBT techniques incorporated into interactive web-based activities focused on psychoeducation, recognition of physiological symptoms of anxiety, relaxation training, cognitive strategies of coping statements and cognitive restructuring, graded exposure, problem-solving approaches, self-reinforcement, and relapse prevention. Each session comprised pages that included the presentation of information or material, examples of technique application, activities to facilitate the knowledge acquisition and application of skills to the young person's circumstances, quizzes to consolidate learning, and homework activities to promote the application of skills in real-world contexts. The self-help program has previously demonstrated its acceptability and feasibility [9].

Depending on age, participants completed either the child program (7-12 years) or the adolescent program (12-17 years), with 12-year-olds given a choice of either program. Although there were accompanying parent programs, these were not included in this study. BRAVE Self-Help is delivered without any therapist support, and there are no timing restrictions between sessions; however, the sessions must be completed in a predetermined sequence. Automatic reminders to complete sessions are sent to a young person via email.

Participants

Participants included 10,366 Australian youth aged 7 to 17 years with elevated anxiety (4140 children aged 7-12 years; 6226 adolescents aged 12-17 years) who registered for the BRAVE Self-Help program between July 1, 2014, and October 26, 2018. Table 1 presents a full summary of the baseline characteristics of participants according to program grouping.

Table 1. BRAVE Self-Help baseline participant characteristics (N=10,366).

Characteristics	Child program (n=4140)	Adolescent program (n=6226)	Total participants (N=10,366)
Age (years), mean (SD)	9.34 (1.48)	14.55 (1.66)	12.47 (3.01)
Gender, n (%)			
Male	2192 (52.95)	1480 (23.77)	3672 (35.42)
Female	1948 (47.05)	4532 (72.79)	6480 (62.52)
Other	0 (0)	214 (3.44)	214 (2.06)
Transgender or transsexual	0 (0)	40 (0.64)	40 (0.39)
Transgender or transsexual	0 (0)	12 (0.19)	12 (0.12)
Genderqueer	0 (0)	59 (0.95)	59 (0.57)
Androgynous	0 (0)	28 (0.45)	28 (0.27)
None of the above	0 (0)	75 (1.21)	75 (0.71)
Remoteness area, n (%)			
Major cities	2324 (56.14)	3559 (57.16)	5883 (56.75)
Inner regional	1013 (24.47)	1424 (22.87)	2437 (23.51)
Outer regional	499 (12.05)	712 (11.44)	1211 (11.68)
Remote	111 (2.68)	141 (2.27)	252 (2.43)
Very remote	38 (0.92)	20 (0.32)	58 (0.56)
Missing	155 (3.74)	370 (5.94)	525 (5.07)
Number of sessions completed, mean (SD)	3.04 (2.98)	2.04 (2.51)	2.39 (2.67)
Baseline anxiety			
CAS-8[a], mean (SD)	14.16 (3.04)	15.75 (3.42)	15.11 (3.36)
Elevated, n (%)	2275 (54.95)	2819 (45.28)	5094 (49.14)
Clinical, n (%)	1865 (45.05)	3407 (54.72)	5272 (50.86)

[a] CAS-8: Children's Anxiety Scale 8-item.

The BRAVE Self-Help program is an open-access intervention offered to young people and families throughout Australia; thus, registration does not require referral from a health care professional. Children and adolescents who registered for the program were referred by school-based professionals (3480/10,366, 33.57%); referred by external health professionals (1973/10,366, 19.03%); referred by parents, friends, or family members (1330/10,366, 12.83%); referred through *beyondblue* (645/10,366, 6.22%); self-referred through internet searching (840/10,366, 8.1%); or referred through other means (eg, word-of-mouth, radio, magazine, or advertising; 676/10,366, 6.52%). A full breakdown of referral sources is provided in Multimedia Appendix 1.

Eligible participants were required to have registered for the BRAVE Self-Help program between July 2014 and October 2018 and to have completed the Children's Anxiety Scale 8-item (CAS-8) [25] during the registration process. All participants had access to BRAVE Self-Help (single-cohort longitudinal design); there was no randomization or comparison condition. Participants were not required to demonstrate symptomatic levels of anxiety to register for the program; however, only those with elevated anxiety were included in this study. Of the participants included in this study, 49.14% (5094/10,366) showed elevated levels of anxiety (CAS-8 ≥84th percentile or T-score ≥60) and 50.89% (5272/10,366) showed clinical levels of anxiety (CAS-8 ≥96th percentile or T-score ≥65). As the primary objective was to examine the trajectories of session completion and reductions in anxiety, there were no inclusion criteria regarding the minimum number of completed program sessions.

Measures

All measures were embedded within the BRAVE Self-Help program. Further data were collected via BRAVE program analytics regarding adherence to the program.

Sociodemographics

Basic demographic information, including age, gender, and location (postcode), was collected during the registration process. Age was measured in years, and the residential location was assessed using postcode. Postcode data were coded according to the Australian Standard Geographic Classification system [26], and participants were grouped into the categories of major cities, inner regional, outer regional, remote, and very remote locations. In terms of gender, participants were able to select from male, female, transgender or transsexual, transgender or transsexual, genderqueer, androgynous, or other. For the purposes of analysis, gender was subsequently recoded into male, female, and other.

Anxiety Severity

Anxiety levels were measured using the CAS-8 [25]. The CAS-8 comprises eight items asking the young person to rate how often each item (eg, “I worry what other people think of me”) applied to them. Items are rated on a 4-point scale ranging from 0 (*never*) to 3 (*always*). Items are summed to produce a total score ranging from 0 to 24, with higher scores indicating greater levels of anxiety.

The CAS-8 has been used in large-scale school-based prevention program trials with subsequent population-level, gender-standardized norms for comparison [25]. Scores ≤83rd percentile (≤T-score 59: CAS-8 score ≤9 for males and 11 for females) are considered *normal*; scores ≥84th percentile (above T-score 60: CAS-8 score ≥10 for males and 12 for females) are considered indicative of *elevated anxiety* and scores ≥94th percentile (above T-score 65: CAS-8 score ≥13 for males and 16 for females) indicate clinical levels of anxiety. For this study, and as per procedures of March et al [9], for other gender, scores ≥11 were considered indicative of *elevated* and scores ≥15 were considered indicative of *clinical* anxiety. The CAS-8 was completed by participants at baseline or session 1 and then at the commencement of each subsequent session (ie, up to nine time points after baseline). For example, if a participant had completed five sessions, they would have CAS-8 data at baseline and sessions 2, 3, 4, and 5. The CAS-8 has demonstrated good psychometric properties, with a reliability coefficient α of .89 in previous studies [25] and an average internal consistency across data collection points of 0.83 in this study.

Program Adherence

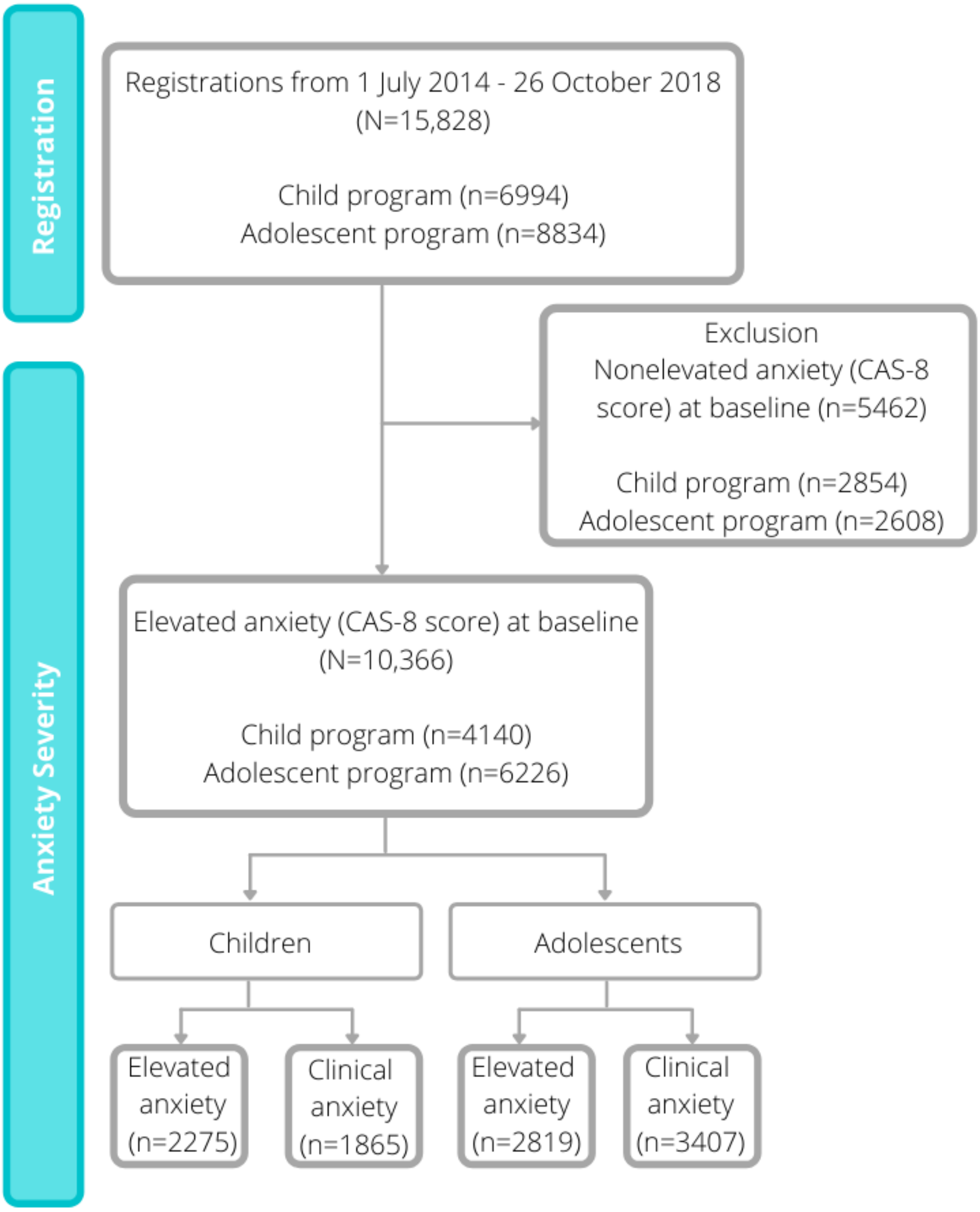
Program adherence was measured as the number of sessions completed by each participant over a period of 20 weeks from the date of registration. The number of sessions completed was automatically recorded by the program.

Procedure

Data for this study were collected as a part of a large community effectiveness trial of the BRAVE Self-Help program (ethical approval H13REA264 from the governing university). During the registration process, participants were required to read a developmentally appropriate web-based participant information sheet and provide informed consent. Children aged below 16 years were also required to obtain parental consent to continue with registration. After providing consent, participants created a profile and completed an initial questionnaire, including basic demographic data (age, gender, location, referral source, and email contact address) and baseline anxiety assessment (CAS-8). Participation in the program was voluntary, and participants could choose to provide anonymous information (eg, nickname) if they chose. They could also discontinue using the program or withdraw from the study at any time without adverse consequences.

Participant data were recorded for a 20-week period from the date of registration, thus allowing sufficient time for the completion of the 10 sessions. Figure 1 provides a visual representation of the selection process for the inclusion and exclusion of data and the final sample included in the study.

Figure 1. Participant inclusion in the BRAVE Self-Help program. CAS-8: Children's Anxiety Scale, 8-item.



Analytic Strategy

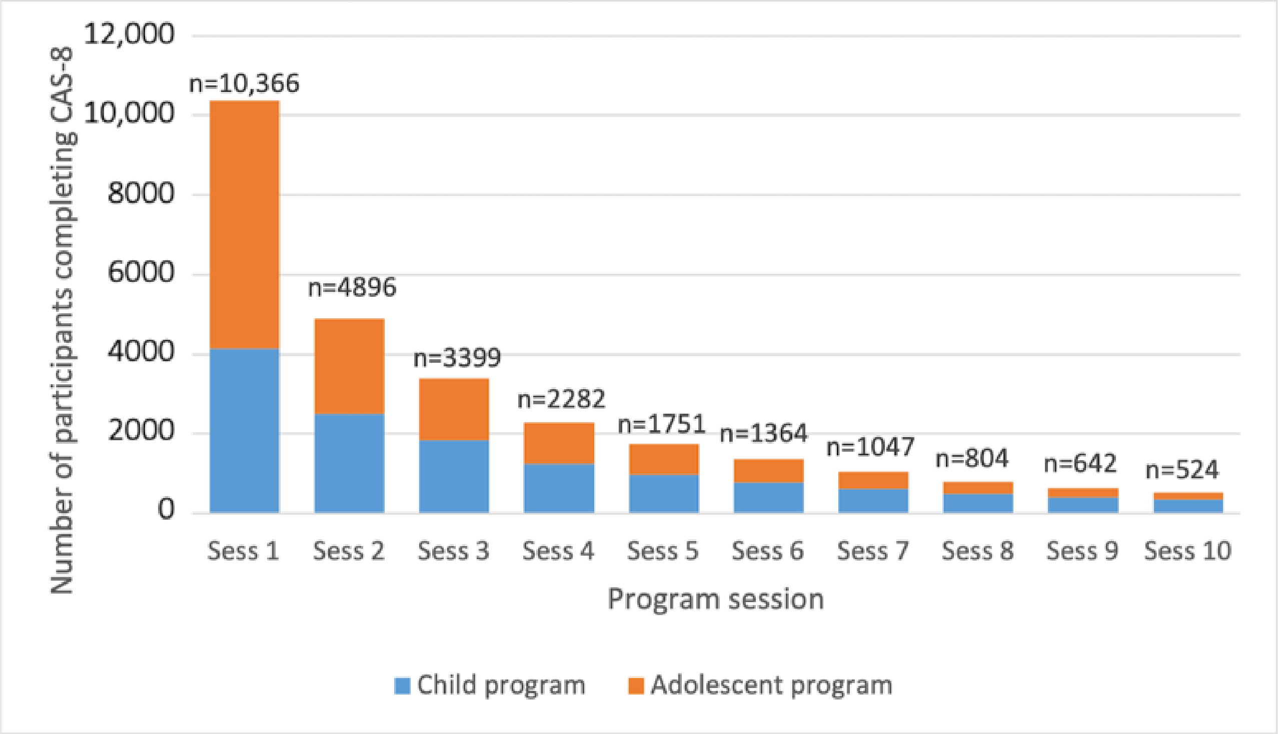
Trajectories of anxiety symptoms based on CAS-8 scores were identified using growth mixture models (GMMs), with intercept, linear change, and quadratic change estimated using all available data from the baseline assessment and up to nine subsequent measurement occasions. GMM was used to identify latent classes of participants with distinct longitudinal trajectories, with all available data included in the models [27]. The GMM approach is a form of latent class analysis that identifies distinct subgroups, combined with growth modeling that estimates linear and quadratic trajectories over time. The methodology classifies the heterogeneity of individual trajectories in symptoms over time into a discrete number of latent classes. Models with between one and five latent classes were tested to identify an optimal number of latent classes based on a significant Bootstrapped Likelihood Ratio Test (BLRT) [28]. We also considered the size of each latent class, as models with classes that represent <5% of the total sample are difficult to identify [28]. After selecting an optimal number of classes, predictors of latent class membership were tested using logistic regression models to identify participants' characteristics (eg, baseline anxiety severity, gender, age, and geographic location), who showed differential responses to the intervention, and to characterize the relationship between adherence and response to the BRAVE Self-Help program. GMM analyses were conducted using Mplus version 7 (Muthén & Muthén), whereas descriptive and regression analyses were conducted using SPSS version 25 (IBM Corp).

Results

Program Adherence

The number of participants completing each session decreased throughout the program. As indicated in Figure 2, only half of the participants completed two sessions of the program.

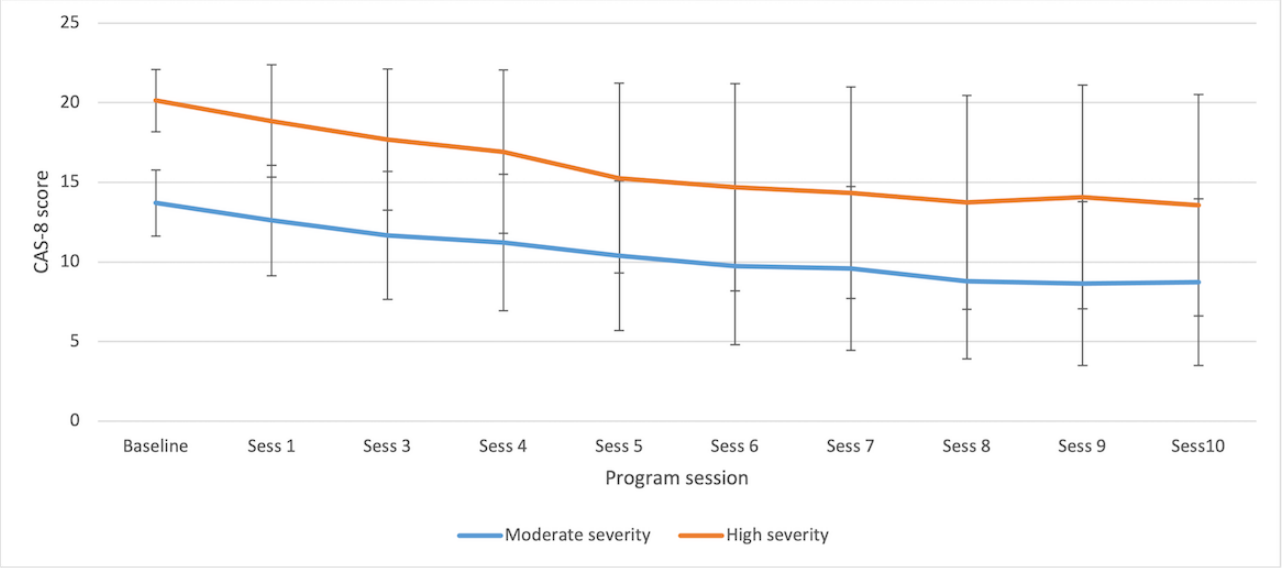
Figure 2. Rates of program adherence. CAS-8: Children's Anxiety Scale, 8-item.



Trajectories of Anxiety Symptoms

The GMM with two classes had a significantly better fit than a single-class solution based on the BLRT statistic (*P*<.001); however, the BLRT for a three-class model was not significant as compared with the two-class model (*P*=.99). Furthermore, in the three-class model, one of the classes accounted for 0.7% (73/10,366) of the sample. Consequently, a two-class model was selected. Scores on the CAS-8 for the two total classes are shown in Figure 3. On the basis of the observed trajectories, the two classes were labeled as *high anxiety severity* (*HAS*; 2280/10,366, 21.99% of the sample, shown in orange), and *moderate anxiety severity* (*MAS*; 8086/10,366, 78.01% of the sample, shown in blue). On the basis of the GMM model, the intercept for the CAS-8 scores in the HAS group was 19.72 (SE 0.09), with a negative slope (estimate=−1.39; SE 0.11; *P*<.001). The intercept for the MAS group was 13.75 (SE 0.04), with a negative slope (estimate=−0.97; SE 0.04; *P*<.001). A quadratic relationship was also evident in both the HAS (estimate=0.08; *P*<.001) and MAS (estimate=0.05; *P*<.001) groups, showing that the rate of change in CAS-8 scores decreased over time for both classes.

Figure 3. Trajectories of anxiety symptoms for the two latent classes of high and moderate anxiety severity based on observed mean (SD). CAS-8: Children's Anxiety Scale, 8-item.



Predictors of Class Membership

A logistic regression model was used to identify the factors associated with class membership. The outcomes are presented in Table 2. Teen program participants had 31% greater odds of being in the HAS class than those receiving the child program (*P*<.001). For every year increase in age, participants were 4% more likely to fall in the HAS class (*P*=.007). Females had twice greater odds of being in the HAS class than males (*P*<.001). Participants of other gender had 47% greater odds of being in the HAS class than females (*P*=.007). The effects of remoteness of residence were not significant (Table 2). In terms of program adherence, those participants who completed a greater number of sessions were less likely to be classified as HAS, with the likelihood of being in the HAS class decreasing by 3% with the completion of each additional session (*P*=.01). There were no effects on the date of registration or the number of activities completed in session 1.

Table 2. Logistic regression model of class membership: odds of having a high compared with moderate anxiety severity class trajectory.

Variable	Estimate (SE)	Chi-square (*df*)	*P* value	Odds ratio (95% CI)
Program: teen versus child	0.27 (0.05)	29.9 (1)	*<.001* [a]	1.31 (1.19 to 1.44)
Age at registration	0.04 (0.02)	7.2 (1)	*.007*	1.04 (1.01 to 1.07)
Gender		148.5 (2)	*<.001*	
Male versus female	−0.69 (0.06)	135.8 (1)	*<.001*	0.50 (0.45 to 0.56)
Other versus female	0.38 (0.14)	7.2 (1)	*.007*	1.47 (1.11 to 1.95)
State of residence		17.3 (8)	*.03*	
Missing versus SA[b]	−0.44 (0.50)	0.8 (1)	.38	0.64 (0.24 to 1.71)
ACT[c] versus SA	−0.10 (0.19)	0.3 (1)	.57	0.90 (0.62 to 1.30)
NSW[d] versus SA	−0.23 (0.09)	6.0 (1)	*.01*	0.79 (0.66 to 0.95)
Northern Territory versus SA	0.18 (0.28)	0.4 (1)	.52	1.19 (0.69 to 2.05)
Queensland versus SA	−0.28 (0.10)	8.5 (1)	*.004*	0.75 (0.62 to 0.91)
Tasmania versus SA	−0.40 (0.18)	5.0 (1)	*.02*	0.67 (0.47 to 0.95)
Victoria versus SA	−0.33 (0.10)	11.3 (1)	*.001*	0.72 (0.59 to 0.87)
Western Australia versus SA	−0.31 (0.11)	8.4 (1)	*.004*	0.73 (0.59 to 0.91)
Remoteness area		4.0 (5)	.54	
Missing versus major city	0.18 (0.117)	2.8 (1)	.10	1.20 (0.97 to 1.48)
Inner regional versus major city	−0.01 (0.064)	0.0 (1)	.93	0.99 (0.88 to 1.12)
Outer regional versus major city	−0.01 (0.084)	0.0 (1)	.90	0.99 (0.85 to 1.16)
Remote area versus major city	−0.05 (0.168)	0.1 (1)	.78	0.96 (0.69 to 1.32)
Very remote area versus major city	−0.37 (0.398)	0.9 (1)	.34	0.69 (0.32 to 1.49)
Date of registration	−0.01 (0.021)	7.4 (1)	.45	0.99 (0.95 to 1.02)
Number of sessions completed	−0.03 (0.011)	12.2 (1)	*.01*	0.97 (0.95 to 0.99)
Activities completed in session 1	0.00 (0.005)	1.5 (1)	.40	1.00 (0.99 to 1.01)
Constant	4.49 (8.44)	0.3 (1)	.59	N/A[e]

[a] Italics indicate statistical significance (*P*<.05).

[b] SA: South Australia.

[c] ACT: Australian Capital Territory.

[d] NSW: New South Wales.

[e] N/A: not applicable.

Discussion

Principal Findings

This study examined the trajectories of responses to a web-based, open-access, self-help intervention for youth anxiety. The results suggested two classes of trajectories that could be distinguished by high versus moderate baseline levels of anxiety and levels of change over time. Irrespective of trajectory, participants, on average, obtained benefits from the program, with participants generally showing significant linear reductions in anxiety. From a baseline average of around 20 (>98th percentile for females and males), those in the HAS trajectory class showed reduced anxiety scores of 6.58 points (or 5.68 points based on model estimates that accounted for missing data) on the CAS-8; however, this level remained within the elevated range. In contrast, the MAS trajectory class showed reductions of 3.87 points (or 4.31 points based on model estimates) on the CAS-8 from a baseline of 12.6 (84th percentile for females; 94th percentile for males) to a level in the nonelevated range. Indeed, on average, those in the MAS class obtained a clinically meaningful benefit (scores within the nonelevated range) by session 6.

The finding that the HAS class tended to remain in the elevated range of anxiety scores despite showing significant reductions from a very high starting point suggests that at least a proportion of this group may require additional assistance over and above the self-help iCBT program. The finding also revealed that the HAS class completed fewer sessions than their MAS counterparts. It is possible that lower levels of perceived symptom improvement among participants in the HAS class contributed to lower motivation to continue engaging with the program, or a greater difficulty completing sessions due to ongoing symptom severity and difficulty implementing strategies. Thus, a therapist-supported model or stepped-care approach may be beneficial for this group, whereby HAS participants either receive additional support from the outset or are monitored (in terms of anxiety reduction and session compliance) and are referred for additional therapist support as necessary. HAS participants could be easily identified at the beginning of the program (due to higher initial scores), and subsequently referred, monitored, and provided with additional support or intervention elements if their response to the program was poor. Preliminary results from case studies of a stepped-care model of BRAVE highlight the potential of this approach [29].

The study results also suggested that the rate of anxiety reduction decreased over time for both trajectory classes, with greater reductions occurring in the first six sessions than in later sessions. Importantly, in line with the findings of Christensen et al [18], the results showed that young people can show significant reductions in symptoms after brief iCBT programs. The findings are also partially consistent with the findings of Chu et al [19] for face-to-face CBT for youth anxiety; however, Chu et al [19] showed a more rapid initial decrease and a clearer plateau than this study. The results are also consistent with those of Queen et al [20], who demonstrated a large reduction in symptoms during the first eight weeks of face-to-face treatment and a far smaller drop in symptoms in the second eight weeks of follow-up treatment. It would seem that around six sessions of iCBT may be sufficient for many users, with the option of further session completion for those who choose to do so, or for whom poor treatment response suggests they may be indicated. Importantly, with the knowledge that six sessions may be sufficient for many users, this provides an opportunity to develop shorter intervention programs that may be more appealing and motivating for young people and ultimately attract more users.

In terms of predictors of class membership, the study found that adolescents and females were more likely to be in the HAS class compared with MAS class than children and males. These findings are perhaps unsurprising given that anxiety levels are known to increase with age and are higher among women [30]. Given that the HAS class tended to complete fewer sessions and were less likely to reach a nonelevated status, it is important that the greater representation by females and adolescents is considered to ensure that the needs of these participants are being considered in program design and delivery. For example, our previous research indicated that adolescents are more likely to complete the program alone without parental support. It is possible that additional forms of support, whether from a web-based therapist, school teacher, peer coach, or even automated chatbot could enhance treatment outcomes for adolescents. It may also be feasible to build web-based reward systems designed for adolescents that provide enhanced support to increase motivation and program adherence. Earlier dropouts among HAS participants may suggest that those with elevated symptoms found it more difficult to engage in the program. Nevertheless, the two classes had similar levels of initial engagement (based on activity completion), suggesting that other factors, such as perceived treatment efficacy, may have influenced adherence.

The implications of this research's findings are not limited to the BRAVE program and provide useful insights for other web-based interventions. For example, when there is a broad range of users who engage with an internet intervention, with diverse profiles, particularly related to symptom severity, the results of this study indicate that care should be taken to consider the needs of these subgroups. Particular consideration should be given to whether the service model is appropriate for them, whether the service needs to be tailored to profiles (eg, with additional support), or whether the service needs to be targeted to those who will benefit the most. However, it is important to note that there are drawbacks to targeting more narrowly—there is still a clear demand for the BRAVE program even among those in the high severity class, which suggests that many young people with anxiety may not be receiving the care they need from other sources (whether web-based or in-person).

Strengths and Limitations

There are a number of clear strengths of this study. It had a large sample size, included both children and adolescents, used naturalistic data from a clinical service without stringent eligibility criteria, and collected symptom-level data throughout the completion of the program. However, alongside these strengths, this study has a number of limitations. High attrition was observed, and although models were robust to missing data, dropout may be associated with treatment response. All outcome measures were self-reported; thus, there was no clinical verification of the symptom level. Furthermore, as the data were collected in the context of clinical service delivery, there was no control group. This makes it unclear whether factors external to the program may have influenced the trajectories and whether the reductions in anxiety were attributed to the treatment or were the result of spontaneous recovery over time. Finally, limited psychosocial factors were measured; thus, other factors, such as ruminative style, personality, social support, and previous exposure to treatment, may have influenced the observed trajectories.

Future Research Directions

Recent worldwide events have resulted in a significant shift in mental health care service needs, as numerous lockdowns during the COVID-19 pandemic severely impacted face-to-face mental health service access and provision. This subsequently led to the conversion of many services to telehealth, videoconferencing, and other digital modalities to provide continuity of care. With an increased access to digital mental health services, and likely increased experiences of distress at the community level, it will be important to examine whether the use of the BRAVE Program changes throughout and after COVID-19. Future research should examine whether users presenting to the web-based program during and after the pandemic present with different profiles and symptom presentations and whether their experience with the web-based program leads to similar outcomes as standard BRAVE program users.

Conclusions

Young people completing the BRAVE Self-Help program tend to fall into two trajectory classes that can be reliably identified in terms of high versus moderate baseline levels of anxiety and subsequent reductions in symptoms. Both classes showed significant reductions in anxiety, with the greatest level of change being achieved within the first six sessions for both classes. Those in the MAS class tended to show reductions in anxiety symptoms to levels below the elevated range, whereas those in the high symptom group tended to remain in the elevated range despite improvements. Thus, those in the high severity group who do not respond well to iCBT on a self-help basis may benefit from a stepped-care approach or additional support.

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Conflicts of Interest

SM, SHS, and CD acknowledge that although intellectual property for BRAVE-ONLINE is owned by UniQuest, they may potentially benefit from future royalties related to the program.

Multimedia Appendix 1
Breakdown of referral sources to the BRAVE self-help program (N=10,366).
[DOCX File , 23 KB - mental_v8i6e27981_app1.docx]

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Abbreviations

BLRT: Bootstrapped Likelihood Ratio Test
CAS-8: Children's Anxiety Scale 8-item
CBT: cognitive behavioral therapy
GMM: growth mixture model

HAS: high anxiety severity
iCBT: internet-based cognitive behavior therapy
MAS: moderate anxiety severity

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Corrigenda and Addenda

Correction: Association Between Improvement in Baseline Mood and Long-Term Use of a Mindfulness and Meditation App: Observational Study

Argus J Athanas[1*], BSc; Jamison M McCorrison[2,3*], BSc; Susan Smalley[4], PhD; Jamie Price[5], JD; Jim Grady[5], BA; Paul Wehner[6], BA; Julie Campistron[5], MBA; Nicholas J Schork[1,3,7,8], PhD

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Correction of: https://mental.jmir.org/2019/5/e12617/

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In “Association Between Improvement in Baseline Mood and Long-Term Use of a Mindfulness and Meditation App: Observational Study” (JMIR Ment Health 2019;6(5):e12617) the authors noted one error.

In the originally published paper, author Paul Wehner's name was inadvertently not included in the list of authors, and the full list of authors and affiliations appeared as follows:

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The correction will appear in the online version of the paper on the JMIR Publications website on June 30, 2021, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Original Paper

Indications of Depressive Symptoms During the COVID-19 Pandemic in Germany: Comparison of National Survey and Twitter Data

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Abstract

Background: The current COVID-19 pandemic is associated with extensive individual and societal challenges, including challenges to both physical and mental health. To date, the development of mental health problems such as depressive symptoms accompanying population-based federal distancing measures is largely unknown, and opportunities for rapid, effective, and valid monitoring are currently a relevant matter of investigation.

Objective: In this study, we aim to investigate, first, the temporal progression of depressive symptoms during the COVID-19 pandemic and, second, the consistency of the results from tweets and survey-based self-reports of depressive symptoms within the same time period.

Methods: Based on a cross-sectional population survey of 9011 German adolescents and adults (n=4659, 51.7% female; age groups from 15 to 50 years and older) and a sample of 88,900 tweets (n=74,587, 83.9% female; age groups from 10 to 50 years and older), we investigated five depressive symptoms (eg, depressed mood and energy loss) using items from the Patient Health Questionnaire (PHQ-8) before, during, and after relaxation of the first German social contact ban from January to July 2020.

Results: On average, feelings of worthlessness were the least frequently reported symptom (survey: n=1011, 13.9%; Twitter: n=5103, 5.7%) and fatigue or loss of energy was the most frequently reported depressive symptom (survey: n=4472, 51.6%; Twitter: n=31,005, 34.9%) among both the survey and Twitter respondents. Young adult women and people living in federal districts with high COVID-19 infection rates were at an increased risk for depressive symptoms. The comparison of the survey and Twitter data before and after the first contact ban showed that German adolescents and adults had a significant decrease in feelings of fatigue and energy loss over time. The temporal progression of depressive symptoms showed high correspondence between both data sources (ρ=0.76-0.93; P<.001), except for diminished interest and depressed mood, which showed a steady increase even after the relaxation of the contact ban among the Twitter respondents but not among the survey respondents.

Conclusions: Overall, the results indicate relatively small differences in depressive symptoms associated with social distancing measures during the COVID-19 pandemic and highlight the need to differentiate between positive (eg, energy level) and negative (eg, depressed mood) associations and variations over time. The results also underscore previous suggestions of Twitter data's potential to help identify hot spots of declining and improving public mental health and thereby help provide early intervention measures, especially for young and middle-aged adults. Further efforts are needed to investigate the long-term consequences of recurring lockdown phases and to address the limitations of social media data such as Twitter data to establish real-time public mental surveillance approaches.

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KEYWORDS

depressive symptoms; GEDA/EHIS survey; Twitter; COVID-19; pandemic; social contact ban; temporal progression; data correspondence; public mental health surveillance; depression; survey; social media; data; infodemiology; infoveillance; twitter; mental health; public health; surveillance; monitoring; symptom

Introduction

Background

Worldwide, approximately 330 million people actively use Twitter at least once a month [1]. In Germany, as in other countries, the proportion of active Twitter users has increased over the past years and reached 17.1% of the population aged between 16 and 69 years in 2019 [2]. In light of this large group of users, web-based social communication platforms such as Twitter were proposed as potential sources of public health surveillance and early disease warning systems for the general population [3]. Recently, a review on the use of Twitter as a tool for health research revealed that approximately 23% of eligible studies were from the public health research realm [4]. The review showed that 26% of the studies used Twitter data for the surveillance of infectious diseases (eg, influenza [4]). However, a systematic investigation on the incremental value and reliability of Twitter as a tool for monitoring public *mental* health has not yet been conducted.

Worldwide, depressive disorders are among the most frequent mental diseases and among the three leading causes of nonfatal health loss and disability [5]. National health survey data similarly suggest a steady increase in depressive symptoms (eg, having little interest or pleasure in doing things and feeling down, depressed, or hopeless) over the past decades, with a recent prevalence of 10.4% among the adult population living in Germany [6]. Considering these findings and indications that mental health problems such as depressive symptoms may increase during epidemic or pandemic crises [7], it is of significance to strengthen the public mental health evidence in general and during the recent COVID-19 pandemic in particular.

Twitter Communication on Depressive Symptoms

Research on social media content and its individual psychological functions and effects has significantly increased over the past 15 years [8]. Explorations of why individuals discuss mental health issues on Twitter and the content of these discussions have revealed that establishing a sense of community are among the most frequent themes, aside from seeking personal relief and expressing thoughts or feelings [9,10]. Digitally mediated communication offers easy and low-threshold possibilities to connect to others and to express and share experiences of psychosocial stressors [9,11]. This is of particular relevance since depressive disorders have been associated with experiences of social rejection [12] and feelings of social isolation [13]. Despite the strong evidence on the role of social support for the developmental course of depression [14], it has been pointed out how the mode of social interaction (ie, in-person or digitally mediated contact) can be decisive in this regard [15]. Given the recent ban on in-person social contact during the COVID-19 pandemic, it is assumed that social media use has become particularly relevant to the general population [16]. Thus, the analysis of trends in social media to draw conclusions on the mental health status and needs of a population could be an interesting tool for mental health provision and policy.

Furthermore, previous research indicated promising approaches to detect signs of depression in tweets [17] and predict the individual onset of a depressive episode based on supervised algorithms, including content and linguistic style analyses of tweets (eg, for negative affectivity [18]). Although much rarer than tracking or predicting the temporal progression of individuals' mental health, researchers have monitored the course of mental health discussion in social media over time to draw conclusions on a current or prospective public mental health state. One example is a study from McClellan and colleagues [19] that showed how Twitter messages could be used to help to identify periods with more frequent content related to depression and suicide in social media and the association of this content with societal events such as World Suicide Prevention Day or the suicide of a prominent actor. The results demonstrated the potential of longitudinal social media analysis for identifying public mental health conditions that may otherwise be overlooked by mental health professionals [19]. However, solely computational approaches to capture depressive symptoms from tweets have also been criticized because of their disregard for the context of keywords and for theoretically driven approaches to identify keywords [20]. For instance, Mowery and colleagues [20] found that the majority of tweets containing predefined depression-related keywords were not necessarily indicative of depressive symptoms on closer examination. Hence, the implementation of reliable indicators for automated detection is essential for future investigations.

Twitter Communication on Depressive Symptoms During the COVID-19 Pandemic

In the context of the current pandemic situation, social media has gained even more attention as a tool providing the opportunity to discuss diverse issues related to the SARS-CoV-2 virus and potentially relevant information for policy makers [21]. By analyzing the content of English language tweets and their number of likes from February to March 2020, Abd-Alrazaq and colleagues [21] drew conclusions on the scope and relative relevance of COVID-19–related topics. One major finding was that individuals most frequently liked tweets referring to economic loss. In addition, a few studies have examined the course of the development of COVID-19–related English tweets. For instance, Lwin et al [22] captured how feelings of fear decreased, whereas feelings of anger and sadness increased over time. Another analysis based on US tweets captured higher frequencies of stress, anxiety, and loneliness in the time period from March to May 2020 compared to the same period in 2019 [23]. Further results on the course of tweets, including tweets on depressive symptoms during the COVID-19 pandemic, are not yet available.

Population-Based Evidence on Depressive Symptoms During the COVID-19 Pandemic

Although research on the psychological burden of quarantine and the psychological burden for high-risk groups such as medical staff during other pandemic situations has already yielded important results [24], findings on the general population under social contact bans during a pandemic are relatively rare. The first results from the COVID-19 pandemic based on a comparison of nationally representative US data from March to April 2020 and from 2017 to 2018 suggested a more than threefold higher prevalence of depression symptoms in the 2020 study period [25]. A large cross-sectional survey including 7236 Chinese residents conducted during the COVID-19 pandemic in February 2020 also indicated a relatively high prevalence of depressive symptoms at 20.1% [26,27]. A recent cross-sectional online study of 15,704 German residents conducted in the period from March to May 2020 also found an increased proportion of depressive symptoms at 14.3% [28] (as opposed to 10.4% as indicated by national survey data a few years before [6]). However, another representative German health survey found no significant differences in overall depressive symptomatology in 2020 compared to that in 2019 but indicated differences in single symptoms and specific time frames [29]. Additionally, it must be considered that most research has been cross-sectional, and investigations on the temporal progression and interrelatedness of depressive symptoms with social distancing measures in response to COVID-19 infection rates are not yet well established. Only a few results seem to underpin the assumption that strict stay-at-home orders are associated with decreasing mental health. One example is a Spanish survey that showed how depressive symptoms immediately increased after the stay-at-home order in March 2020 [30]. Thus, it may be advantageous to differentiate between different time periods and different symptoms to generate additional knowledge on the potential consequences of the current pandemic situation for the general population.

This Study

Previous research has focused on the use of either cross-sectional surveys or social media data to investigate depressive symptoms. A systematic comparison of both data sources over time has not yet been performed. In this study, we aim to bridge this gap to gain knowledge on the prevalence of population-based depressive symptoms by examining the same standardized indicators but with different data sources. The central research questions are as follows: what is the developmental course of depressive symptoms in the general population before, during, and after the social contact ban decreed by the German government due to the COVID-19 pandemic and do tweets on depressive symptoms mirror population-based survey data?

Correspondingly, we aimed to, first, examine the temporal progression of depressive symptoms during the COVID-19 pandemic and, second, explore the consistency of the results between tweets and survey-based self-reports of depressive symptoms within the same time period. Based on these findings, we aimed to draw conclusions on how to interpret results from the two different data sources on the current mental health status of a certain society at a certain point in time and the comparability and validity of such results. These analyses focus on depressive symptoms during the beginning of the COVID-19 pandemic in Germany as observed through Twitter and national survey data. The results could facilitate the comprehensive and prompt understanding and monitoring of future variation in public mental health, with particular benefits for critical situations such as those during the COVID-19 pandemic.

Methods

Sample and Procedure

Survey

These analyses are based on two different samples. The first sample represents a subsample of 9011 survey participants (n=4783, 51.7% female; age groups: n=151, 4.5% 15-17 years; n=424, 8.4% 18-24 years; n=746, 13.7% 25-34 years; n=1616, 19.9% 35-49 years; and n=6074, 53.6% 50 years and older) drawn from a recently conducted German national health survey (GEDA/EHIS-19; April 2019 to August 2020; for further information, see Damerow et al [29]). The data collection period considered is calendar week 1 to calendar week 31 (January 1 to June 30) of 2020. During this period, the German government for the first time implemented social distancing measures to contain the spread of the SARS-CoV-2 virus (ban on major events on March 10, closing of borders on March 15, and ban on in-person contact on March 22). For a better understanding of the development of depressive symptoms during that time, we also examined a period of 11 weeks before and after the implementation of social distancing measures (the gradual reimplementation of the ban on contact started on May 2 with the reopening of hairdresser's, food services, etc). Keeping in mind that the transition between strict lockdown and relaxation was not suddenly all-embracing, we first aggregated the data on a weekly basis and then summarized and labelled the three periods *before* (calendar week 1-11), *during* (calendar week 12-18), and *after* (calendar week 19-31) the contact ban.

Twitter

The second sample is constituted of Twitter users. We collected tweets from Germany (N=95,201) via the public Twitter application programming interface (API) by querying tweets that contained terms indicative of depressive symptoms as formulated in the standardized Patient Health Questionnaire (PHQ-8; see the following section) [31]. We then applied the Symanto proprietary linguistic analysis model with the collected tweets to identify the tweets with self-references (ie, first-person pronouns and verbs), which would indicate that the mentioned depressive symptom was related to the user themselves [32,33]. This Twitter corpus corresponded to the period from January 1 to July 30, 2020. In the same way as the survey data, the Twitter data were first aggregated on a weekly basis and then summarized into the three periods *before*, *during*, and *after* the contact ban. Two items (*less appetite* and *problems concentrating*) needed to be excluded from further analyses due to the relatively low frequencies of related tweets (<12 a day). The item *moving or speaking slowly* was excluded because there were problems correctly identifying this item in the tweets. For the remaining five items from the PHQ-8, we had 88,900 tweets (n=74,620, 83.9% female; age groups: n=11,385, 12.8% 10-17 years; n=51,272, 57.7% 18-24 years; n=11,485, 12.9% 25-34 years; n=9408, 10.6% 35-49 years; and n=5350, 6% 50 years and older).

Based on previous suggestions for how to improve health-related Twitter-based research [4], we also took demographic characteristics (region of residence, age, and sex) of the Twitter users into account if applicable. The number of tweets that included regional references was 60,321. Since stratification by the 16 German federal districts led to small sample sizes and loss of statistical power, we used the participants' sex and age group as covariates for the regression modeling only. Descriptive statistics on the frequency of depressive symptoms grouped by sex, age group, and region can be obtained from Multimedia Appendix 1 (Tables S1 and S2).

The regional information was derived from publicly available location data on Twitter users. Twitter does not provide information on users' age and gender. Thus, we used Symanto proprietary text analytics models [34,35] that predict age and gender based on the content of users' tweets. These models were trained via deep learning technology [36] on millions of short texts by authors with known age and sex to identify distinct lexical and semantic patterns (eg, topics, word usage, and writing style) from each demographic group [37]. By applying the prediction models on the collected tweets, we inferred the age group and sex of the anonymous Twitter users to provide richer demographic information. The prediction models have been benchmarked against state-of-the-art models and have shown similar performance to public benchmarks for other languages, such as PAN'14 [38].

Measurement of Depressive Symptoms

Survey

We analyzed the same five items from the PHQ-8 [31] as in the lexical Twitter analysis (see description in following section). These items indicated the experience of diminished interest, depressed mood, insomnia or hypersomnia, fatigue or loss of energy, and feelings of worthlessness or inappropriate guilt. To make the results more comparable to the frequencies derived from Twitter data, the original responses to the PHQ-8 that were provided on a 4-point rating scale, ranging from *not at all* (0) to *nearly every day* (3), were dichotomized into *not at all affected* (0) and *affected* (1), thereby yielded (relative) frequencies averaged across participants.

Twitter

The terms used in the Twitter queries (previously mentioned) were curated to provide linguistic representations of the depressive symptoms in the Twitter analysis. The curation of this dictionary was based on a language processing methodology (see Figure 1 for an overview of the Twitter data collection process). We first manually produced a set of keywords (ie, seed words) by taking the items of the PHQ-8 as the basis. For instance, for the item that referred to depressed mood, three seed words were selected in this step: (1) "Niedergeschlagenheit" (dejection), (2) "Schwermut" (melancholy), and (3) "Hoffnungslosigkeit" (hopelessness). In the next step, to enrich the seed words, we extracted a corpus from a Reddit forum wherein the authors created and exchanged depression-related content in German [39]. This text corpus was then fed into the Symanto vocabulary refinement tool, which analyzes texts and represents each word with semantic dimensions using long short-term memory neural networks [40]. Using the seed words, this tool automatically identified words and phrases from the corpus that were semantically related to each of the seed words. For the item of depressed mood, for example, enrichment via the Reddit corpus revealed semantically related words to the three seed words, such as "aussichtslos" (hopeless), "ausweglos" (hopeless), "bedrückt" (depressed), "entmutigt" (discouraged), and "schlechte Stimmung" (bad mood). By doing so, we obtained an expanded vocabulary of depressive symptom keywords that were then used to collect the tweets. Having followed the tweet collection, we filtered out retweets so that only original tweets with the exact match of keywords (including hashtags and quoted tweets) would appear in the final data set. The final number of tweets among users varied between 1 and 10 tweets per week, with 96% (n=46,607) of the users accounting for 1 tweet only. Additionally, we applied syntactic rules to ensure that the keywords were mentioned in a self-reference manner. Example tweets that appeared in the final data set are provided in Textbox 1. Finally, we used the averaged frequency of daily tweets including depressive symptom keywords as a comparable measure to the (relative) frequencies derived from the survey.

Figure 1. Flowchart summarizing the Twitter data collection process.

Textbox 1. Example tweets from the final Twitter data set for each of the used Patient Health Questionnaire-8 items. Both the original German tweets and English translations are provided.

Diminished interest

- “Ich habe keine Lust mehr auf Praktikum? So viel Heteronormativität ertrage ich nicht.”
- “I don't feel like doing an internship anymore? I can't stand that much heteronormativity.”

Depressed mood

- “Es ist aussichtslos. Ich bin ins Mark erschüttert.”
- “It is hopeless. I am shaken to the core.”

Insomnia or hypersomnia

- “Sind das nur Einschlafprobleme, oder leide ich unter Insomnie?”
- “Are these just problems falling asleep, or do I suffer from insomnia?”

Fatigue or loss of energy

- “Ja schon...Ich fühle mich immer so energielos.”
- “Yes I do...I always feel so low on energy.”

Feelings of worthlessness

- “Du denkst du könntest mich verletzen? Bro ich bin die Enttäuschung der Familie.”
- “You think you could hurt me? Bro I am the disappointment of the family.”

Inappropriate guilt

- “Ich denke nur darüber nach, wie es gefunden werden würde, wie sich meine Schwester fühlte. Schon mit dem Vater weg und jetzt bin ich tot. Die Szene von mir tot. Ich kann es nicht ertragen zu sterben, weil ich weiß, dass sie traurig sind”
- “I just think about how it would be found, how my sister felt. Already gone with the father and now I'm dead. The scene of me dead. I can't bear to die because I know they are sad.”

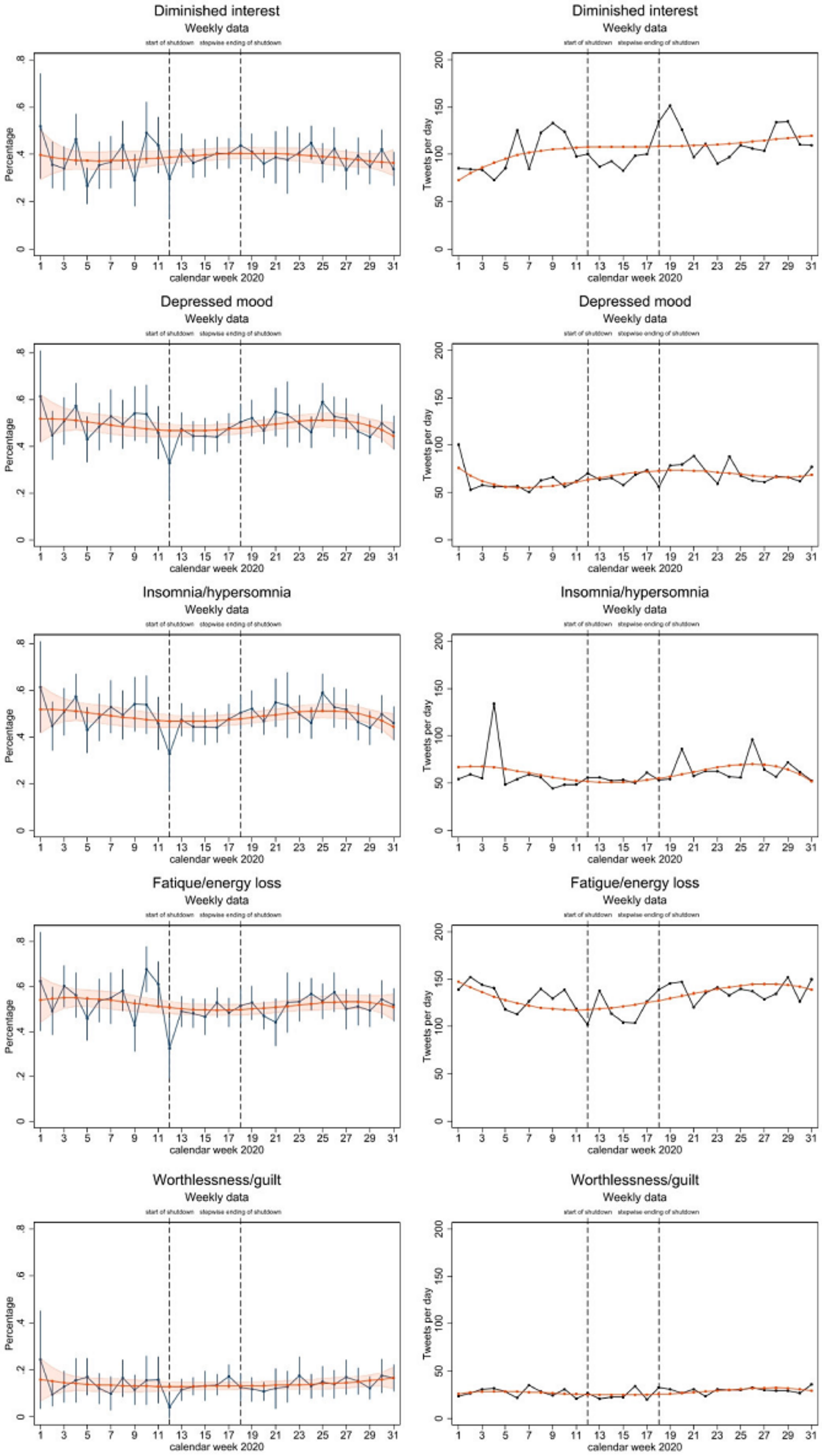
Ethical Approvement and Data Availability

The GEDA/EHIS survey was conducted in accordance with the data protection provisions set out in the Federal Data Protection Act, and the Ethics Committee of the Charité Universitätsmedizin Berlin approved the study (No. EA2/070/19). The procedures used in this study adhere to the tenets of the Declaration of Helsinki. Participants gave their informed written consent. The Twitter data used in this study was collected via the Twitter Public API, and the use follows the Twitter Developer terms. No sensitive data is derived or inferred from individual Twitter users. Geo-data is solely used in aggregated format. A scientific use file of the GEDA/EHIS survey data will be available on request from the Health Monitoring Research Data Centre at the Robert Koch Institute in Berlin, Germany (email: fdz@rki.de) after release by the statistical office of the European Union (Eurostat). The full list of keywords and further information on text analytics technology applied in this project will be available on request at Symanto Research GmbH & Co KG (e-mail: info@symanto.com).

Statistical Analyses

We first conducted five logistic regression models (one for each PHQ item, with the PHQ items as the outcome variables) to predict the weekly number of depressive symptoms. The participant’s age, sex, and age × sex interactions were entered as control variables (model 1). As there were some weekly fluctuations in the survey data, these time estimates were smoothed by integrating the time variable *calendar week* as a fourth-degree polynomial (model 2). Both models were plotted together in one graph (Figure 2). To analyze whether there was a change in the number of depressive symptoms during the period of the first German social contact ban (calendar weeks 12-18), a third model (model 3) included a categorical variable dividing the survey into three time periods: before the contact ban (calendar weeks 1-11), during the contact ban, and after the stepwise relaxation of the contact ban (calendar weeks 19-31). We tested whether there was a significant change in the contact ban variable during these three time periods using an adjusted Wald test. Additionally, we pairwise compared the margins *before*, *during*, and *after the contact ban*. Models 1 to 3 were calculated using survey procedures to account for the complex sampling and weighting to balance the potential bias in significant demographic variables of the German population structure (eg, socioeconomic status, municipality, and migration background; see Damerow et al [29] for further details).

Figure 2. Temporal progression of five depressive symptoms in the survey data (on the left) and Twitter data (on the right) from January to August 2020 (calendar weeks 1-31). The dark gray line represents the weekly averaged frequency, and the orange line represents the smoothed progressions by fourth-degree polynomial.



Following the same procedure used for the survey data, we aggregated the Twitter data on a weekly basis. Depressive symptoms were measured based on the number of tweets per day containing terms indicative of depressive symptoms, and we built a linear regression model (model 4) with age, sex, and age × sex interaction as the control variables. Again, these estimates were smoothed by integrating the calendar week in model 5 as a fourth-degree polynomial. In model 6, the influence of the contact ban was analyzed in the same way as in model 3.

Next, we investigated similarities in the time course of depressive symptoms between the Twitter and survey data. Due to the different scaling of frequencies in the Twitter data (absolute count) and survey data (binary variable indicating the presence or absence of symptoms for each survey respondent), and to the explorative character of these analyses, including possible violation of linearity, we calculated Spearman rank-order correlations for each of the five depressive symptoms. Correlations based on weekly aggregated smoothed margins are shown in Figure 2. The analyses were run with StataSE 15.1 (Stata Corp).

Results

Differences in Depressive Symptoms Before, During, and After the First Social Contact Ban

The differences in the frequencies of depressive symptoms among the three time periods largely followed the same pattern in the survey and Twitter data, as did the lower frequencies of insomnia and hypersomnia, fatigue and energy loss, and worthlessness and guilt, and the higher frequency of depressed mood during the contact ban than before and after the contact ban (Tables 1 and 2, Figure 2, and Table S3 in Multimedia Appendix 1). However, the differences among the time periods were significant only for fatigue and energy loss for both the survey and Twitter respondents and for worthlessness and guilt for the Twitter respondents. Whereas depressive symptoms after the contact ban were similar to those before the contact ban for the survey respondents, for several depressive symptoms, the frequency of symptoms after the contact ban was even higher than that before the ban for the Twitter respondents. Significant differences before and after the contact ban were found for diminished interest, depressed mood, and fatigue and energy loss (Tables 1 and 2, Table S3 in Multimedia Appendix 1, and Figure 2).

Table 1. Predictive margins of simple slopes resulting from regression analyses (model 3, survey data; model 6, Twitter data) for before, during, and after the contact ban.

Data	Diminished interest, margin (95% CI)	Depressed mood, margin (95% CI)	Insomnia/hypersomnia, margin (95% CI)	Fatigue/energy loss, margin (95% CI)	Worthlessness/guilt, margin (95% CI)
Survey data					
Before (18.1%)	0.38 (0.35-0.42)	0.27 (0.24-0.30)	0.50 (0.46-0.53)	0.54 (0.51-0.57)	0.14 (0.11-0.16)
During (24.1%)	0.40 (0.38-0.43)	0.28 (0.25-0.30)	0.47 (0.44-0.50)	0.50 (0.47-0.52)	0.13 (0.11-0.15)
After (57.8%)	0.38 (0.36-0.41)	0.27 (0.25-0.29)	0.49 (0.47-0.52)	0.52 (0.49-0.54)	0.14 (0.13-0.16)
Twitter data					
Before (33.7%)	99.4 (90.3-108.5)	60.5 (55.8-65.1)	60.6 (51.6-69.7)	129.0 (122.1-135.8)	27.7 (25.7-29.7)
During (21.0%)	99.6 (88.5-110.8)	65.1 (59.3-70.8)	54.2 (42.6-65.7)	115.7 (107.3-124.1)	23.9 (21.3-26.5)
After (45.3%)	115.0 (106.8-123.3)	71.2 (67.0-75.5)	64.3 (55.8-72.8)	141.7 (135.7-147.8)	30.3 (28.5-32.0)

Table 2. *P* values indicating the significance of the comparisons before, during, and after the contact ban resulting from the Wald test.

Data	Diminished interest, *P* value	Depressed mood, *P* value	Insomnia/hypersomnia, *P* value	Fatigue/energy loss, *P* value	Worthlessness/guilt, *P* value
Survey data					
Before vs during	.34	.90	.23	.04	.74
Before vs after	.94	.75	.80	.21	.75
During vs after	.29	.61	.25	.29	.44
Twitter data					
Before vs during	.97	.22	.39	*.02*[a]	*.02*
Before vs after	*.01*	*.001*	.56	*.006*	.06
During vs after	*.03*	.09	.17	*<.001*	*<.001*

[a] Italics indicate significant results at *P*<.05.

Differences in Depressive Symptoms by Sex and Age Group

Between January and August 2020, the frequency of depressive symptoms among the survey respondents varied from 13.9% (n=1011) for feelings of worthlessness or inappropriate guilt to 51.6% (n=4472) for fatigue or loss of energy. Additionally, across the tweets, feelings of worthlessness were the least frequent depressive symptom (n=5103, 5.7%), and fatigue or loss of energy was the most frequent (n=31,005, 34.9%; see Table S1 in Multimedia Appendix 1). In general, female respondents reported depressive symptoms more frequently than male respondents, as indicated by the significant sex comparisons and age × sex interactions in Table S3 in Multimedia Appendix 1. The same result was found with both the Twitter and survey data. When we also considered the age of respondents, we observed that young adult women (younger than 25 years) most frequently reported depressive symptoms according to both the survey and Twitter data. Although depressive symptoms did not significantly differ between sexes among middle-aged adults, the frequency of symptoms was higher in female survey respondents aged 50 years than in male survey respondents, except for feelings of worthlessness and guilt. Correspondingly, the overall comparisons between age groups showed that older survey respondents (50 years and older) more frequently reported depressed mood and insomnia and hypersomnia than respondents younger than 18 years and reported diminished interest and worthlessness and guilt less frequently than age groups younger than 35 years and fatigue and energy loss less frequently than age groups between 25 and 49 years (Table S3 in Multimedia Appendix 1). The Twitter data similarly showed a higher frequency of depressed mood in older adults (50 years and older) than in respondents younger than 18 years. Another similarity was that Twitter respondents 50 years and older reported diminished interest less frequently than those aged 18 to 24 years and reported fatigue and energy loss less frequently than those aged 25 to 34 years. Contrary to the survey respondents, older adult Twitter users (50 years and older) reported feelings of worthlessness and guilt more frequently than all other age groups.

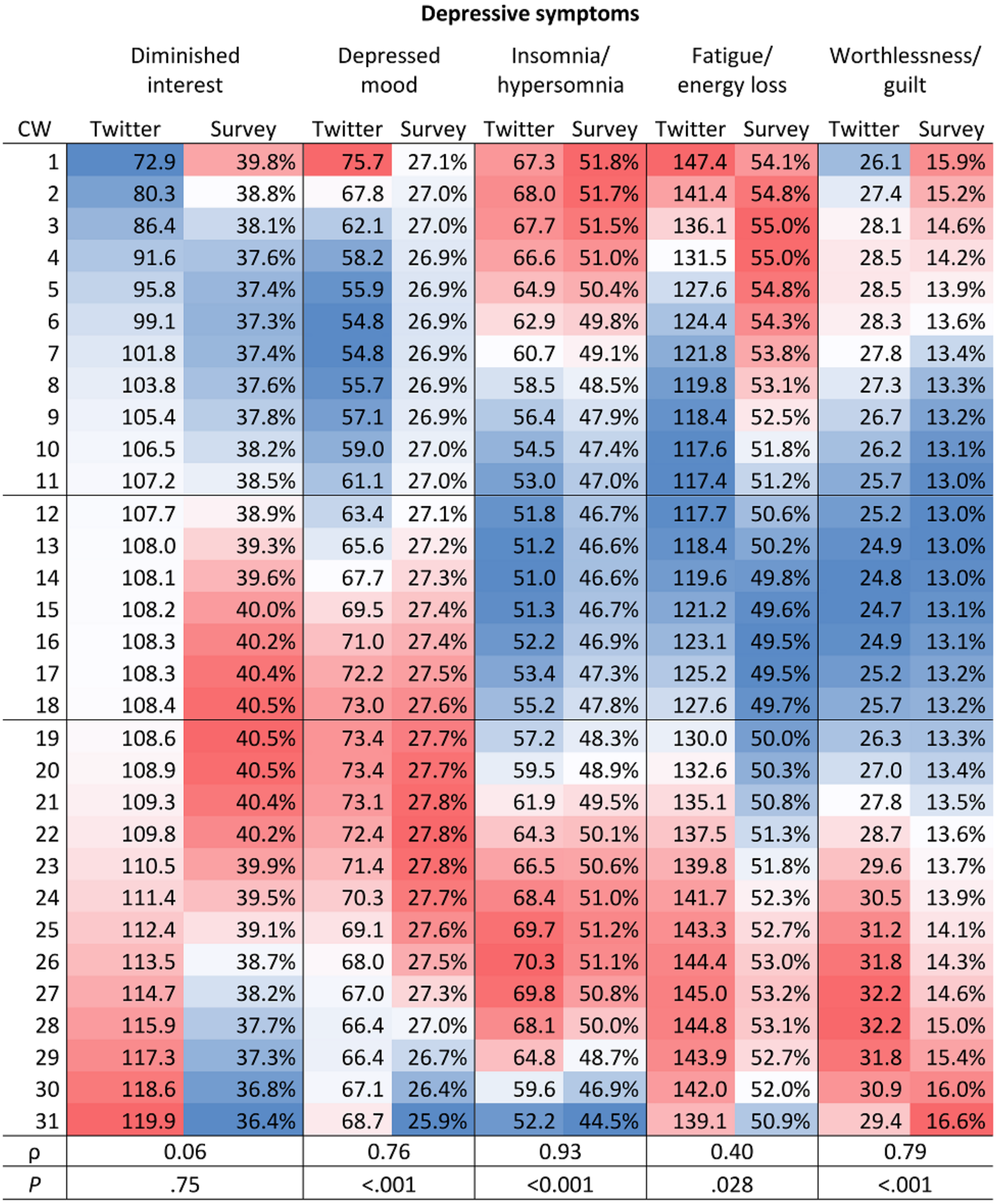
Additionally, the regional frequencies of depressive symptoms showed relatively good correspondence between the survey and Twitter data. The German districts of Nordrhein-Westfalen, Bayern, and some parts of Berlin had the highest number of overall depressive symptoms in the given time period. Notably, Nordrhein-Westfalen and Bayern also had the highest COVID-19 infection rates in Germany. The frequencies of depressive symptoms from the survey and Twitter data grouped by age group and sex as well as the regional frequencies grouped by the German federal districts can be obtained in Tables S1 and S2 in Multimedia Appendix 1.

Associations in Depressive Symptoms Between Survey and Twitter Data Over Time

Spearman rank-order correlations were calculated to assess the relationships between depressive symptoms based on the margins derived from smoothed curves over time (by calendar week) from the survey and Twitter data. The results showed moderate to strong positive correlations for depressed mood, insomnia and hyposomnia, fatigue and energy loss, and feelings of worthlessness and guilt (Figure 3). Diminished interest was not significantly correlated between the survey and Twitter data.

A closer look at the predictive margins of the weekly averaged and smoothed frequencies (model 4), as shown in Figures 2 and 3, indicated that the correspondence between depressive symptoms in the survey and Twitter data became even more evident when time shifts were taken into account. Whereas the courses of the symptoms of insomnia and hypersomnia and worthlessness and guilt were similar, reaching a minimum during the contact ban (as indicated by the blue color), depressed mood and fatigue and energy loss showed differences in temporal shifts in the Twitter and survey data. The frequencies of depressed mood and fatigue and energy loss in the Twitter data declined earlier before the contact ban and increased earlier during the contact ban than the frequencies of the same symptoms in the survey data.

Figure 3. Predictive margins of the smoothed curves of depressive symptoms in the Twitter and survey data by CW from January to August 2020 and the Spearman rank correlation results. Color shading: white represents the mean values, dark blue indicates the lowest values, and dark red indicates the highest values. CW: 1-11 "before," 12-18 "during," and 19-31 "after" the German social contact ban. CW: calendar week.



Depressive symptoms

	Diminished interest		Depressed mood		Insomnia/ hypersomnia		Fatigue/ energy loss		Worthlessness/ guilt	
CW	Twitter	Survey	Twitter	Survey	Twitter	Survey	Twitter	Survey	Twitter	Survey
1	72.9	39.8%	75.7	27.1%	67.3	51.8%	147.4	54.1%	26.1	15.9%
2	80.3	38.8%	67.8	27.0%	68.0	51.7%	141.4	54.8%	27.4	15.2%
3	86.4	38.1%	62.1	27.0%	67.7	51.5%	136.1	55.0%	28.1	14.6%
4	91.6	37.6%	58.2	26.9%	66.6	51.0%	131.5	55.0%	28.5	14.2%
5	95.8	37.4%	55.9	26.9%	64.9	50.4%	127.6	54.8%	28.5	13.9%
6	99.1	37.3%	54.8	26.9%	62.9	49.8%	124.4	54.3%	28.3	13.6%
7	101.8	37.4%	54.8	26.9%	60.7	49.1%	121.8	53.8%	27.8	13.4%
8	103.8	37.6%	55.7	26.9%	58.5	48.5%	119.8	53.1%	27.3	13.3%
9	105.4	37.8%	57.1	26.9%	56.4	47.9%	118.4	52.5%	26.7	13.2%
10	106.5	38.2%	59.0	27.0%	54.5	47.4%	117.6	51.8%	26.2	13.1%
11	107.2	38.5%	61.1	27.0%	53.0	47.0%	117.4	51.2%	25.7	13.0%
12	107.7	38.9%	63.4	27.1%	51.8	46.7%	117.7	50.6%	25.2	13.0%
13	108.0	39.3%	65.6	27.2%	51.2	46.6%	118.4	50.2%	24.9	13.0%
14	108.1	39.6%	67.7	27.3%	51.0	46.6%	119.6	49.8%	24.8	13.0%
15	108.2	40.0%	69.5	27.4%	51.3	46.7%	121.2	49.6%	24.7	13.1%
16	108.3	40.2%	71.0	27.4%	52.2	46.9%	123.1	49.5%	24.9	13.1%
17	108.3	40.4%	72.2	27.5%	53.4	47.3%	125.2	49.5%	25.2	13.2%
18	108.4	40.5%	73.0	27.6%	55.2	47.8%	127.6	49.7%	25.7	13.2%
19	108.6	40.5%	73.4	27.7%	57.2	48.3%	130.0	50.0%	26.3	13.3%
20	108.9	40.5%	73.4	27.7%	59.5	48.9%	132.6	50.3%	27.0	13.4%
21	109.3	40.4%	73.1	27.8%	61.9	49.5%	135.1	50.8%	27.8	13.5%
22	109.8	40.2%	72.4	27.8%	64.3	50.1%	137.5	51.3%	28.7	13.6%
23	110.5	39.9%	71.4	27.8%	66.5	50.6%	139.8	51.8%	29.6	13.7%
24	111.4	39.5%	70.3	27.7%	68.4	51.0%	141.7	52.3%	30.5	13.9%
25	112.4	39.1%	69.1	27.6%	69.7	51.2%	143.3	52.7%	31.2	14.1%
26	113.5	38.7%	68.0	27.5%	70.3	51.1%	144.4	53.0%	31.8	14.3%
27	114.7	38.2%	67.0	27.3%	69.8	50.8%	145.0	53.2%	32.2	14.6%
28	115.9	37.7%	66.4	27.0%	68.1	50.0%	144.8	53.1%	32.2	15.0%
29	117.3	37.3%	66.4	26.7%	64.8	48.7%	143.9	52.7%	31.8	15.4%
30	118.6	36.8%	67.1	26.4%	59.6	46.9%	142.0	52.0%	30.9	16.0%
31	119.9	36.4%	68.7	25.9%	52.2	44.5%	139.1	50.9%	29.4	16.6%
ρ	0.06		0.76		0.93		0.40		0.79	
P	.75		<.001		<0.001		.028		<.001	

Discussion

In this study, we investigated indications of depressive symptoms before, during, and after the first social contact ban decreed by the German government due to the COVID-19 pandemic using survey and Twitter data from January to July 2020. We moreover differentiated between the age group and sex of the survey and Twitter respondents.

Differences in Depressive Symptoms Before, During, and After the First Social Contact Ban

In contrast to previous indications of heightened depressive symptoms during the COVID-19 pandemic [25,27,28,30] and during lockdown periods [30], these findings reflect only a few significant differences in depressive symptoms before, during, and after the contact ban. In fact, the results indicate a temporary decrease in some depressive symptoms during the contact ban. The most distinct finding suggests that individuals had fewer problems related to fatigue and energy level during the contact ban than before or after the ban according to survey and Twitter data.

The explanations for the diverging results could be related to the fact that only a few previous studies have differentiated between diverse depressive symptoms or taken temporal fluctuations into account. Correspondingly, these findings are more in line with evidence on distinct mental health problems, showing a decrease in such problems immediately before the lockdown and the declaration of national emergencies in the United States (eg, fear [22]) and a steady increase thereafter (eg, stress and anger [22,23,40]). Similar temporal patterns of decreases and increases in depressive symptoms have been found in other challenging societal situations such as the global financial crisis in 2007 [41]. Within this context, a possible explanation for temporarily decreasing depressive symptoms over time was increased leisure time offering opportunities to foster social contact, pursue positive health behaviors (eg, a healthy diet and individual sports), or reduce work-related stress levels [42,43]. Moreover, emphases on collective experience and shared suffering as opposed to crises attributed to personal failure have been suggested as potential promoters of coping [41]. These assumptions are consistent with theories on coping with future stressful events (proactive coping [44]) and on expectancies of control [45]. The proactive coping approach postulates that coping in preparation for future stressors, for instance, to avoid or minimize negative effects, is associated with reduced stressor reactivity [46]; this approach is complemented by the idea that the controllability of a stressful situation can influence the efficacy of coping strategies and stress-related psychopathology [45]. In particular, an external locus of control (ie, a perception that something is outside of one’s personal power, such as in the hands of fate or the authorities) has been discussed as advantageous for coping success and mental health [47]. Thus, an anticipatory character and external locus of control combined with the collective experience of the actual pandemic crisis may have positively influenced depressive symptoms during the first German lockdown. The forced break and temporary release from several work- or social-related obligations may have been a relief and a chance to recover and gain energy for many people [43]. A few studies have shown positive behavioral adjustment during the COVID-19 pandemic in the general population, such as having a better diet [42], pursuing hobbies and interests, or spending more time outdoors [43].

Differences in Depressive Symptoms by Sex and Age Group

However, there seem to be population groups that are not consistent with the general results and need specific attention. Evidence from economic crises, for instance, showed a high risk of mental burden for particular groups such as middle-aged men looking for work but not for the general population [41]. As opposed to (solely) economic crises, during the COVID-19 pandemic, it is not middle-aged men but young adult women who seem to be at high risk for depressive symptoms. This pattern was consistently evident in both the survey and Twitter data, and agrees with previous findings in Germany and in other countries [28,30,48] independent of the pandemic situation. It has already been discussed that the generally enhanced risk of depressive symptoms in females and young adults may have been amplified in light of the pandemic situation [26,49] and thus requires public attention and further exploration.

Additionally, the survey and Twitter data were consistent regarding the average relative frequency of depressive symptoms across the German federal districts. The two districts showing the comparatively highest numbers of depressive symptom reports were also those with the highest COVID-19 infection rates during the investigation period. Thus, one may conclude that Twitter data can reflect the cumulative occurrence of depressive symptoms within the general population based on demographic characteristics such as sex and regionality.

Associations in Depressive Symptoms Between Survey and Twitter Data Over Time

A closer inspection of the temporal progression based on weekly averaged depressive symptoms from January to July 2020 emphasized similarities between the two investigated data sources. The correlations between the Twitter and survey data were moderate to high for depressed mood, insomnia and hypersomnia, fatigue and energy loss, and worthlessness and guilt. Interestingly, the results also suggest differences in reactions to the social contact ban, with the Twitter respondents seeming to react earlier than the survey respondents in terms of depressed mood and fatigue and energy loss. This observation may lead to the conclusion that Twitter users proactively react to the given circumstances; however, the reasons for temporal shifts are not yet well understood and require further investigation.

Despite the aforementioned similarities, there were also some differences between the survey and Twitter data that require further attention. Exceptions to the decreasing trend after the initiation of the lockdown period were found for the symptoms of depressed mood and diminished interest, which remained relatively constant in the survey respondents and continuously increased in the Twitter respondents, even after the relaxation of the social contact ban. This finding can be interpreted to indicate either that Twitter is an attractive tool for people experiencing depressed mood and diminished interest or that individuals are more willing to disclose information of that kind on Twitter than in a survey. The finding that the number of reports of depressive symptoms was estimated to be approximately 8% higher [20] in tweets than in responses to a national health survey conducted in 2019 [6] (18.2% vs 10.4%) supports the first assumption. On the other hand, motivations to tweet and to participate in a survey likely differ, but the evidence is inconclusive so far. Although there is evidence suggesting a disproportionate use of social media by individuals with mental problems or real-life relationship problems to overcome feelings of social isolation [11,50], other investigations have indicated a rather balanced use of social media in the general population compared to that in mentally ill individuals [51,52] and a lack of a relationship between social media use and (mental) health status [51,52]. Some findings even suggest a less active use of Twitter in individuals with diagnosed depression as compared to a nondepressed control group [17]. Within the context of the COVID-19 pandemic, the newly available leisure time during the social contact ban and the reduction of face-to-face contact may also have contributed to the higher use of Twitter as a medium to share thoughts and feelings. Previous results pointed toward the potential of social media to overcome loneliness and social isolation particularly in older adults [53] and have been discussed in terms of the pandemic situation [54]. Frequent social media use, however, was found to be associated with negative mental health status among Chinese citizens during the COVID-19 pandemic [55]. Further evidence is needed to get a clearer picture of the positive and negative effects of social media use and effects during the COVID-19 pandemic.

Limitations

Apart from the potential benefit of Twitter as a tool to reflect public mental health conditions, there are some limitations of this study that have to be considered. First, although the proportion of Twitter users in the general population is constantly rising, we cannot rule out sampling and access bias. This study showed a disproportionate number of tweets across different population groups, reflecting an imbalance compared with other user statistics [56,57]. Consequently, the comparability of the survey and Twitter samples was limited. Second, the frequency of reported depressive symptoms cannot be interpreted as epidemiological prevalence rates because of the different coding and analysis approaches that were used in this study to enhance comparability. In addition, a general limitation of the study is related to the fact that depressive symptoms can be subject to seasonal variation [58], and this influence cannot be ruled out with this data. Accordingly, there is evidence suggesting that temporal, spatial, or geographical characteristics (eg, local weather or location-specific health characteristics) and other personal characteristics (eg, personality) can influence the content and sentiment of tweets [59-61]. Although this study considered the Twitter user's location if applicable (ie, users revealed their living area) and the results indicate that depressive symptoms vary by local infection rates, the information is vague and further effort is needed to take other relevant and reliable characteristics into account. Furthermore, the lockdown may have affected the responsibilities of not only the Twitter users but also the survey respondents (eg, due to increased leisure time and better accessibility), which cannot be yet estimated.

Conclusions

Overall, these results indicate rather small differences in depressive symptoms associated with social distancing measures during the COVID-19 pandemic and highlight the need to differentiate between positive (eg, energy level) and negative (eg, depressed mood) associations and variations over time. The inclusion of individual characteristics such as the age and sex of both survey and Twitter respondents helped to add new insight into the distribution of depressive symptom indications. As a result, we found exceptions with young adult women, who represented a high-risk group for depressive symptoms, and individuals living in federal districts with high infection rates.

These findings also underscore previous suggestions of the potential of Twitter data to help identify hot spots of declining and improving public mental health and to thereby help provide early intervention measures [23]. We were able to add knowledge to the consistency of findings based on two different data sources and its potential for public mental health monitoring. More precisely, we found considerable overlap between the Twitter and survey data, which offer notable entry points for monitoring public mental health, especially for young and middle-aged adults, but further investigation is also required. For instance, some of the key symptoms of depression (eg, energy loss) seemed to be relatively reliably detected in Twitter data, and these Twitter data showed high similarity with the corresponding survey data. Moreover, the temporal progression of depressive symptoms showed relatively high correspondence between the two data sources, providing notable indications of general trends in public mental health states for the time periods before, during, and after the social contact ban. The correspondence of these findings indicate how learning algorithms predicting socioeconomic characteristics and mental health states can continue to grow and help create opportunities to enhance information content and expand research applicability.

However, these results also highlight the need to consider limitations and challenges, and perform further validation to establish real-time public mental surveillance approaches [62]. For example, conclusions based on Twitter data will be limited since researchers are blind to several potentially confounding characteristics in Twitter data (eg, the basic population size). More differentiated analyses may allow more reliable approximation of Twitter user proportions and of mental health–related topics, for instance, by putting further emphasis on metadata like retweets, hashtags, or the number of followers [63]. Considering the sentiment of tweets may also contribute to a better approximation of the actual experience of mentioned depressive symptoms in users [17]. In sum, future investigations need to clarify the role of possible explanatory factors for differences between Twitter and survey data sources, such as the motivation or willingness to share and communicate sensitive mental health information in different contexts and the ability of individuals to remember and reflect such information. For instance, although depressed mood may be easy to communicate, feelings of worthlessness or guilt may not be.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary materials.
[DOCX File , 28 KB - mental_v8i6e27140_app1.docx]

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Abbreviations

API: application programming interface
PHQ-8: patient health questionnaire

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Original Paper

Psychological Crisis Intervention for COVID-19 Lockdown Stress in Patients With Type 1 Diabetes Mellitus: Survey Study and Qualitative Analysis

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Abstract

Background: The COVID-19 pandemic has challenged the worldviews of most people. Social isolation after the COVID-19 lockdown has not only led to economic difficulties but also resulted in adverse psychological reactions. As in most countries, including Poland, this situation has been very challenging for patients with type 1 diabetes mellitus (T1DM). In Poland, a crisis intervention team for patients with T1DM was established. The goal of the team was to provide psychological support for these patients, if needed, and to present information concerning how these patients may obtain medical consultations and prescriptions.

Objective: We aimed to analyze the psychological parameters and main emotional reactions of patients with T1DM during the COVID-19 lockdown.

Methods: An email with information concerning the possibility of having a web-based consultation with psychologists and psychiatrists and an attached set of psychological tests was sent to all patients with T1DM who were under the care of an outpatient diabetes clinic. The consultations were performed by licensed clinical psychologists and psychologists. This study was approved by the Bioethics Committee of the Jagiellonian University in Krakow, Poland.

Results: The patients who decided to use psychological support had statistically higher levels of anxiety (state P=.043; trait P=.022), stress (P=.001) than those of patients from the group who did not seek support.

Conclusions: The presented intervention team may be perceived as an example of important and successful cooperation and communication between specialists of different fields of medicine (diabetology, psychiatry, and psychology) in a crisis situation.

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KEYWORDS

COVID-19; pandemic; type 1 diabetes mellitus; crisis psychological intervention; anxiety; stress; psychosomatics; diabetes; type 1; psychology; crisis situation; intervention

Introduction

Background

The COVID-19 pandemic, with its subsequent mental health consequences, has challenged the worldviews of most people. Social isolation after the COVID-19 lockdown has not only led to economic difficulties but also resulted in adverse psychological reactions. People's most common reactions when faced with such life-threatening circumstances are stress, anxiety, and depression [1]. People with diabetes and other comorbid conditions, such as asthma, heart failure, raised serum creatinine levels, and an age of >65 years, have turned out to be at higher risk of SARS-CoV-2 infection complications and the emotional burden related to such complications [2].

Regardless of the potential spread of COVID-19, as with influenza-related mortality, diabetes is an important risk factor for adverse outcomes [3]. With the medical focus being largely centered on COVID-19, the clinical support needed by patients living with noncommunicable diseases, including type 1 diabetes mellitus (T1DM), has been severely affected. Treatment delays, the discontinuation of routine care, a lack of services, and the uncertainty surrounding medicine availability have left these patients more at risk than ever before. A survey of 155 countries by the World Health Organization reported the dramatic curtailment of health services for patients living with noncommunicable diseases during the COVID-19 pandemic. It was reported that diabetes treatment has been partially or completely disrupted in 49% of the countries surveyed [4]. Glycemic control is important for any patient with COVID-19. Although there is limited data about the association between blood glucose levels and the disease course of COVID-19 at present, data regarding other infections, such as SARS (severe acute respiratory syndrome) and influenza H1N1 infection, have shown that patients with poor glycemic control have an increased risk of complications and death [5-7]. In many countries. organizing proper care for people with T1DM in a pandemic situation became a pressing issue [8]. In the United Kingdom, the National Diabetes Inpatient COVID Response Group was formed at the end of March 2020 to support the provision of diabetes inpatient care during the COVID-19 pandemic. It was formed in response to two emerging needs. The first was to ensure that basic diabetes services were secured and maintained at a time when there was a call for redeployment to support the need for general medical expertise across secondary care services. The second was to provide simple, safe diabetes guidelines for use by specialists and nonspecialists treating inpatients with confirmed or suspected SARS-CoV-2 infection [9]. As in most countries, including Poland, the COVID-19 pandemic has been very challenging for patients with T1DM, especially during the first 2 months of the pandemic lockdown. In the Malopolska region, around 600 patients with T1DM found themselves in a difficult situation due to the transformation of the University Hospital in Krakow into an infectious diseases center for patients with COVID-19. Thus, some diabetologists who were working on a regular basis in the Outpatient Diabetology Clinic have been transferred to work with patients with COVID-19 and cut off from their patients with T1DM. In Poland, a crisis intervention team for patients with T1DM was established. The goal of the team was to provide psychological support for these patients, if needed, and to present information concerning how these patients may obtain medical consultations and prescriptions.

Aim of This Study

This study presents data from telephone consultations that were carried out by the crisis intervention team between April 14 and May 11, 2020, and subsequent interventions.

Methods

Study Design

An email with information concerning the possibility of having a web-based (email, Skype, or telephone) consultation with psychologists and psychiatrists and an attached set of psychological tests was sent to 473 patients with T1DM who were under the care of an outpatient diabetes clinic. Of all the individuals who received the email, 50 patients filled in the set of questionnaires and reported their mental condition, and 34 patients did not need psychological support. However, by means of email or telephone contact, these 34 patients asked questions concerning medical issues (eg, how they may contact their diabetologist, how they may obtain prescriptions for insulin, etc), and they were given proper information. In total, 20 patients decided to attend telephone-based psychological consultations. There were 24 consultations conducted from April 14 to May 11, 2020. The average consultation time was 45 minutes; the shortest consultation lasted 20 minutes, and the longest consultation lasted 1.5 hours.

The crisis intervention team included the following: 2 psychiatrists (one was a professor in psychiatry and the head of the Department of Psychiatry, and the other one was also a psychotherapist), 2 clinical psychologists (one with a specialization in psychosomatics and one with a specialization in adult psychopathology; the latter was also a certificated psychotherapist), 1 certificated supervisor of psychotherapy, and 1 professor and regional consultant in diabetology

This study was approved by the Bioethics Committee of the Jagiellonian University in Krakow, Poland, on January 4, 2020 (approval number: 1072.6120.78.2020).

The set of psychological tools included the following:

1. The Coping Inventory for Stressful Situations (CISS)—a 4-factor model of humans coping with adversity developed by Endler et al [10]. Their construct differentiates the following three types of coping: task-oriented coping, emotion-oriented coping, and avoidant-oriented coping.
2. The State-Trait Anxiety Inventory (STAI) by Spielberger et al [11]—a commonly used measure of trait and state anxiety.
3. The Perceived Stress Scale-10 (PSS-10) designed by Cohen et al [12]—the most widely used psychological instrument for measuring the perception of stress.
4. The General Health Questionnaire-30 (GHQ-30)—a screening tool for identifying minor psychiatric disorders in the general population and within community or nonpsychiatric clinical settings, such as primary care settings or general medical outpatient care settings. It assesses a respondent's current state and asks if that state differs from their usual state [13].

Studied Group

In total, 20 persons—7 men and 13 women—contacted a psychologist. All the consulted persons were patients of the University Hospital in Krakow undergoing insulin pump T1DM treatment.

During the first period of lockdown, 1 person needed 3 consultations (1 woman), 2 people had 2 consultations, and 17 people had single consultations. The average age of the consulted persons was 25 years. Further, 6 patients who asked for a crisis consultation were currently undergoing or had previously undergone psychotherapy.

The data on the underlying psychiatric diagnoses at the time of this study were not complete; 2 patients indicated having depression, 3 said that they had anxiety disorder, and 1 admitted having eating disorder. As a result of the consultations, of the 20 patients consulted, 7 were diagnosed with anxiety disorder (chapter F4 of the International Classification of Diseases, Tenth Revision [ICD-10]) and depression (chapter F3 of the ICD-10), 5 were diagnosed with personality disorder (chapter F6 of the ICD-10), and 2 were diagnosed with eating disorder (chapter F5 of the ICD-10). The diagnoses were based on the ICD-10. Additionally, in 11 patients, adjustment disorder was diagnosed and directly connected to the pandemic situation as a comorbid or main diagnosis. At the consultation stage, the patients claimed that their basic need was to discuss their situations with a psychologist. However, during the later stages of the diagnostic process, 7 patients were referred to psychiatrists for consultation and 5 patients were offered pharmacotherapy. There was no additional survey conducted at the end of this study, but all patients who required further diagnostic procedures and treatment were provided with these benefits.

Data Availability

The data that support the findings of this study are available from the corresponding author, KC, upon reasonable request.

Results

Consultation Topics

The main problems that were discussed with the patients with T1DM during telephone intervention during the pandemic lockdown are categorized and presented in Textbox 1.

Of the 20 patients who attended the telephone consultations, 10 submitted their set of questionnaires, and the rest decided to stay anonymous or refused to fill in the questionnaires for various reason.

We decided to carry out statistical analyses for the group of 10 patients who submitted their questionnaires, bearing in mind that they only made up half of the group that underwent psychological intervention, and we compared their results to the results of patients with T1DM who did not need intervention but also filled in the questionnaire screening tools during the pandemic lockdown.

Statistical analyses were carried out using the IBM SPSS Statistics 25 package (IBM Corporation). *U* Mann-Whitney tests were performed. The classical threshold α value of .05 was used as the level of significance.

Textbox 1. Main topics issued by the patients during crisis intervention and their descriptions.

Fear of SARS-CoV-2 infection

- The patients reported high levels of anxiety.
- Worried that they may become infected with SARS-CoV-2 and that they may die or experience complications of diabetes after being infected, 5 patients described nightmares related to the COVID-19 pandemic.

Feeling depressed

- After a few weeks of lockdown, 13/20 (65%) of the patients who asked for a consultation reported a feeling of sadness, a lack of energy, depressiveness, and a feeling of helplessness.
- Some patients indicated that they were sad because they lost control over their diabetes as a result of an emotional crisis and lockdown-related changes in their daily routine.

Fear of insufficient medical care

- In total, 19/20 (95%) of the patients admitted that they experienced some level of stress, sadness, or anger because of limited access to the attending physician, especially patients who had their planned visits postponed or cancelled.

The fear that the attending physician will get hurt or that he will become sick with COVID-19

- As some of the patients had information regarding their attending physician being transferred to work with patients with COVID-19, they expressed fears that he may become infected and that he may not come back to his previous work.
- In total, 3/20 (15%) patients were angry that the hospital “preferred” patients with COVID-19 and took their diabetologist away.
- In total, 4/20 (20%) patients hoped that by conducting the crisis telephone calls, they would be able to send supporting words to their doctors. The patients wished their doctors strength and all the best, which reflected good patient-diabetologist relations and the patients’ positive attitudes toward their diabetologists.

Disorganization of everyday functioning

- In total, 16/20 (80%) of the patients who used the telephone interventions admitted to having serious problems with their daily functioning, which intensively affected their type 1 diabetes mellitus control. The dysfunctions included diet modifications, problems with regularly exercising, and financial and work difficulties that resulted in changes in work routine and lowered income (a few patients feared that they would not be able to use an insulin pump because of the loss of work).

The fear that insulin will not be available

- In total, 3/20 (15%) of the patients had a strong fear that insulin would not be available and that they would die as a result. After longer conversations, it turned out that the three patients had family trauma concerning Siberia or Auschwitz experiences, which could be interpreted as transmitted family war experiences related to a high level of fear concerning a lack of supplies.

Family conflicts due to being together for a long time

- In total, 14/20 (70%) of the consulted patients reported some family tensions or conflicts related to the need to spent a lot of time together in an unexpected lockdown situation.
- The patients connected their stress with worse glycemic control.

Need to describe how the patient is coping with an epidemic (to gain reinforcement)

- In total, 5 patients decided to attend the consultations to make sure that they were coping well and to describe how they cope with everyday lockdown challenges concerning type 1 diabetes mellitus and how they support other patients with the disease. They also searched for reinforcement and the possibility of not being alone during their everyday challenges.

Worsening of previously present symptoms of mental disorders

- In total, 5 of the consulted patients turned out to have comorbidities to a type 1 diabetes mellitus psychiatric diagnosis. Further, they previously underwent psychological or psychiatric treatment. Some of them had limited access to their therapist and felt the need to discuss their current state. Others were still in contact with their therapist, but they felt that they needed additional crisis consultations.
- All patients who needed further psychotherapy or psychiatric consultations were taken care of, and such help was provided.

Level of Anxiety in the Examined Groups Measured With the STAI

In the first step, we checked whether the levels of state and trait anxiety varied between the studied groups. As shown in Table 1, there were statistically significant differences in terms of both these variables. A higher level of anxiety was recorded for the group of patients who asked for psychological intervention. The strength of the observed effects was moderately high (Table 1).

Table 1. Level of anxiety in the examined groups.

Anxiety type	Scores of patients with T1DM[a] who asked for psychological intervention (n=10), mean (SD)	Scores of patients with T1DM who did not ask for psychological intervention (n=39), mean (SD)	*U*	Z	*P* value	*r*
State anxiety	47.80 (11.29)	40.08 (9.36)	113.5	−2.02	.04	0.29
Trait anxiety	47.20 (8.09)	40.46 (8.09)	102.5	−2.30	.02	0.33

[a] T1DM: type 1 diabetes mellitus.

Level of Stress in the Examined Groups Measured With the PSS-10

In the second step, we checked whether the levels of experienced stress were different between the studied groups. As shown in Table 2, a statistically significant difference was noted. A higher level of stress was recorded for the group of patients who needed crisis intervention. The strength of the observed effect was high (Table 2).

Table 2. Level of stress in the examined groups.

Type of stress	Scores of patients with T1DM[a] who asked for psychological intervention (n=10), mean (SD)	Scores of patients with T1DM who did not ask for psychological intervention (n=39), mean (SD)	*U*	Z	*P* value	*r*
Level of perceived stress	23.60 (5.42)	15.44 (6.30)	62.0	−3.30	.001	0.47

[a] T1DM: type 1 diabetes mellitus.

Styles of Coping With Stress in the Examined Groups Measured With the CISS

Table 3 shows that there was 1 statistically significant difference in coping strategies between the patients with T1DM who asked for intervention and those who did not. In the intervention group, a higher emotion-focused coping style level was noted. The differences in task-oriented coping style (*P*=.27), avoidant-oriented coping style (*P*=.35), distraction seeking (*P*=.42), and social diversion (*P*=.053) levels between the 2 groups were not statistically significant.

Table 3. Styles of coping with stress in the examined groups.

Style	Scores of patients with T1DM[a] who asked for psychological intervention (n=10), mean (SD)	Scores of patients with T1DM who did not ask for psychological intervention (n=39), mean (SD)	*U*	Z	*P* value	*r*
Task-oriented style	53.40 (10.34)	56.67 (9.08)	150.5	−1.11	.27	0.16
Emotion-oriented style	49.30 (6.86)	38.23 (10.51)	60.0	−3.36	.001	0.48
Avoidant-oriented style	40.00 (5.87)	42.54 (8.64)	157.0	−0.94	.35	0.13
Distraction seeking	18.30 (3.83)	17.56 (5.68)	162.5	−0.81	.42	0.12
Social diversion	13.90 (4.12)	16.92 (3.92)	117.5	−1.93	.053	0.28

[a] T1DM: type 1 diabetes mellitus.

General Mental Health Condition Measured With the GHQ-30

Finally, we checked whether the level of general mental health, which was measured as both a condition and a feature of the examined patients, varied between the studied groups. As can be seen in Table 4, there were statistically significant differences in all three analyzed variables. Higher scale scores were noted for the group that needed crisis intervention. The strength of the observed effects was very large for the anxiety and depression scale scores and large for the other two variables (Table 4).

Table 4. General mental health in the examined groups.

Mental health variables	Scores of patients with T1DM[a] who asked for psychological intervention (n=10), mean (SD)	Scores of patients with T1DM who did not ask for psychological intervention (n=39), mean (SD)	*U*	Z	*P* value	*r*
Fear and depression	2.58 (0.30)	1.85 (0.41)	20.0	−4.36	<.001	0.62
Interpersonal relations	2.38 (0.41)	1.97 (0.39)	97.0	−2.51	.01	0.36
General functioning	2.76 (0.53)	2.30 (0.25)	87.0	−2.73	.006	0.39

[a] T1DM: type 1 diabetes mellitus.

Discussion

Principal Findings

A wide array of evidence—ranging from epidemiological evidence to animal model evidence—points toward the role of psychological stressors in T1DM pathogenesis. Various mechanisms have been proposed, including the hypothalamic-pituitary-adrenal axis, the influence of the nervous system on immune cells, and insulin resistance [14]. Studies have also indicated that general psychological stress plays a role in the glycemic control of individuals with T1DM [15]. A study of 1396 people with diabetes by Joensen et al [16] showed that worries related to the COVID-19 pandemic are highly prevalent. The participants were most frequently worried about "being overly affected due to diabetes if infected with COVID-19" (56%), were worried that "people with diabetes are characterized as a risk group" (39%), and were worried about "not being able to manage diabetes if infected with COVID-19" (28%). Further, 25% of the participants experienced diabetes distress at the beginning of the COVID-19 pandemic [16]. With regard to young people and adolescents, stress and social isolation may affect brain health and development. A UK survey that was conducted during the COVID‐19 pandemic found that 83% (1752/2111) of young people with a history of mental health needs felt that their mental health was worse. Further, one-quarter of participants (5/20, 25%) were no longer able to access their usual mental health support [17].

The 2020 pandemic lockdown situation has turned out to be a globally recognized stressor, especially for people with chronic diseases. For individuals with T1DM, this situation has resulted in a multifaceted threat related to their limited access to their attending physician, changes in the everyday organization of life, a sense of threat related to the possibility of being infected and experiencing complications, and many other detriments. Health care providers face the new challenges of providing optimal medical and psychological care for this group of patients and taking into account the difficulties related to the epidemiological situation. University Hospital in Krakow took up this challenge through the collaboration between the Department and Clinic of Metabolic Diseases and the Department of Psychiatry and created a crisis intervention team for patients with T1DM that was available 24 hours per day during the first stage of the lockdown. The patients who decided to engage with this psychological support team reported a set of specific emotional problems and difficulties that, in their opinion, had a major impact on their glycemic control during this period. The patients presented a wide range of problematic issues concerning various aspects of their lives; however, all of these issues were related to their diabetes control. The possibility of using psychological support was a form of intervention that did not replace diabetological consultation but helped the patients deal with the stressful situation and thus release their tension and improve their feelings of control over the disease. Additionally, the consultations were a source of information on how to obtain medical support, if needed. In the group of patients who decided to use psychological support, 10 persons filled in a set of questionnaires that assessed their mental condition. Their test results indicated high levels of stress, anxiety, and general mental psychopathology in comparison to the patients with T1DM who did not ask for psychological support during the lockdown. Further, it was found that this group of patients was less task oriented and that they reacted very emotionally to the stressful COVID-19 pandemic situation.

Although this study made important observations, it also has some limitations. As the crisis intervention team was designed under the specific conditions of the first stage of pandemic, the main aim was to provide support to the patients as soon as possible. Thus, we did not collect sociodemographic data from all of the patients. Additionally, some of the patients who wanted consultations for their situations did not send their set of questionnaires, as they wished to keep their anonymity. Therefore, we could not analyze the questionnaire results of the whole intervention group. Given these conditions, we also did not focus on analyzing the correlation between the metabolic parameters of the patients and their mental health test results. As the work of the crisis intervention team has continued, we were able to include data on the diagnostic process.

Although the results cannot be generalized due to the small sample, they may suggest that there is a group of patients with T1DM who need regular, special psychological attention due to psychological conditions, which may influence their glycemic control. Apart from their reactions to stress, some patients turned out to have comorbid personality disorder or eating disorder. These disorders develop over time, with some developing from early childhood. Thus, we assumed that these disorders were present before the pandemic lockdown and that this stressful situation was, for some patients, a moment of decompensation. This observation requires further analysis and attention.

Conclusion

The presented intervention team may be perceived as an example of important and successful cooperation and communication between specialists of different fields of medicine (diabetology, psychiatry, and psychology) in a crisis situation. Although consultations were conducted for a small group of patients, the content of the consultations indicated the legitimacy of and the need for such cooperation on a regular basis, as the mental health of patients with T1DM and their stress management are two of the essential factors in achieving glycemic control.

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Authors' Contributions

KC and TK conceptualized this study. KC, BM, TK, and DD were responsible for the methodology. KC, BM, and TK conducted the formal analysis. KC and TK conducted the investigation. KC prepared and wrote the original draft of the manuscript. TK, DD, MTM, and BM reviewed and edited the manuscript. TK, DD, and MTM supervised this study. All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

CISS: Coping Inventory for Stressful Situations
GHQ-30: General Health Questionnaire-30
ICD-10: International Classification of Diseases, Tenth Revision
PSS-10: Perceived Stress Scale-10
SARS: severe acute respiratory syndrome

STAI: State-Trait Anxiety Inventory
T1DM: type 1 diabetes mellitus

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