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Original Paper

Design Considerations for the Integrated Delivery of Cognitive Behavioral Therapy for Depression: User-Centered Design Study

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Abstract

Background: Adherence to computerized cognitive behavioral therapy (cCBT) programs in real-world settings can be poor, and in the absence of therapist support, effects are modest and short term. Moreover, because cCBT systems tend toward limited support and thus low-intensity treatment, they are typically most appropriate for people experiencing mild to moderate mental health difficulties. Blended therapy, that is, combining direct therapist contact with cCBT or psychoeducational materials, has been identified as one possible approach to address these limitations and widen access to individual CBT for depression. Building on the initial success of blended therapy, we explore an integrated approach that seeks to seamlessly combine face-to-face contact, electronic contact, and between-session activities. Integration also considers how the technology can support therapists' workflow and integrate with broader health care systems. The ultimate aim is to provide a structure within which therapists can deliver high-intensity treatments, while also greatly reducing face-to-face contact.

Objective: The research aimed to explore patients' and therapists' views on using a system for the delivery of individual treatment for depression that integrates face-to-face therapist contact with access to online resources and with synchronous online therapy sessions that allow collaborative exercises, and to establish design requirements and thus key design considerations for integrated systems that more seamlessly combine different modes of communication.

Methods: We conducted a series of four user-centered design studies. This included four design workshops and seven prototype testing sessions with 18 people who had received CBT for depression in the past, and 11 qualitative interviews and three role-play sessions with 12 CBT therapists experienced in the treatment of depression. Studies took place between July and December 2017 in Bristol, United Kingdom.

Results: Workshops and prototyping sessions with people who had received CBT identified three important requirements for integrated platforms delivering CBT therapy for depression as follows: (1) features that help to overcome depression-related barriers, (2) features that support engagement, and (3) features that reinforce learning and support the development of new skills. Research with therapists highlighted the importance of the therapist and client working together, the impact of technology on therapists' workflow and workload, challenges and opportunities related to the use of online resources, and the potential of

technology to support patient engagement. We use these findings to inform 12 design considerations for developing integrated therapy systems.

Conclusions: To meet clients' and therapists' needs, integrated systems need to help retain the personal connection, support both therapist- and patient-led activities, and provide access to materials and the ability to monitor progress. However, developers of such systems should be mindful of their capacity to disrupt current work practices and increase therapists' workload. Future research should evaluate the impact of integrated systems on patients and therapists in a real-world context.

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KEYWORDS

cognitive behavioral therapy; depression; mental health; blended therapy; integrated therapy; user-centered design; qualitative research

Introduction

Background

Cognitive behavioral therapy (CBT) is an effective treatment for depression [1]. To make it more accessible and widely available at a lower cost, computerized CBT (cCBT) interventions have been developed. They allow patients to complete a set of modules in their own time, giving them control over their own therapy (eg, MoodGYM [2] and SilverCloud [3]). Some cCBT packages have been endorsed by the National Institute for Health and Clinical Excellence (NICE) as part of the stepped care pathway in the treatment of depression in the United Kingdom, mostly to provide low-intensity treatment [4]. However, adherence to cCBT is often poor owing to low acceptability and a lack of therapist involvement [5] and, as a result, effects are modest and short term [6]. Moreover, cCBT is often inflexible and does not allow identification of conditional beliefs or detailed formulations [7] that are crucial elements of CBT and important for those with more severe and chronic depression [8], and for long-term outcomes [9].

“High intensity” and “low intensity” are terms used in the United Kingdom to distinguish two types of mental health support. Low-intensity interventions are generally brief, with a smaller number of sessions, usually about six. These can be delivered via phone or in a group setting, may use a health technology such as guided self-help, and are typically delivered by a paraprofessional. cCBT with some therapist support is offered in UK Improving Access to Psychological Therapies (IAPT) as one of a suite of low-intensity interventions for less severe illnesses. High-intensity treatment is usually delivered individually and face-to-face by a more expert therapist over more and longer sessions (characteristically 12 1-hour sessions). Current UK evidence does not support the idea that cCBT alone can be an alternative to high-intensity CBT [10]. Nevertheless, because of its structured approach, CBT is particularly suited to the integration of computer and mobile technology with a therapist-led treatment. Exercises that take place outside the psychotherapeutic sessions are an important part of CBT, and adherence to these can increase effectiveness [6,11]. Enabling patients to complete exercises, such as worksheets online, as opposed to doing them on paper, may improve adherence and engagement [12], and accessing them on mobile devices may enable discreet and convenient ways of completing them [13]. Working online with specially adapted interactive materials can be supported by timely reminders and wider use of digital media.

Moreover, previous research has shown that real-time delivery of CBT using instant messaging is acceptable and effective [14-17], and there is evidence that cCBT with additional guidance from a therapist can be as effective as face-to-face therapy [18-20] and may save clinician time without reducing effectiveness [21].

In recent years, blended CBT has emerged as a promising alternative to cCBT. Blended systems combine online components with direct contact with a therapist [22-26], and initial evidence suggests that this approach is acceptable to patients as a way of receiving therapy and engaging with treatment [22,26]. Literature on blended therapy describes different combinations of online components and therapist contact, including the use of existing cCBT systems with limited feedback from the therapist [23], face-to-face therapy with additional access to online resources [22], or a combination of therapy sessions with online modules and mood tracking [24]. This paper not only draws on the lessons of blended therapy, but also takes an additional step, with focus on the development of more fully *integrated systems* to support high-intensity CBT. Rather than combining face-to-face contact with existing online support (eg, cCBT systems), an integrated approach focuses on the ground up development of platforms that more seamlessly integrate face-to-face contact, electronic contact, online sessions and collaboration, and between-session activities. Collaborative activities, which the therapist and patient complete together during online sessions, and between-session activities, which patients complete on their own, are complementary, as are face-to-face and electronic contact. Integration not only includes providing different options for how the therapist and patient work together, but also considers how the system supports the therapist's workflow and how the system could be integrated with current practices and broader health care systems. The overall aim is to support patient engagement and provide a structure within which therapists can deliver high-intensity treatment, while also greatly reducing face-to-face contact.

Objectives

The overall objective of this paper is to provide design guidelines for integrated platforms that support high-intensity CBT. A recent systematic review found that digital mental health technologies that show potential in randomized controlled trials (RCTs) are often less successful when deployed in real-world settings, that is, as implemented (disseminated) outside of research settings [27]. The authors conclude that this issue can be partially addressed through the collection and reporting of

implementation data on an ongoing basis. However, it can also be addressed pre-RCT through a process of user-centered design [28]. Central to user-centered design is strong evidence that the long-term success of digital systems is greatly improved by actively involving potential users of a future technology throughout the design lifecycle of that technology. User-centered design recognizes that it is not possible to fully state the requirements of a novel digital system at the outset of the design process. Instead it emphasizes the need for requirements to be developed and refined on an iterative basis through active involvement of representative users. This involvement can take a number of forms, including design workshops, where potential functionalities and problems are mutually explored [29], and the evaluation and critique of early prototype systems with users. Through these approaches, the resulting technology is more able to incorporate the needs, values, and lived experiences of potential users. The value of user-centered design in developing digital health interventions is increasingly recognized [30-32], and its use is becoming more commonplace [33,34].

The research described in this paper involved the first stage of the INTERACT project (a large program of research that brings together a multidisciplinary team to develop and evaluate a platform for delivering integrated therapy for depression). The details of a longitudinal pilot study evaluating the near-final version of the platform have been provided [35]. The project will ultimately result in a large-scale multicenter RCT of the INTERACT platform. In this paper, the overarching goal is to explore how best to design an online platform that enables close integration of direct therapist contact with access to online resources. Addressing this goal resulted in design recommendations that were directly relevant to the INTERACT platform [35]. However, these design recommendations also provide guidance that can be generalized to support the design of other integrated systems. This generalizable guidance is the core contribution of this paper.

Methods

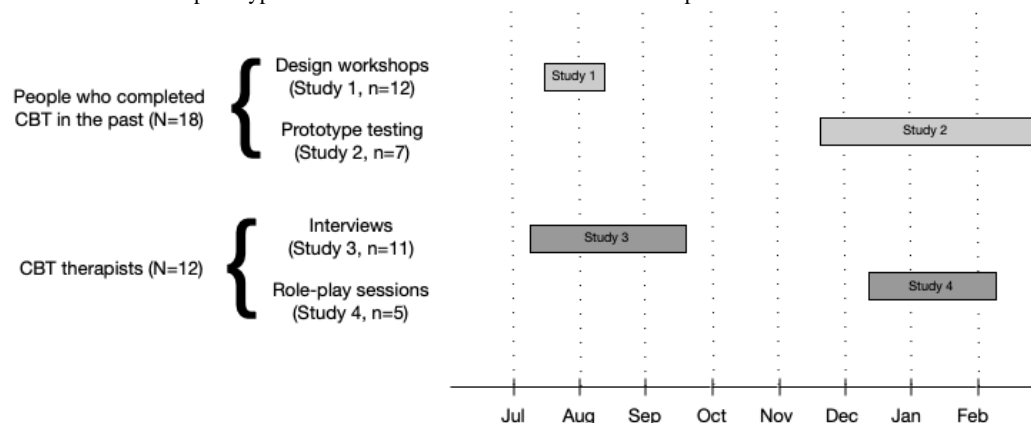
Design

The objectives in the paper are addressed through a series of user-centered design studies with patients and therapists. User-centered design methods differ from traditional qualitative

approaches in that potential users are actively encouraged to make suggestions with regard to the potential design and functionality of the system. In total, we conducted four studies. Our first two studies (1 and 3) focused on identifying general high-level requirements for an online platform for delivering integrated therapy for depression. Our later studies (2 and 4) addressed these requirements in greater detail, making use of concrete system prototypes to develop detailed design guidelines. Two studies were conducted with people who received therapy in the past, which allowed us to understand their needs (Study 1, design workshops) and test patient-facing components of the platform (Study 2, prototype testing sessions). Two studies were also conducted with therapists to gather the initial requirements (Study 3, interviews) and to validate and explore them in greater depth (Study 4, therapy session role plays). [Figure 1](#) presents the order and length of the studies and how they related to each other. Each study has been described in more detail in the following sections.

The prototypes used in later studies (Studies 2 and 4) were informed by the requirements gathered during workshops and interviews (Studies 1 and 3, respectively). The requirements were discussed among the research team and reported to the development team to identify what type of functionality may be needed, how it may work, and what types of activities will keep people engaged with the treatment. While it is not possible (owing to space constraints) to provide full details of each design decision, it is helpful to provide two illustrative examples of this process. During workshops in Study 1, participants expressed strong preferences with regard to tracking their progress. They did not want to see how much work they still had left to complete, but preferred to see how far they have come. The prototype tested in Study 3 reflected this finding and explicitly showed a record of past sessions and worksheets shared by the therapist. Similarly, during therapist interviews (Study 2) when discussing communication with patients between therapy sessions, therapists expressed concerns over increased workload and patients sending large amounts of messages. To address this concern, the prototype used in Study 4 included a platform inbox that asked patients to choose a specific topic for their message (eg, reschedule a session and worksheet query) to keep it focused and reduce between-session communication

Figure 1. Study flow and number of participants. The period between the studies was dedicated to the analysis of Study 1 and 3 results, and identifying design requirements that informed the prototypes used in Studies 2 and 4. The research took place in 2017.



The research was approved by the National Health Service (NHS) Ethics Committee (Integrated Research Application System Study ID: 221433) and had Health Research Authority approval.

Participants

People Who Received CBT in the Past

We recruited people who received CBT in the past through local IAPT services and people who had participated in earlier RCTs conducted by members of the research team [9]. The latter group had received one-to-one CBT as part of the trial for treatment-resistant depression and had consented to being contacted about future research.

Individuals eligible to take part were those aged 18 years or older, who had a history of depression and had received CBT for depression in the past. Excluded were those who were currently receiving treatment from a psychiatrist for depression; had a history of bipolar disorder, schizophrenia, personality disorder, or substance misuse/alcohol addiction (in the past year); or reported during the screening call that they were not feeling well enough to attend sessions. All participants were given an option to attend the workshops (Study 1) and/or participate in prototype testing sessions (Study 2).

In total, we recruited 18 participants. Among these, 12 attended the workshops (Study 1) and seven attended the prototype testing sessions (Study 2); one person participated in both activities. The mean age of the participants was 48.5 years (SD 13.4 years; range 22-72 years), and the majority (13/18, 72%) were women; eight had participated in previous trials and 10 were recruited from local IAPT services. Only four had experience with cCBT. Full background details are provided in [Multimedia Appendix 1](#).

CBT Therapists

We recruited therapists by contacting those who previously had worked with the research team on an earlier trial [9] and contacting clinical/service leads of local IAPT services to ask them for their support in promoting the study to therapists

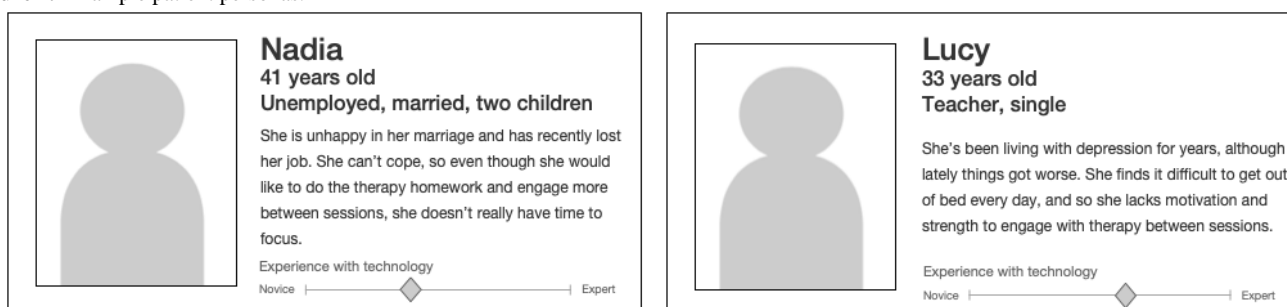
providing high-intensity CBT within their service (ie, treatment that is delivered to people with medium or severe depression over a longer time period, predominantly face-to-face, and that focuses on both behavioral and cognitive aspects of therapy). We telephoned potentially interested therapists to provide more details or arranged short sessions to describe the study to a group of potential participants at their service. In total, we recruited 12 therapists. Among these, 11 attended the individual interviews (Study 3) and five attended the role-play sessions (Study 4); four attended both. The mean age of the therapists was 43 years (SD 8.8 years; range 30-57 years), and the majority (13/18, 72%) were women. They were all white people. On average, they had worked as a CBT therapist for 8.1 years (SD 5.0 years; range 3-20 years). Among them, 10 worked for the NHS, one for a private practice, and one for both. Further details are provided in [Multimedia Appendix 2](#).

Study 1: Design Workshops With People Who Received CBT in the Past

Materials

We created four short patient personas (see [Figure 2](#) for examples) to serve as prompts during workshops. User personas are part of the user-centered design process [36-38]. They are a way to represent typical users of a computer system and help to empathize with target users and understand their needs. Our personas represented people with depression to illustrate varying circumstances and reasons for treatment (they were aged 19-48 years; two were women; one had comorbid anxiety and one was dealing with grief), as well as additional information about their technical skills. Further details are provided in [Multimedia Appendix 3](#). They were created in collaboration with clinicians on the research team (DK and RS) and coauthors who worked on depression trials in the past (NW, DK, KT, and DT) to represent a range of potential target patients who could benefit from the system we were developing. We used them to make it easier for participants to draw from their own experiences of CBT without the need to explicitly describe their own situation and to help them reflect on how CBT could be improved for others.

Figure 2. Example patient personas.



Procedures

In Study 1, we conducted four design workshops. The first two took place in July 2017, and the discussion focused on barriers of access to cCBT and CBT more broadly, and how technology could widen access. The final two workshops took place in August 2017. They focused on engagement with therapy and

therapeutic materials, identifying barriers to engagement and exploring how technology could help to overcome them.

The workshops were facilitated by two researchers (KS and DT). Each workshop lasted 2 hours and was attended by three to five people. All workshops started with a short description of a potential integrated platform for delivering CBT and planned activities for the session. The attendees had the

opportunity to ask questions, and then, written informed consent was obtained. Participants were asked to complete a short questionnaire covering sociodemographic details, information about their history of depression, and the treatment they received in the past. After the introductions and a warm-up activity, attendees were divided into two groups. Groups discussed the topics specific for each workshop (ie, access to cCBT and engagement), how they might affect the user personas, and how technology could help to overcome barriers and support engagement.

At the end of each workshop, each attendee received a £20 gift voucher. With participant consent, all workshops were audio recorded.

Study 2: Prototype Testing With People Who Received CBT for Depression in the Past

To validate the requirements gathered as part of Study 1, we conducted a series of prototype testing sessions. Known as usability testing sessions [39], their aim is to identify issues and areas for improvement during real-life usage scenarios. Evidence suggests that small numbers of participants (n=5-15) are sufficient to identify the key user-centered issues in a prototype [39,40].

Materials

Based on the results of Study 1 and prior literature, we built a functional prototype of an online platform for delivering integrated therapy for depression. The prototype included a homepage that showed the time of the next session, homework tasks, and a list showing worksheets that have been shared with the patient by the therapist; a personal profile page with a field for therapy goals; a library of resources listing several psychoeducational resources; and an “online session page” with an instant messenger enabling synchronous communication with the therapist and collaborative worksheet editing. Screenshots of the prototype are presented in [Multimedia Appendix 4](#).

Procedures

Prototype testing sessions were conducted one-to-one with a researcher and each lasted approximately 60 minutes. Written informed consent was obtained from all participants. Those who had not attended earlier design workshops were also asked to complete a brief questionnaire about their background.

To gain insights into participants' thinking, sessions involved a think aloud protocol [39], that is, participants were given specific tasks to complete (eg, complete worksheets, send a message to a therapist, and participate in an online therapy session) and were asked to describe what they were thinking while they were doing it to encourage them to comment on the experience. To provide context for the tasks, participants were given patient cards based on the user personas from Study 1, which provided information about recent events and their worries (see [Multimedia Appendix 4](#) for more details). They were asked to complete the tasks on behalf of these patients rather than provide their own information to help them generalize their experiences. Each session started with a practice task to familiarize participants with thinking aloud when using

a prototype. All sessions were audio-recorded with consent. Each participant received a £10 gift voucher for their participation.

Study 3: Qualitative Interviews With Therapists

Procedures

Therapists were interviewed at their workplace or at the university; one therapist was interviewed at home. The interviews lasted 45 to 60 minutes and were conducted by the first author. Each interview started with questions about the therapist's current approach to delivering CBT for depression, including their use of worksheets and other materials, client engagement, and their use of technology. Thereafter, the researcher described a potential integrated system to elicit feedback and gather further views regarding using technology for delivering CBT. Finally, the researcher showed paper prototypes [41] illustrating some of the features that could be available in an integrated system to elicit further feedback and help improve the design. The paper prototypes ([Multimedia Appendix 5](#)) were based on the literature on blended therapy systems, existing services (eg, Ieso [42]), the results of Studies 1 and 2, and insights from the therapists on the research team. They also served as a starting point for a discussion about the use of technology to manage workload, keep track of clients and their needs, and deal with risk. The interviews were audio-recorded and transcribed verbatim by an external transcription service.

For their participation, each therapist received £27. The rate was worked out on the basis of their standard hourly rate. If therapists were interviewed during their usual working hours, the payment was made to their employer, but if they were interviewed during nonworking hours, the payment was made to them directly.

Study 4: Platform Role-Play Sessions With Therapists

To evaluate the prototype of the platform with therapists, we conducted therapy role plays with CBT therapists. Role plays have been successfully used to design therapeutic systems and are well suited to the mental health care setting [43]. This format enabled therapists to better understand how delivering integrated therapy could work in practice and helped to elicit therapists' tacit knowledge of therapy interactions.

Materials

Each therapist used a separate laptop during the session. To support the role plays, we used the same prototype used in Study 2 and set up demonstration accounts with therapist and patient information already added, including homework tasks, completed worksheets, and therapy goals. Based on the personas from Study 1, we provided patient cards and patient scenarios. Participants role playing “patients” received a more detailed scenario card that summarized events that had taken place since their last therapy session and suggested topics to cover during the role play. The scenarios were informed by the types of patients described by therapists in Study 3 and reflected the main components of CBT [44]. They were approved by clinicians (DK and RS) on the research team after running a test role-play session during which one researcher (DT) acted

as a patient and another researcher (DK) acted as a therapist. All study materials, including screenshots of the platform and patient scenarios, are presented in [Multimedia Appendix 6](#).

Procedures

We conducted three role-play sessions (two sessions with pairs of therapists and one session with a therapist paired up with a researcher [DT] who acted as a patient). Each session lasted 90 minutes and was facilitated by the first author. After obtaining written informed consent, therapists were asked to complete a brief questionnaire to provide information about their sociodemographic characteristics, professional background, and experience.

To familiarize them with the prototype, therapists were walked through it first. Thereafter, they were given patient cards and specific scenarios in order to role play a session. The therapist role playing a “therapist” was given a simple patient card and was able to look up patient information in the system. The therapist role playing a “patient” was given a patient card and a scenario card. Therapists were free to run the session however they wanted with minimum input from the researchers who were present to take notes. They were able to pause the role play at any time to comment on the system, ask for clarifications, and offer suggestions for improvements. Role plays were followed by a discussion about therapists’ experience of using the prototype, their views on delivering therapy this way, and their views on how a system like this could fit into their current practice. The sessions were audio-recorded with consent. Each therapist was paid £41 for their time; this was based on their hourly rate. If the session was conducted during the therapist’s work time, we paid their employer, but if it was conducted during nonwork time, we paid the therapist directly.

Data Analysis

Notes from the workshops (Study 1) were copied onto sticky notes, and together with sticky notes generated by the participants, they were used in affinity mapping [45]. To identify key themes, all sticky notes were placed on a wall and two researchers (KS and DT) analyzed them thematically [46] by grouping them into clusters of similar themes and rearranging them as the analysis progressed. At the end, each cluster was described as a specific theme.

Notes from the prototype testing sessions (Study 2) and role plays (Study 4) were summarized. To identify wider themes relating to delivering therapy via technology and an integrated approach, we copied session notes onto a virtual board with interactive sticky notes [47], where three researchers (KS, DC, and CP) used affinity mapping [45] to create clusters of notes with similar topics and to identify key themes.

The interviews (Study 3) were transcribed, and the transcripts were analyzed inductively using a thematic approach [46]. First, three researchers (KS, DC, and CP) read the same two transcripts, discussed potential codes, and agreed to conduct open coding without a predefined coding frame. The transcripts were then uploaded to NVivo 11 (QSR International) for Mac, and one researcher (KS) coded the entire data set using a bottom-up approach, which involved coding the transcripts at the sentence level with detailed descriptive codes; no predefined

coding guide was used. Codes and coded extracts were regularly reviewed throughout the coding stage. After all transcripts had been coded, the researchers discussed the codes and started collating them into themes using the virtual board with interactive post-it notes [47]. This led to the establishment of an initial set of themes, which were later reviewed together with the coded extracts, which led to further changes and discussions.

While all studies were analyzed separately, in the following sections, we report the combined results representing patients’ (Studies 1 and 2) and therapists’ (Studies 3 and 4) views and experiences.

Results

Studies 1 and 2: Findings From Design Workshops and Prototype Testing Sessions With People Who Received CBT for Depression in the Past

We identified three overlapping themes describing the key types of features for an integrated platform for delivering CBT for depression as follows: features that help to overcome depression-related barriers; features that support engagement; and features that reinforce learning and developing new skills. They are described below with illustrative quotes.

Patient Theme 1: Overcoming Depression-Related Barriers

Both studies highlighted participants’ awareness of internal barriers inherent to people living with depression and ways of overcoming them. As depression can make it difficult for people to engage with treatment, the technology for delivering CBT for depression should provide content that is simple and easy to find and understand, to reduce these barriers.

For me, I would like it to be simple, not too many things going on [...] Non-busy, non-frightening, taking it in chunks, so you can absorb the information fairly easily. [Patient #14, 46-year-old female; prototype testing]

Drawing from their past experiences, participants highlighted the danger of becoming overwhelmed and thus the need to manage expectations, to release materials as and when they become relevant and needed.

When we’re depressed, we don’t always feel like exploring. [Patient #15, 59-year-old female; prototype testing]

Participants emphasized the importance of positive framing. With CBT’s focus on analyzing and reframing negative automatic thoughts, being able to, for example, record positive events, emphasize their goals, and see what they have achieved, was seen as important to motivate users and help them cope.

You’ve got there [a field to complete that asks] ‘what you want to get out of therapy’ which I think is a more positive than asking ‘what are you struggling with’ [...] It’s much more positive to have it that way and I think every time you’ve gone to your profile page, you don’t want to be reminded of the things you’re

struggling with. [Patient #16, 39-year-old male; prototype testing]

Patient Theme 2: Supporting User Engagement

Workshop participants thought that the most important part of CBT was the relationship with the therapist; therefore, the features supporting mutual understanding and trust, as well as enabling the collaborative aspects of therapy (eg, completing worksheets together) were key to engaging people.

I would like some reassurance that I'm not just doing this and it's been read. You should probably get some feedback and know that somebody will be listening, [that] it's not just going to cyberspace. [Patient #1, 63-year-old female; workshop]

Participants from both studies thought that enabling personalization and customization were important in supporting engagement, as they helped to identify with the treatment and made it more relevant. Allowing users to add their own notes and providing materials relevant to their situation were all mentioned as important factors in keeping people engaged with CBT.

I want MY personal page so that you know you're not on just some general CBT page, you're on your personal page that shows what I've already done and where I am. [Patient #6, 52-year-old female; workshop]

Participants also emphasized the importance of features that help people stay on top of their treatment, for example, reminders to complete a homework task or prepare for the next therapy session. They also wanted to be able to track progress and be able to see how far they have come since the beginning of therapy.

I like the idea that I can track where you are and how much you have done. It's not really how much you have to do, it's about validating that you've done [it] [Patient #3, 59-year-old female; workshop]

Feedback was mentioned as key in supporting engagement. Participants felt that it should be two-fold as follows: the therapist should be able to provide personalized feedback, and on another level, an automatic built-in feedback mechanism that confirms task completion would also be helpful, as users would know that their actions have been saved and acknowledged.

You could give people an incentive, a [...] reward for just having done the thing. And then we wanted to distinguish that from getting feedback from therapist on what you've done, which is a bit different that just having done it. Automated rewards and proper feedback. People need both of those things in order to stay motivated. [Patient #3, 59-year-old female; workshop]

Patient Theme 3: Supporting Learning and Acquisition of New Skills

Participants argued that to be effective, the technology should support the acquisition and maintenance of new skills. They

believed that access to resources (eg, relevant reading materials or videos) would be crucial in supporting therapy. It would also allow people to revisit topics covered in earlier therapy sessions or after the therapy has ended.

I think CBT is not a one-off thing, I think it's something you can use on and on and on, and if you've got this [...] you can go back and see and revisit things, because life goes round and round in circles, really, and I think that's something quite useful. [Patient #14, 46-year-old female; prototype testing]

Participants believed that contact with the therapist was key in learning these skills, although there was no consensus with regard to the best way to contact the therapist. While some participants would prefer to receive therapy face-to-face, others liked the flexibility the online setting offered. The majority, however, agreed that meeting the therapist at least at the beginning is important to establish rapport and build the relationship.

I think you need to meet people and when you're feeling vulnerable you need to understand how people convey themselves over email and over telephone. When you're very emotional, you always take the worst-case scenario, so I think once you've met somebody and built that relationship... Maybe have the first [session] together and maybe one more later. [Patient #14, 46-year-old female; prototype testing]

Studies 3 and 4: Findings From Qualitative Interviews and Platform Role-Play Sessions With Therapists

The interviews with therapists provided broad themes and helped to understand the impact technology could have on their current practice. The role-play sessions enabled unpacking of the initial findings, as therapists were able to focus on delivering therapy via a new technology. We identified three key themes that are described below with illustrative quotes.

Therapist Theme 1: The Importance of the Therapist and Client Working Together

All therapists acknowledged the importance of face-to-face contact. They all believed that to build rapport, it is necessary to see the other person. As a result, they worried that online contact would limit additional cues and body language they relied on during therapy.

That feeling that you have in the room with someone I think is more powerful in a room than it is on the phone. I'm not saying that you don't get some of that on the phone, but I think that the information that you get is probably slightly different. [Therapist #8, 45-year-old female; interview]

Despite being open to trying other types of contact and seeing the benefits of using technology to work and communicate with their clients, therapists worried that there would be less time to focus on the content of therapy as they would need to keep checking whether the client is engaging, looking at the right page, etc.

Doing that little role-play [...] it felt like there were many more things to be thinking about. It felt much more clunky than if I was sat face-to-face with a patient. It didn't feel very natural and it didn't feel particularly therapeutic. Just that, for instance, me saying to [T5] "Would you mind refreshing that page so I can see it?", having to say to her "OK, I'm going to bring up on your screen a worksheet" [...] it didn't feel as if it flowed in the same way as speaking and writing in a session. [Therapist #6, 30-year-old female; role-play session]

Therapists had concerns about technology giving clients too much control and were worried they would want to focus on topics not related to therapy goals. While this can already happen in face-to-face therapy, technology could make it easier. At the same time, they thought that the online format could also make it easier for patients to take ownership of their treatment and facilitate engagement, which is necessary for positive outcomes.

I guess, yeah, the struggles in the past of computerized CBT has been this idea that it's very... kind of having to fit the client into the program that's already there and fit them into the boxes, whereas [integrated approach] sounds much more guided by the patient, there's lots of elements to it. It's not just kind of one strand, [...] but much more idiosyncratic and lots more flexibility. [Therapist #6, 30-year-old female; interview]

Therapist Theme 2: Impact of Technology on Therapists' Workflow and Workload

All therapists agreed that introducing a new technology to their practice would change how they deliver therapy and would have an impact on their workload. In particular, they worried about extra work that they may need to do between therapy sessions.

If you've got sessions booked in you've got specific time slots, but I suppose therapists would have to think about how they allocate time to review worksheets and I just think that's the kind of thing that could potentially add up. [Therapist #4, 36-year-old female; interview]

In addition, they expressed concerns that if clients were able to message them between therapy sessions, it would not only have a negative impact on therapists' workload but also complicate how they manage risk.

I think it's really good but [my concern] is whether people then start bombarding you with questions. Or if people are sending you stuff that is potentially like risk stuff. Someone was to send you a message to say "I'm feeling really suicidal" and that's not necessarily something you're going to pick up straight away [Therapist #9, 35-year-old female; interview]

If the email is emotion-laden and talking about all sorts of problems [...] I can imagine that feeling quite hard to deal with, and perhaps one getting a little bit worried that one isn't providing a good service [...] It feels like something [that] could be a little bit damaging to the therapist's sense of well-being really,

depending on how many come and what they're like. [Therapist #7, 53-year-old male; interview]

The use of technology could also lead to a positive change. Therapists reported that in their current practice, they often did not have enough time to prepare for sessions in advance. An integrated approach would make it easy to see whether clients have done their homework and what they would like to talk about, and to share their background details.

The more information the better, really, from the therapist's point of view. [...] So you would want to know of trauma and previous struggles with low mood and anxiety, and perhaps whether they had any previous therapy or CBT [Therapist #12, 34-year-old female; role-play session]

Therapists also appreciated the ability to access digital resources by either party at any time. Having this shared space would allow them to easily locate and share materials, and track client engagement with these materials. Delivering therapy online also meant that session transcripts could potentially become therapeutic materials that clients could revisit at any time.

Having that kind of transcript would be really useful for the patient to be able to access in between sessions because it's obviously serving as a useful prompt regarding what's been discussed. [Therapist #6, 30-year-old female; interview]

Therapist Theme 3: Supporting Clients' Engagement With Therapy

Therapists reported that being able to see the same worksheet and doing things together would help clients understand complex topics and better engage with therapy. Asking clients to complete the worksheets themselves would increase accountability, although therapists would like to be able to step in and support clients if necessary.

It is good to encourage people to write things down themselves because this means that they've got that kind of control of what they do over there, quite active in a sense. But I wonder when people are very depressed, whether that's quite a lot of effort and you can just as easily repeat something back to them and say 'do you want this written down?' and then do it for them. [Therapist #3, 32-year-old female; role-play session]

Therapists also believed that technology could support clients' motivation. This could be achieved by simplifying all tasks, providing reminders, making everything easily available, and reducing any frictions or barriers related to homework completion.

I'm just thinking about homework and how that comes into it, whether there's anything in between sessions to remind them to do it, what they're doing, or whether before a therapy session they need to just think about what they've done. [Therapist #9, 35-year-old female; interview]

Finally, therapists considered the ability to see if the clients are logging in and doing their work as another tool for supporting

engagement. However, they did acknowledge potential issues with this type of monitoring.

This might feel a bit like Big Brother if you mention that “you haven’t logged on for a week” [...] But I mean, this is to be expected probably, isn’t it, it’s an online thing [...] this could encourage them to engage more [Therapist #12, 34-year-old female; role-play session]

Discussion

Principal Findings

The perspectives offered by people who received CBT in the past and therapists who deliver it provided valuable insights on the potential use of integrated therapy systems. We discuss these insights below and provide 12 generalizable design recommendations to support designers of integrated systems. These recommendations are summarized in [Table 1](#).

Table 1. List of design considerations for blended systems that aim to further integrate online resources and contact with a therapist.

Area	Design considerations
Therapeutic relationship	<ol style="list-style-type: none"> 1. Use face-to-face sessions to build rapport and trust, and online sessions to support skills development. 2. Allow therapists and patients to collaboratively work together on skill-related exercises, such as worksheets. 3. Keep a record of therapist-patient communication and make resources and transcripts available to patients well beyond the end of therapy, and/or enable the download of all materials for later use.
Personalized treatment	<ol style="list-style-type: none"> 4. Provide a wide selection of exercises and worksheets and enable the therapist to select appropriate resources to offer to the patient. 5. Consider ways in which the therapist (and perhaps even the patient) could take ownership of such materials; potentially modifying and creating new worksheets in response to their particular preferences and needs.
Supporting learning	<ol style="list-style-type: none"> 6. Support both therapist-directed and patient-led usage, within and between sessions: <ul style="list-style-type: none"> • When therapist-directed, it should be clear to patients what is expected of them. Materials for immediate use within a session and to be used between sessions (eg, this week’s worksheet) should be in the foreground, together with expected tasks. • At the same time, patients should have the option to explore materials that are relevant but not of immediate use.
Engagement and accountability	<ol style="list-style-type: none"> 7. Make patient commitments explicit and allow them and their therapists to review and update progress on these commitments. 8. Use automated feedback as a positive reward for engagement, but do not use it as a substitute for personal feedback from the therapist. 9. Allow therapists to review and provide feedback on worksheets completed by patients between therapy sessions.
Changing context	<ol style="list-style-type: none"> 10. Take into consideration the context in which therapists operate, as well as their workload, work patterns, and expectations. 11. Support between-session contact in a way that allows therapists to set and maintain boundaries and manage patients’ expectations. 12. Support risk management, but do not place responsibility on the therapists between therapy sessions. Instead, make it clear to patients where they can get help if they are distressed and require immediate support.

Support for the Therapeutic Relationship Versus Skills Coaching

Both patients and therapists reflected on the potential changing nature of the therapeutic relationship in the context of an integrated system. The major challenge they saw was the difficulty in creating a human and supportive environment remotely. Therapists were concerned that this would interfere with their ability to “read” the other person’s needs, whereas patients emphasized the importance of building rapport and trust early, which may not always be possible with online contact. These concerns are consistent with findings of a Delphi study and interviews by van der Vaart et al who explored the combination of face-to-face and online therapy [25]. They reported that some participants were concerned that limited face-to-face contact could weaken the patient-therapist bonding and lack of non-verbal communication could cause interpretation issues or lead to poor communication. However, there was an agreement that while the initial session would benefit most from

face-to-face contact, others could be online. Moreover, there is evidence showing that using instant messaging to deliver and receive therapy is acceptable and can be effective [14-17].

At the same time, both groups recognized that an online system could actually make it easier to focus on the skill-based aspects of the work together and avoid the potential “trap” (from a CBT perspective) of “talking round and round stuff.” This is in line with findings in the study by van der Vaart et al [25] who noted that the online format is the best for the most practical aspects of therapy. In addition, existing research suggests that digital worksheets can support engagement with homework [12,13], but our results show that this could go further. Easy access to resources, creation of archives of past sessions, and keeping track of progress could all support long-term learning beyond the end of therapy. This leads to the following design considerations for systems that aim to further integrate online resources and contact with a therapist:

1. Use face-to-face sessions to build rapport and trust, and online sessions to support skills development.
2. Allow therapists and patients to collaboratively work together on skill-related exercises, such as worksheets.
3. Keep a record of therapist-patient communication and make resources and transcripts available to patients well beyond the end of therapy, and/or enable the download of all materials for later use.

The Value of Personalization and Flexibility

Both patients and therapists spoke of the need for flexibility in the choice of skills one could learn and materials one could access. In particular, it was important for patients to learn not only the skills that would help them with their depression in the short-term, but also how to use these new skills in the future. Participants emphasized the need for different formats of materials (video and text) to match different people's needs. Participants also saw the expertise and intuition of the therapist in responding to patients' needs as valuable, enabling them to tailor the treatment for each patient, which would make it more useful and more engaging. This was identified as a potentially relevant advantage of an integrated approach over versions of cCBT that tend to be inflexible [7]. This suggests that the acceptability of such a system (to both therapists and patients) would be strongly influenced by its ability to support this flexibility. Research into blended therapy and the evaluations of existing systems that include therapist involvement show that this may indeed be the case [22-25]. This finding is also consistent with other recent research on digital mental health outside of the CBT space, which again found that therapist-led [48] and patient-led tailoring [49] can help to increase patient engagement. Therefore, this leads to the following design considerations:

4. Provide a wide selection of exercises and worksheets and enable the therapist to select appropriate resources to offer to the patient.
5. Consider ways in which the therapist (and perhaps even the patient) could take ownership of such materials; potentially modifying and creating new worksheets in response to their particular preferences and needs.

Therapist-Led Versus Patient-Led Tailoring

Both therapists and patients commented on the personal nature of a therapeutic journey. Therapists emphasized the value of it being guided by the patient, while patients expressed concerns regarding the impact of severe depression on their motivation to do this. While this initially may appear contradictory, on closer observation, it is more complementary. Patients recognize that as they develop skills and become more confident, the responsibility moves toward them. This is a classic example of learning, with a period of support (*scaffolding*) by the expert leading to a growing confidence in the learner, allowing them to become independent [50]. This leads to the following design considerations:

6. Support both therapist-directed and patient-led usage, within and between sessions:

- When therapist-directed, it should be clear to patients what is expected of them. Materials for immediate use within a session and to be used between sessions (eg, this week's worksheet) should be in the foreground, together with expected tasks.
- At the same time, patients should have the option to explore materials that are relevant but not of immediate use.

Engagement and Accountability

Both therapists and patients noted the potential benefits of therapists being able to see patient activity between sessions to encourage engagement, although they did have concerns about potential "big brother" aspects. Participants identified two different aspects of this monitoring relationship and noted that both have value. The first is a simple acknowledgment (possibly automated) that a patient has followed through on a commitment (such as filling in a worksheet), and the second is the human touch of the therapist actually looking at and reviewing the work. Combining automated and human feedback in this way has potential to be more engaging and leads to the following design considerations:

7. Make patient commitments explicit and allow them and their therapists to review and update progress on these commitments.
8. Use automated feedback as a positive reward for engagement, but do not use it as a substitute for personal feedback from the therapist.
9. Allow therapists to review and provide feedback on worksheets completed by patients between therapy sessions.

The Changing Role of the Therapist

Therapists recognized the change in their role and expectations that a more integrated system might bring and expressed concerns regarding this change. An integrated approach offers the possibility of a greater diversity of interactions within the therapeutic relationship. Some patients felt that simply having the online system always available would make their therapy more salient in their daily life, instead of being just a once-a-week contact. However, this obviously bears risks, which the therapists identified.

The first risk is related to workload. It is well known that technology can increase administrative burden without provision of extra time to carry it out [51]. An integrated system has the potential to create new work that is actually contributing to the therapeutic relationship, for example, responding to questions, reviewing worksheets a patient has completed, and sending an encouraging email to a patient who is not engaging. Therapists rightly highlighted the need to identify such work and timetable it explicitly into their day and workload, as demand for treatment is high [4,52]. The second risk is related to the nature of this between-session contact, as it can blur therapeutic boundaries, create an expectation for the patient that the therapist is always available, and make therapists feel more responsible for vulnerable patients. Any changes in the relationship induced by an integrated system must avoid an expectation on the patient's part that it is the therapist's job to manage risk between therapy sessions. This leads to the following design considerations:

10. Take into consideration the context in which therapists operate, as well as their workload, work patterns, and expectations.

11. Support between-session contact in a way that allows therapists to set and maintain boundaries and manage patients' expectations.

12. Support risk management, but do not place responsibility on the therapists between therapy sessions. Instead, make it clear to patients where they can get help if they are distressed and require immediate support.

Limitations and Future Work

As our research was qualitative in nature, we have engaged a relatively small number of participants. However, our participant number is consistent with user-centered design studies, and repeated evidence has shown that these methods can provide generalizable design guidelines [28,53-55]. As such, the research we conducted enabled us to gather design requirements and collect feedback on the prototype, which then informed the development of an integrated platform. The longitudinal evaluation study of the near-final version of the platform has been published previously [35].

The majority of our participants were women. This may be because women are more likely than men to seek mental health treatment [56] and the IAPT workforce is predominantly female [52]. In terms of implications, it could mean that the resulting

platform will better meet the treatment needs of women than men. However, male participants did take part in both the workshops and later prototype testing studies, and their opinions have also informed the design of the platform. In addition, none of the participants were from black, Asian, and minority ethnic (BAME) communities, and therefore, some of the findings might not reflect the views of these populations. We acknowledge that there are inequalities in access to mental health care that disproportionately affect BAME communities [56], leading to difficulties in recruiting members of BAME communities for research studies [57].

Conclusions

By engaging end users and drawing from the user-centered design methods for eliciting design requirements, we identified 12 design considerations for developing integrated therapy systems. To meet users' needs, such systems should be able to help retain the personal connection between the therapist and the client; support both therapist- and patient-led activities; and provide access to materials and should ensure the ability to monitor progress. However, developers of such systems should be mindful of their capacity to disrupt current work practices and increase therapists' workload. Future work should evaluate the clinical effectiveness and cost-effectiveness of integrated systems in a real-world context, including barriers and enablers of implementing such systems, as well as the impact of different design decisions on delivering treatment in primary care settings.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Information about the participants who attended design workshops and prototype testing sessions.

[\[PDF File \(Adobe PDF File\), 83 KB - mental_v7i9e15972_app1.pdf \]](#)

Multimedia Appendix 2

Information about the therapists who attended role plays and interviews.

[\[PDF File \(Adobe PDF File\), 74 KB - mental_v7i9e15972_app2.pdf \]](#)

Multimedia Appendix 3

Study materials used during design workshops (Study 1).

[\[PDF File \(Adobe PDF File\), 146 KB - mental_v7i9e15972_app3.pdf \]](#)

Multimedia Appendix 4

Study materials used during prototype testing (Study 2).

[PDF File (Adobe PDF File), 679 KB - [mental_v7i9e15972_app4.pdf](#)]

Multimedia Appendix 5

Study materials used during interviews (Study 3).

[PDF File (Adobe PDF File), 359 KB - [mental_v7i9e15972_app5.pdf](#)]

Multimedia Appendix 6

Study materials used during role plays (Study 4).

[PDF File (Adobe PDF File), 861 KB - [mental_v7i9e15972_app6.pdf](#)]

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Abbreviations

- BAME:** black, Asian, and minority ethnic
- CBT:** cognitive behavioral therapy
- cCBT:** computerized cognitive behavioral therapy
- IAPT:** Improving Access to Psychological Therapies
- NHS:** National Health Service
- NICE:** National Institute for Health and Clinical Excellence
- RCT:** randomized controlled trial

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Original Paper

Suicidal Thoughts and Behaviors and Their Associations With Transitional Life Events in Men and Women: Findings From an International Web-Based Sample

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Abstract

Background: Although numerous studies have demonstrated sex differences in the prevalence of suicidal thoughts and behaviors (STB), there is a clear lack of research examining the similarities and differences between men and women in terms of the relationship between STB, transitional life events, and the coping strategies employed after experiencing such events when they are perceived as stressful.

Objective: This study aims to examine the differences between men's and women's experiences of STB, sociodemographic predictors of STB, and how coping responses after experiencing a stressful transitional life event predict STB.

Methods: A web-based self-report survey was used to assess the health and well-being of a voluntary community-based sample of men and women aged 16 years and older, living in Australia, Canada, New Zealand, the United Kingdom, and the United States, who were recruited using web-based social media promotion and snowballing.

Results: In total, 10,765 eligible web-based respondents participated. Compared with men, a significantly greater proportion of women reported STB ($P < .001$) and endorsed experiencing a transitional life event as stressful ($P < .001$). However, there were no gender differences in reporting that the transitional life event or events was stressful for those who also reported STB. Significant sociodemographic adjusted risk factors of STB included younger age; identifying as a sexual minority; lower subjective social connectedness; lower subjective intimate bonds; experiencing a stressful transitional life event in the past 12 months; living alone (women only); not being in employment, education, or training (women only); suddenly or unexpectedly losing a job (men only); and experiencing a relationship breakdown (men only). Protective factors included starting a new job, retiring, having a language background other than English, and becoming a parent for the first time (men only). The results relating to coping after experiencing a self-reported stressful transitional life event in the past 12 months found that regardless of sex, respondents who reported STB compared with those who did not were less likely to engage in activities that promote social connections, such as talking about their feelings ($P < .001$). Coping strategies significantly explained 19.0% of the STB variance for men ($F_{16,1027} = 14.64$; $P < .001$) and 22.0% for women ($F_{16,1977} = 36.45$; $P < .001$).

Conclusions: This research highlights multiple risk factors for STB, one of which includes experiencing at least one stressful transitional life event in the past 12 months. When individuals are experiencing such events, support from services and the community alike should consider using sex-specific or targeted strategies, as this research indicates that compared with women, more men *do nothing* when experiencing stress after a transitional life event and may be waiting until they experience STB to engage with their social networks for support.

KEYWORDS

suicidal ideation; suicide; suicide, attempted; men; women; sex differences; life change events; adaptation, psychological; health surveys

Introduction

Background

Despite a considerable increase in global efforts to address suicidal thoughts and behaviors (STB), a corresponding decrease in the prevalence of death by suicide has not been observed [1]. STB are strong predictors of suicide deaths [2], contributing to substantial disability among individuals and having broader impacts on the individual's social networks and the wider economy [3-5]. Suicide continues to be a significant public health concern [6], and improving our understanding of the factors associated with STB to mitigate risk, enhance health promoting behaviors, and evolve current support systems is clearly an ongoing need.

Men die by suicide significantly more frequently than women [7,8], although lifetime STB are higher among women than men [9]. This gender paradox is even more pronounced in high-income countries [8]. Furthermore, men in their middle years are at one of the highest risks for suicide in English-speaking, high-income countries such as Australia, Canada, the United Kingdom, and the United States [10-13].

Suicide and its relationship to transitional life events during adulthood is starting to receive increased attention in the literature [6,14]. A systematic review by Lui and Miller [6] found evidence of an association between negative life events, which they define as *life stressors*, and STB. Transitional life events can relate to one's stage of development (such as retirement), historical events (such as war), and idiosyncratic factors (such as a change in an individual's health status) [15]. To date, however, there has been an insufficient level of international research examining how transitional life events relating to different life stages predict STB in both men and women. This may be important, as such transitional life events can initiate a shift in the purpose and the direction of life [15], and unsuccessful transitions at certain stages may be associated with higher levels of psychological vulnerability. Indeed, transitional life events have the potential to impact individuals differently, with some individuals perceiving them as stressful (ie, a negative life event) and some not.

During transitional life events, an individual needs to use coping strategies, which can be adaptive or maladaptive, to adapt to the new stage in life [16,17]. In brief, maladaptive coping has been referred to as dysfunctional, regressive, or avoidant coping in the literature [18]. For example, Zuckerman and Gagne [19] highlight that maladaptive coping can involve disengagement, denial, blame, or self-punishment. It is hypothesized that these are key risk factors for STB. Adaptive coping, on the other hand, has often been defined as functional, transformative, or approach focused, where individuals use coping strategies such as problem solving, help seeking, and emotional expression in response to stressors [18]. Interestingly, a meta-analysis by Tamres et al

[20] reported sex differences in coping, with women predominantly engaging in more adaptive or *expressive* types of coping strategies. How an individual copes (ie, in adaptive or maladaptive ways) if they perceive the life event as stressful may also be associated with STB. However, to our knowledge, comparing both adaptive and maladaptive coping strategies of men and women who have, or have not, experienced STB after experiencing a transitional life event has not been studied.

Objectives

This substudy analyzes data collected in an international research project, the Global Health & Wellbeing Survey [21,22], and provides a unique opportunity to explore, on a larger scale, men's and women's experiences of STB and their associations—with a particular focus on transitional life events, how these events are perceived, and how an individual copes when experiencing these events.

The aims of this substudy are to assess (1) the differences between men and women in their experience of STB, transitional life events, and their perception of the event in the past 12 months; (2) the sociodemographic (including demographics, social connections, and transitional life events) predictors of STB in the past 12 months for men and women; and (3) the sex differences in the methods of coping with stressful transitional life events for those who have experienced STB compared with those who have not.

Methods

Design

A web-based survey methodology was used to assess the views of a voluntary community sample living in 5 target countries, including Australia, Canada, New Zealand, the United Kingdom, and the United States.

Participants

The survey sample included men and women (aged 16 years and older) who reported that they had lived in 1 of the 5 target countries for the best part of the past 12 months.

Procedure

The primary study received institutional ethics approval from the University of Sydney's Human Research Ethics Committee (protocol number 2015/412). The open survey was tested before being hosted on the web from July 1, 2015, to December 11, 2015. A web-based advertising methodology was used to recruit respondents in the 5 target countries. Several strategies were used for survey dissemination and recruitment, including using multiple social media channels (eg, Facebook, Twitter, YouTube, and Instagram) [23]; layering of recruitment messages [24]; and passive snowballing via social media to spread study information through sharing, liking, and tweeting [23,25]. Both paid (via Facebook and YouTube, with budget set at Aus \$10

[US \$7.6] per participant, maximum spend of Aus \$100,000 [US \$76,400]) and free social media advertising (via a Facebook page, Twitter, and Instagram) were used. Recruitment targeting, based on age, sex, and region, was carried out through paid Facebook advertising channels to increase responses from harder-to-reach groups. This approach was supplemented by a traditional snowballing technique [26], in which respondents and wider networks forwarded the study to others. Respondents gave consent through the web and understood that they could cease participation at any time and that their responses were confidential and nonidentifiable. No incentives to participate were provided. Depending on participant answers, the survey took between 20 and 45 min to complete.

Measures

Items in this substudy were extracted from the full Global Health & Wellbeing Survey. The number of questions completed by each participant varied depending on the skip pattern. The following are the areas of interest specific to this substudy: demographics, social connectedness, transitional life events, and STB.

Demographics

Demographic items included sex (response options: men vs women); age (responses collapsed into age groups 16-24 years, 25-44 years, 45-64 years, and ≥ 65 years); language background (language background other than English [LBOTE] vs English); living in a rural or remote location (responses collapsed into yes vs no); living arrangement (living alone vs not living alone); employment, education, and training status (responses collapsed into not in education, employment, or training [NEET] vs in education, employment, or training [EET]); and sexual orientation (responses collapsed into heterosexual vs lesbian, gay, bisexual, transsexual, queer, intersex, or asexual [LGBTQIA]).

Social Connectedness

Perceived social support and conflict in close relationships were measured by the 5-item Schuster's Social Support and Conflict Scale [27] (Cronbach $\alpha=.71$; $n=8139$). The 12 items on the care dimension of the Intimate Bond Measure [28] were used as an indicator of perceived care from one's partner (Cronbach $\alpha=.96$; $n=8102$).

Transitional Life Events

Respondents indicated whether or not they had experienced any of 7 specific transitional life events over the past 12 months, including finishing high school or secondary school, starting university or college, starting a new job, becoming a parent for the first time, suddenly or unexpectedly becoming unemployed, relationship breakdown, and retiring. Those who affirmed they had experienced one of these events were asked whether they found this experience stressful (*yes* or *no*). If *yes*, respondents were asked about their coping strategies. Items included a range of adaptive and maladaptive coping strategies (eg, *get professional help* or *become aggressive*).

STB

Respondents' level of suicidality over the past 12 months was measured using the suicidal thoughts and acts subscale from

the Psychiatric Symptom Frequency Scale (PSFS) [29], which was originally developed in the United Kingdom and has been used in both Australia and North America [30-33]. The subscale consists of 5 items concerning suicidal thoughts and acts that are each presented with dichotomous response options (*yes* and *no*). From the subscale, we can infer 4 different areas of suicidality: (1) suicidal thoughts, a desire to end one's life without a specific plan; (2) suicide plans, formulating a strategy to end one's life; (3) suicide attempts, nonfatal self-injurious behavior that includes some intent to end one's life; and (4) STBs, the combination of an individual engaging in suicidal thoughts, plans, and/or attempts (Cronbach $\alpha=.82$; $n=8705$).

Analysis

Survey data were prepared and analyzed using IBM SPSS Statistics for Windows, version 22.0 (2013; IBM Corp). A 95% confidence level was used across all the analyses.

Chi-square tests were conducted to assess for significant differences between men and women in their experience of STB and transitional life events in the past 12 months (aim 1). Subsequently, Cramer V was calculated to determine the strength of the association. To adjust for type 1 error, a Holm-Bonferroni correction was applied.

Owing to the significant gender differences highlighted in aim 1, 2 logistic regression analyses (separately for men and women) were conducted to address aim 2. Following previously established procedures [34], 2 logistic regressions were run separately for men and women to identify sociodemographic (including demographics, social connectedness, specific transitional life events experienced in the past 12 months, and whether these life events were perceived as stressful) predictors of STB based on the PSFS.

To address aim 3, additional chi-square and Cramer V analyses were conducted to compare sex differences in coping after experiencing transitional life events for those who have experienced STB with those who have not (aim 3). For all analyses, no missing data were imputed, and 95% confidence levels were used. Again, a Holm-Bonferroni correction was applied to adjust for type 1 error. Owing to the noted sex differences, 2 additional linear regression analyses were used to examine the association between coping items and STB by sex. Missing data were excluded listwise. Regression model assumptions of linearity, homoscedasticity, independence, and normality (evaluated using standard residual-based diagnostic procedures) were met, with collinearity estimates among variables in both models being acceptable (tolerance >0.40 ; Durbin Watson >1.0).

Ethical Standards

The authors assert that all procedures that contributed to this work complied with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

Results

Respondent Participation Rates and Characteristics

A total of 16,510 people were presented with the consent and eligibility screen. Of these, the total eligible sample was 10,765 respondents (10,765/16,510, 65.20%). Of those excluded, 75.30% (4326/5745) did not provide consent to participate and 12.36% (710/5745) were aged younger than 16 years.

In total, 31.11% (3349/10,765) of eligible participants were from Australia, followed by 18.00% (1938/10,765) from the United Kingdom, 17.54% (1888/10,765) from Canada, 17.07% (1838/10,765) from the United States, and 16.27% (1752/10,765) from New Zealand. The majority of the participants were women (6464/10,765, 60.05%), aged 45 to 64 years (3625/10,753, 33.71%), not living in rural or remote areas (6787/10,703, 63.41%), living with others (5781/7115, 81.25%), heterosexual (5923/7116, 83.23%), from an English-speaking background (5971/7484, 79.78%), and in paid EET (7220/9998, 72.21%). The details of participant characteristics are presented in [Table 1](#), and a detailed breakdown of sociodemographic variables by sex and country are presented in [Multimedia Appendices 1](#) and [2](#), respectively. Of the respondents who experienced at least one transitional life event in the past 12 months, 70.48% (3142/4458) reported that it was stressful.

STB and Stressful Transitional Life Events

In the past 12 months, almost one-fourth of respondents in the full sample reported thinking about taking their own lives

(2071/8708, 23.78%), 7.81% (680/8708) had made plans, and 3.03% (264/8708) had attempted to take their own life. Compared with men, a significantly greater proportion of women reported experiencing each of the PSFS items, including attempts ($P \leq .001$), plans ($P \leq .001$), and thoughts ($P = .01$). A large effect size (Cramer $V \geq 0.05$) was seen for the item *attempted to take your own life*. All P values remained at the same level of significance after a Holm-Bonferroni correction was applied (see [Multimedia Appendix 3](#) for a full breakdown of the PSFS results).

The frequency statistics of respondents' experience of a major life event or events in the past 12 months and their responses are presented in [Table 2](#) and address aim 1. About half (4450/9029, 49.29%) of all respondents experienced at least one of the 7 presented major life events. Of the respondents who experienced at least one major life event in the past 12 months, 70.45% (3135/4450) reported that it was stressful. Women were significantly more likely than men to endorse experiencing the major life event or events as stressful ($P < .001$). In total, 84.40% (1390/1647) of the respondents who had also experienced STB in the past 12 months reported the major life event or events as stressful. These results were not statistically different between genders. When considering people who had experienced at least one major life event in the past 12 months but reported no suicidal thoughts, significantly more women felt the major life event or events was stressful (women 65.58% [1069/1630] vs men 55.4% [546/986]; $P < .001$). All results remained the same after applying the Holm-Bonferroni correction.

Table 1. Participants' sociodemographics by sex.

Variable	Full sample
Sex (N=10,765), n (%)	
Male	4301 (39.95)
Female	6464 (60.05)
Age (years; n=10,753), n (%)	
16-24	2690 (24.99)
25-44	2444 (22.71)
45-64	3625 (33.68)
≥65	1994 (18.53)
Rural or remote (n=10,703), n (%)	
No	9990 (93.34)
Yes	713 (6.66)
EET^astatus (n=9998), n (%)	
No (not in education, employment, or training)	2778 (27.79)
Yes (EET)	7220 (72.21)
Living arrangements (n=7115), n (%)	
Live with others	5781 (81.25)
Live alone	1334 (18.75)
Language background (n=7484), n (%)	
English	5971 (79.78)
Language background other than English	1513 (20.22)
Sexual orientation (n=7116), n (%)	
Heterosexual	5923 (83.23)
Lesbian, gay, bisexual, transsexual, queer, intersex, or asexual	1193 (16.77)
Social connectedness, mean (SD)	
Intimate bonds (n=8102)	25.5 (9.5)
Social support (n=8139)	9.3 (2.7)
Transitional life event (yes), n (%)	
Became a parent for the first time (n=9035)	145 (1.60)
Finished high school or secondary school (n=9034)	606 (6.71)
Started university or college (n=9032)	799 (8.85)
Started a new job (n=9037)	2153 (23.82)
Suddenly or unexpectedly become unemployed (n=9033)	793 (8.77)
Retired (n=9034)	598 (6.62)
Relationship breakdown (n=9034)	2073 (22.95)
Transitional life event perceived as stressful (n=4458)	3142 (70.48)

^aEET: education, employment, or training.

Table 2. Frequency and experience of major life events, stress responses, and suicidal thoughts and behaviors.

Response	Total sample, n (%)	Men, n (%)	Women, n (%)	Men versus women	Chi-square (df)	P value	Cramer V	Holm-Bonferroni correction
Experienced a major life event								
No	4579 (50.71)	1995 (43.57)	1633 (36.70)	44.3 (1)	<.001	0.07	<.001	<.001
Yes	4450 (49.29)	2584 (56.12)	2817 (63.30)	44.3 (1)	<.001	0.07	<.001	<.001
If yes, did you find this experiences stressful?								
No	1315 (29.55)	563 (34.48)	752 (26.70)	30.1 (1)	<.001	0.08	<.001	<.001
Yes	3135 (70.45)	1070 (65.52)	2065 (73.30)	30.1 (1)	<.001	0.08	<.001	<.001
Suicidal thoughts and behaviors (past 12 months)								
Stressful experience	1390 (84.40)	471 (84.11)	920 (84.56)	0.1 (1)	.80	0.01	.80	.80
Experience not stressful	257 (15.60)	89 (15.89)	168 (15.44)	0.1 (1)	.80	0.01	.80	.80
No suicidal thoughts and behaviors (past 12 months)								
Stressful experience	1630 (62.31)	561 (56.04)	1069 (66.19)	27.1 (1)	<.001	0.10	<.001	<.001
Experience not stressful	986 (37.69)	440 (43.96)	546 (33.81)	27.1 (1)	<.001	0.10	<.001	<.001

Predictors of STB

Adjusted odds ratios (AORs) and 95% CIs for the 2 subsamples (men and women) are presented in [Table 3](#) (see [Multimedia Appendix 4](#) results, including unadjusted risk ratios) and address aim 2. The models explained 24.0% and 31.0% of the variance for men and women, respectively (Nagelkerke R^2 men=0.24; Nagelkerke R^2 women=0.31).

The results presented in [Table 3](#) show that men and women shared some similarities in relation to sociodemographic risks of STB. Specifically, those in younger age groups, particularly those aged 16 to 24 years compared with those aged 65 years or older (men: 16-24 years; AOR 2.89, 95% CI 1.96-4.26; $P<.001$ and women: 16-24 years; AOR 4.03, 95% CI 2.78-5.85; $P<.001$), those who identified as LGBTQIA (men: AOR 1.96, 95% CI 1.56-2.46; $P<.001$ and women: AOR 3.01, 95% CI 2.45-3.71; $P<.001$), and those who perceived a transitional life event they experienced in the past 12 months as stressful (men: AOR 1.38, 95% CI 1.15-1.67; $P=.001$ and women: AOR 1.55, 95% CI 1.34-1.79; $P<.001$), had significantly elevated AOR of STB. For men, significantly higher AOR of STB were observed

for those who experienced a relationship breakdown (AOR 1.45, 95% CI 1.06-1.98; $P=.02$) and those who suddenly or unexpectedly became unemployed (AOR 1.63, 95% CI 1.16-2.29; $P=.005$). For women, identifying as NEET (AOR 1.67, 95% CI 1.31-2.15; $P<.001$) and living alone (AOR 1.38, 95% CI 1.11-1.71; $P=.004$) were associated with increased AOR of STB.

When considering protective factors, men and women had similar findings. Specifically both men and women had significantly lower AOR of STB if they identified as having a LBOTE (men: AOR 0.67, 95% CI 0.51-0.88; $P=.004$ and women: AOR 0.64, 95% CI 0.51-0.80; $P<.001$), reported higher levels of satisfaction with their social support (men: AOR 0.87, 95% CI 0.83-0.90; $P<.001$ and women: AOR 0.78, 95% CI 0.75-0.81; $P<.001$), higher intimate bonds ratings (men: AOR 0.96, 95% CI 0.95-0.98; $P<.001$ and women: AOR 0.98, 95% CI 0.97-0.99; $P<.001$), started a new job (men: AOR 0.73, 95% CI 0.55-0.97; $P=.02$ and women: AOR 0.80, 95% CI 0.65-1.00; $P=.049$), or retired (men: AOR 0.52, 95% CI 0.33-0.82; $P=.004$ and women: AOR 0.44, 95% CI 0.29-0.68; $P<.001$). Men who became a parent for the first time in the past 12 months had lower AOR of STB (AOR 0.30, 95% CI 0.10-0.86; $P=.026$).

Table 3. Adjusted odds ratios for men's and women's self-reported suicidal thoughts and behaviors by sociodemographic variables, including social connections and transitional life events (men, n=2667 and women, n=3826).

Participant characteristics	Suicidal thoughts and behaviors (Psychiatric Symptom Frequency Scale), adjusted odds ratio (95% CI) ^a	
	Men	Women
Sociodemographics		
Age bands (years) versus ≥65		
16-24	2.89 (1.96-4.26) ^b	4.03 (2.78-5.85) ^b
25-44	1.97 (1.38-2.80) ^b	2.71 (1.89-3.89) ^b
45-64	1.96 (1.46-2.64) ^b	1.81 (1.31-2.49) ^b
≥65	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Rural		
Yes	1.04 (0.72-1.50)	1.35 (0.98-1.85)
No	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Sexual orientation		
Lesbian, gay, bisexual, trans, queer, intersex, or asexual	1.96 (1.56-2.46) ^b	3.01 (2.45-3.71) ^b
Heterosexual	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Language background other than English		
Yes	0.67 (0.51-0.88) ^b	0.64 (0.51-0.80) ^b
No	1.00 (1.00-1.00)	1.00 (1.00-1.00)
EET^c		
No (not in education, employment, or training)	1.27 (0.98-1.63)	1.67 (1.31-2.15) ^b
Yes (EET)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Living arrangements		
Live alone	1.27 (0.99-1.61)	1.38 (1.11-1.71) ^b
Live with others	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Social connectedness		
Intimate bonds	0.96 (0.95-0.98) ^b	0.98 (0.97-0.99) ^b
Social support	0.87 (0.83-0.90) ^b	0.78 (0.75-0.81) ^b
Transitional life events		
Became a parent for the first time	0.30 (0.10-0.86) ^d	0.66 (0.31-1.41)
Finished high school or secondary school	1.07 (0.65-1.77)	0.96 (0.69-1.33)
Started university or college	0.81 (0.54-1.21)	0.83 (0.62-1.10)
Started a new job	0.73 (0.55-0.97) ^d	0.80 (0.65-1.00) ^d
Suddenly or unexpectedly become unemployed	1.63 (1.16-2.29) ^b	1.24 (0.93-1.66)
Retired	0.52 (0.33-0.82) ^b	0.44 (0.29-0.68) ^b
Relationship breakdown	1.45 (1.06-1.98) ^d	0.93 (0.73-1.18)
Transitional life event perceived as stressful	1.38 (1.15-1.67) ^b	1.55 (1.34-1.79) ^b

^aAdjusted for all variables.^bSignificant at 99% confidence level.^cEET: education, employment, or training.^dSignificant at 95% confidence level.

Coping After Experiencing a Stressful Life Event

There were 5 areas consistently identified by respondents as top coping strategies, irrespective of gender. These included sleeping too much or too little (2279/3130, 72.81% of all respondents), talking to someone about their feelings (2177/3132, 69.51% of all respondents), eating more or eating

less (2069/3130, 66.10% of all respondents), isolating themselves (1795/3138, 57.20% of all respondents), and talking to someone for advice (1790/3129, 57.21% of all respondents). [Table 4](#) presents further frequency data relating to men's and women's coping responses after experiencing a transitional life event perceived as stressful by self-reported STB in the past 12 months.

Table 4. Frequency of men's and women's coping responses after experiencing a stressful transitional life event for participants who did and did not report suicidal thoughts and behaviors.

Response based on stressful life experience	Suicidal thoughts and behaviors (Psychiatric Symptom Frequency Scale)			
	Men		Women	
	No	Yes	No	Yes
Sample size, range	561-563	467-471	1063-1071	916-919
Became aggressive (% yes)	14.59	27.66	8.71	19.28
Bossy or inflexible or angry (% yes)	28.29	37.58	29.78	43.96
Eat more or less (% yes)	47.51	66.81	62.90	80.07
Engage in spiritual activity (% yes)	31.49	27.66	32.02	30.50
Got professional help (% yes)	25.09	47.66	23.20	46.90
Increased tobacco or alcohol or drugs (% yes)	26.82	43.31	20.02	37.11
Isolated self (% yes)	43.59	75.16	40.24	76.17
Overdo activities (% yes)	20.28	25.32	26.29	32.86
Sleep too much or too little (% yes)	60.85	80.64	65.29	84.31
Spend time with friends or loved ones (% yes)	32.74	22.51	39.70	25.16
Work less or more (% yes)	31.32	42.34	27.81	46.51
Take more risks (% yes)	20.82	35.46	14.41	29.27
Talk to someone about feelings (% yes)	64.48	66.38	75.51	67.14
Talk to someone for advice (% yes)	50.36	56.60	59.31	59.37
Do nothing (% yes)	23.67	33.05	17.57	33.33
Other (% yes)	13.01	16.70	12.32	18.45

An in-depth chi-square and Cramer V analyses using a Bonferroni correction, addressing aim 3, showed that there were multiple sex differences in coping after experiencing a transitional life event that was perceived by the individual as stressful (see [Multimedia Appendix 5](#) for a full breakdown of results). Regardless of whether a respondent experienced STB in the past 12 months or not, women reported significantly higher rates of eating more or eating less (no STB: 62.90% [women] vs 47.51% [men]; $P < .001$ and STB: 80.07% [women] vs 66.81% [men]; $P < .001$) and lower rates of overdoing activities (no STB: 26.29% [women] vs 20.28% [men]; $P < .01$ and STB: 32.86% [women] vs 25.32% [men]; $P < .01$). Conversely, compared with women, men reported significantly higher rates of becoming aggressive (no STB: 8.71% [women] vs 14.59% [men]; $P < .001$ and STB: 19.28% [women] vs 27.66% [men]; $P < .001$); taking more risks (no STB: 14.41% [women] vs 20.82% [men]; $P < .01$ and STB: 29.27% [women] vs 35.46% [men]; $P = .02$); and increasing their use of tobacco, alcohol, or other drugs (no STB: 20.02% [women] vs 26.82% [men]; $P < .01$ and STB: 37.11% [women] vs 43.31% [men]; $P = .03$). Of these, eating more or eating less and becoming aggressive remained

significant after adjusting for multiple comparisons using a Bonferroni correction.

For those who did not experience STB, women reported significantly higher rates of talking to someone about their feelings (75.51% [women] vs 64.48% [men]; $P < .001$), spending more time with friends and loved ones (39.70% [women] vs 32.74% [men]; $P < .01$), and talking to someone for advice (59.31% [women] vs 50.36% [men]; $P < .01$); however, there were no differences between men and women for these variables if the respondent had also experienced STB in the past 12 months. Finally, men reported higher rates of doing nothing (17.57% [women] vs 23.67% [men]; $P < .01$) when they had not experienced STB in the past 12 months; however, there were no differences between men and women for this variable if respondents did experience STB.

When comparing all participant's coping responses after experiencing a transitional life event that was perceived as stressful, the respondents who did report STB were significantly more likely to engage in detrimental activities such as becoming aggressive (22.10% [STB] vs 10.74% [no STB]; $P < .001$); becoming bossy or inflexible or angry with others (41.80%

[STB] vs 29.26% [no STB]; $P < .001$); eating more or eating less (75.58% [STB] vs 57.60% [no STB]; $P < .001$); increasing their use of tobacco, alcohol, or other drugs (39.21% [STB] vs 22.37% [no STB]; $P < .001$); isolating themselves (75.83% [STB] vs 41.40% [no STB]; $P < .001$); overdoing activities (30.31% [STB] vs 24.22% [no STB]; $P < .001$); sleeping too much or too little (83.07% [STB] vs 63.76% [no STB]; $P < .001$); working more or working less (45.10% [STB] vs 29.02% [no STB]; $P < .001$); taking more risks (31.37% [STB] vs 16.62% [no STB]; $P < .001$); and doing nothing (33.24% [STB] vs 19.67% [no STB]; $P < .001$). Furthermore, this group was significantly less likely to engage in the potentially helpful activities of spending more time with friends and loved ones (24.26% [STB] vs 37.30% [no STB]; $P < .001$) and talking to someone about their feelings (66.88% [STB] vs 71.71% [no STB]; $P < .01$). However, they were also significantly more likely to get professional help (47.16% [STB] vs 23.85% [no STB]; $P < .001$).

Table 5 shows 2 linear regression models, which present data on how the different types of coping strategies (after experiencing a transitional life event perceived as stressful)

explained the variance in STB for men and women (aim 3). For men, the regression model significantly explained 19.0% of the variance in STB ($F_{16,1027}=14.64$; $P < .001$; R^2 adjusted=0.19), with 7 variables accounting for this variance at a 95% confidence level. In order of effect size, this included isolating self ($\beta=.21$; $P < .001$), getting professional help ($\beta=.20$; $P < .001$), doing nothing ($\beta=.09$; $P=.004$), becoming aggressive ($\beta=.09$; $P=.004$), sleeping too much or too little ($\beta=.09$; $P=.005$), increasing alcohol and other drug use ($\beta=.06$; $P=.036$), and other ($\beta=.06$; $P=.048$). For women, the regression model significantly explained 22.0% of the variance in STB ($F_{16,1977}=36.45$; $P < .001$; R^2 adjusted=0.22), with 8 significant variables. In order of effect size, this included isolating self ($\beta=.22$; $P < .001$), getting professional help ($\beta=.20$; $P < .001$), doing nothing ($\beta=.12$; $P < .001$), increasing alcohol and other drug use ($\beta=.08$; $P < .001$), sleeping too much or too little ($\beta=.07$; $P=.002$), becoming aggressive ($\beta=.05$; $P=.015$), taking more risks ($\beta=.05$; $P=.027$), and working less or working more ($\beta=.04$; $P=.036$).

Table 5. Linear regression of coping responses after experiencing a stressful transitional life event as predictors of suicidal thoughts and behaviors by sex.

Variable	Linear regression (<i>t</i>)	<i>P</i> value	β	95% CI
STB^a in men				
Became aggressive	2.87	.004	.09	0.04 to 0.19
Bossy or inflexible or angry	-0.72	.47	-.02	-0.09 to 0.04
Eat more or less	1.61	.11	.05	-0.01 to 0.11
Spiritual activity	-1.78	.08	-.05	-0.12 to 0.01
Got professional help	6.10	<.001	.20	0.14 to 0.27
Increased tobacco or alcohol or drugs	2.10	.036	.06	0.00 to 0.13
Isolated self	6.38	<.001	.21	0.15 to 0.28
Overdo activities	-0.56	.55	-.02	-0.09 to 0.05
Sleep too much or too little	2.84	.005	.09	0.03 to 0.16
Spend time with friends or loved ones	-1.43	.15	-.04	-0.12 to 0.02
Work less or more	-1.16	.25	-.04	-0.10 to 0.03
Take more risks	1.60	.11	.05	-0.01 to 0.12
Talk to someone about feelings	0.81	.42	.03	-0.04 to 0.11
Talk to someone for advice	-0.51	.61	-.02	-0.09 to 0.05
Do nothing	2.90	.004	.09	0.03 to 0.17
Other	1.98	.048	.06	0.00 to 0.16
STB in women				
Became aggressive	2.44	.015	.05	0.01 to 0.14
Bossy or inflexible or angry	0.87	.38	.02	-0.02 to 0.06
Eat more or less	1.92	.055	.04	0.00 to 0.09
Spiritual activity	-1.48	.14	-.03	-0.08 to 0.01
Got professional help	8.91	<.001	.20	0.17 to 0.26
Increased tobacco or alcohol or drugs	3.98	<.001	.08	0.05 to 0.14
Isolated self	9.47	<.001	.22	0.17 to 0.27
Overdo activities	-1.38	.17	-.03	-0.08 to 0.01
Sleep too much or too little	3.06	.002	.07	0.03 to 0.13
Spend time with friends or loved ones	-1.55	.12	-.03	-0.08 to 0.01
Work less or more	2.10	.036	.04	0.00 to 0.09
Take more risks	2.22	.027	.05	0.01 to 0.11
Talk to someone about feelings	-1.62	.11	-.04	-0.10 to 0.01
Talk to someone for advice	-0.41	.68	-.01	-0.06 to 0.04
Do nothing	5.27	<.001	.12	0.09 to 0.19
Other	1.82	.06	.04	0.00 to 0.11

^aSTB: suicidal thoughts and behaviors.

Discussion

Principal Findings

This study describes an analysis of men's and women's experience of transitional life events, STB, and coping strategies, with data being gathered in the largest known international web-based survey in this area. In keeping with previous

literature, the proportion of women reporting STB was significantly larger than the number of men reporting STB [35,36]. Following this pattern, women also reported at a significantly higher rate that the transitional life event (or events) they experienced was stressful, compared with men. These findings may suggest that the experience or the perception of stress is different between men and women, as highlighted in previous research [37]. Moreover, the results may indicate that

women have more proactive coping strategies when faced with stressful transitional life events. This is considering the finding that women not experiencing STB were more likely to engage with their social networks when coping with life events they perceived as stressful. To some extent, this rationale supports meta-analytic research that women predominantly engage in more adaptive or *expressive* types of coping strategies [20]. However, in this study, there were no sex differences in reports of feeling stressed once experiencing both a transitional life event and STB. Furthermore, the sex differences in *expressive* style coping after a stressful transitional life event (specifically, talking to someone about feelings, spending time with friends or loved ones, and talking to someone for advice) were present when individuals were not experiencing STB but dissipated once individuals reported STB. Therefore, this study may extend previous meta-analytic findings [20]. Namely, it is possible that women articulate their perceived feelings of stress to others at an earlier stage (ie, when they are not experiencing STB), whereas men might be less likely to seek support from others until they move toward a crisis point.

The results from the logistic regression indicated that both men and women who reported experiencing a stressful transitional life event in the past 12 months had higher AOR of STB. The subsequent linear regression highlighted some potential warning signs for STB, most of which have been identified as predictors of future STB and are among the warning signs for many international guidelines [38]. This included becoming aggressive; self-isolating behavior; changes in sleep; and increased use of tobacco, alcohol, or other drugs for all participants, irrespective of their sex. For women specifically, warning signs also included increased risk taking and changes in work behaviors. Previous research has demonstrated a relationship between suicide and substance abuse [35,39], sleep disturbances [40], and social isolation [41]. This study adds to the literature by highlighting some identifiable signs that individuals experiencing STB engage in after going through a transitional life event (or events) they perceive as stressful.

These warning signs of STB, after experiencing a transitional life event, may be compounded when considering the chi-square finding that both men and women who reported STB, compared with those who did not, were significantly less likely to engage in potentially helpful coping strategies (eg, spending more time with friends and loved ones and talking to someone about one's feelings). These strategies may help buffer a person against distress. Furthermore, it was found that respondents experiencing STB reported higher rates of accessing professional help compared with those who did not report STB, and seeking professional help significantly explained the variance in STB for men and women. Despite this, more than half of all the participants with STB did not seek help. Indeed, one-third of the participants who reported STB (33.2%) said they *did nothing* to cope after a stressful transitional life event. This explained the variance in STB for both sexes in the linear regression. Although research has consistently reported that men are less likely to seek help than women [42], this research found no differences in seeking professional help between men and women when experiencing STB. Notably, seeking professional help significantly explained the variance in STB in both men

and women. Women, however, were more likely to seek professional help when experiencing stress but were not reporting STB. Again, this may indicate that men are waiting until they head toward a crisis point to seek help. This delay seen in men toward help seeking may be because of self-stigma, a wish to handle the problem on one's own, and a low perceived need for care [42].

Other significant findings include that a majority of sociodemographic variables that resulted in higher or lower AOR of STB—such as identifying as LGBTQIA, NEET (women only), suddenly or unexpectedly becoming unemployed (men only), living alone (women only), satisfaction with intimate bonds, satisfaction with social support, starting a new job, becoming a parent for the first time (men only), and relationship breakdown (men only)—arguably relate to an individual's level of social connectedness, or lack thereof. In the literature, social isolation and the absence of social support are established correlates of suicide risk, with O'Conner and Nock [43] suggesting that it is a vital component of contemporary models of suicidal behavior. Furthermore, the higher rates of STB among these various subgroups [44-48] could be attributed to disruptions or distress related to not only their social connectedness but also connectedness more broadly to include their job or perceived sense of purpose, which would be consistent with existing models that characterize the development of strong STB [49].

Implications for Policy and Practice

When taking all these factors together, these findings emphasize the importance of promoting more helpful coping strategies after experiencing a stressful transitional life event. For example, men were more likely to engage in maladaptive coping strategies associated with completed suicides, such as substance abuse [35,39]. Health services and campaigns should focus on helping men recognize and respond to life stressors earlier. This includes equipping them with the skills to identify triggers and early warning signs of stress so that they can take appropriate action, seek help, and engage in more adaptive coping strategies earlier. This is also important for women, particularly given the finding that increased use of tobacco, alcohol, or other drugs was associated with STB for women only. Overall, a greater understanding in the community of these potential warning signs of STB in people who have experienced a stressful transitional life event might also improve the identification, response, and provision of support.

In addition, in accordance with other Australian research recommendations [50], enhancing social connectedness in the general community is crucial, particularly given the findings that isolating oneself as a coping strategy after experiencing a stressful transitional life event explained variance in STB for both men and women. Additional focus should also be placed on supporting and tailoring services to meet the needs of more vulnerable groups highlighted in this research, such as young people, people who identify as LGBTQIA, people experiencing employment-related concerns, people with lower satisfaction toward their social support and intimate bonds, men who experience relationship breakdown, and women who live alone. Overall, interventions that target improving community support

and social connectedness should be considered in health services, educational institutions, and workplace settings, particularly after someone experiences a stressful transitional life event. Research suggests that augmentation of social connectedness through not only traditional face-to-face methods but also digital mental health supports should be considered [50,51], particularly given that these can improve access for more socially isolated individuals [52].

Strengths and Limitations

A key strength of this study is that it is one of the largest samples to date, providing data on transitional life events, coping strategies, and multiple factors related to suicide risk. It is, however, not without limitations—many of which are outlined in the main reports' executive summary, including the nonepidemiological nature of web-based research that holds the potential for avidity and internet bias [21]. Indeed, in this study, suicidal thoughts were common, with 23.8% of the total sample having thought about taking their own life in the past 12 months. Furthermore, suicide plans and attempts over the past 12 months were reported by 7.8% and 3.0% of the respondents, respectively. These rates are far higher than those reported in the literature, with the World Health Organization's 12-month prevalence estimates being at 2.0% for suicidal thoughts, 0.6% for plans, and 0.3% for attempts within developed countries [53]. It is also possible that those with a greater interest in the subject matter were more likely to participate in this research. This research still provides valuable insights as the interactions between variables, not merely the statistical frequencies, provide meaningful information. However, a selection bias could mean that the findings relating to associations between life events, coping mechanisms, and STB may be more specific to higher risk groups. For this reason, we also did not compare differences across countries, although countries presented similar sociodemographics (Multimedia Appendix 2).

Additional limitations of this substudy are as follows. First, the brief screener for STB via the PSFS relies on binary responses and, thus, may be less sensitive to subtle response variances. Second, known predictors of suicide, such as mental ill health, alcohol, and/or other substance misuse [38], were also not considered in the multinomial regression, as we focused on sociodemographic factors. It is acknowledged that their inclusion would influence the results. Furthermore, only 7 transitional life events were considered in the Global Health & Wellbeing Survey. Other transitional life events may warrant further research (such as commencing a long-term relationship, getting

married, and death of a loved one); however, because of the sheer scale of the survey, not all transitional life events could be included. In addition, some transitional life events, specifically experiencing a relationship breakdown and suddenly or unexpectedly becoming unemployed, are acknowledged to be far more of a negative experience than others included in this survey, which may have influenced the results. These were included, however, as they are becoming far more common in the included target countries, nearly one-fourth (22.9%) of the entire sample had experienced a relationship breakdown in the past 12 months. The research also relied on self-report, which asked participants to recall the transitional life events experienced and STB over the past 12 months. This lengthy recall period is a common issue in research [6]. Interview-based approaches instead of self-report checklists may allow for greater resolution in the dating of an event and provide further depth of assessment in the relationship between stressors and STB [6]. However, interview-based research has also been shown to limit the disclosure of sensitive items compared with web-based approaches, particularly for men and people not in education, training, or employment [54]. Thus, the web-based survey approach used in this study may allow for a greater level of disclosure of sensitive information, such as STB.

Conclusions

Although nonepidemiological in nature, the considerable size of the Global Health & Wellbeing Survey provides some key insights into the international landscape for men and women, with good representation from minority subpopulations. Multifaceted approaches toward providing support to individuals experiencing STB after experiencing a stressful transitional life event is crucial. Essential to this includes risk mitigation through systematic identification and assessment [55] and a greater emphasis on health promoting behaviors and coping mechanisms within communities to strengthen resilience. When designing interventions, services should consider using sex-specific or targeted strategies to inform both the early identification of warning signs relating to STB and the provision of effective early intervention to mitigate the immediate risk and long-term impact of STB [56]. Beyond traditional interventions, these results show that enhancing social connectedness and reducing marginalization may be vital. This is especially relevant for groups at risk of marginalization, including those who had lower satisfaction with their social support and intimate bonds and specific populations, such as young people, people who identify as LGBTQIA, and have employment-related issues.

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Conflicts of Interest

IH was an inaugural commissioner on Australia's National Mental Health Commission (2012-2018). He is the Co-Director, Health and Policy, at the Brain and Mind Centre (BMC), University of Sydney. The BMC operates early intervention youth services at Camperdown under contract to headspace. IH has previously supported community-based and pharmaceutical industry-supported (Wyeth, Eli Lilly, Servier, Pfizer, and AstraZeneca) projects focused on the identification and better management of anxiety and depression. He was a member of the Medical Advisory Panel for Medibank Private until October 2017, a Board Member of Psychosis Australia Trust, and a member of the Veterans Mental Health Clinical Reference Group. He is the Chief Scientific Advisor to and an equity shareholder in InnoWell. InnoWell has been formed by the University of Sydney and PricewaterhouseCoopers to deliver the Aus \$30 (US \$22.20) million Australian Government-funded Project Synergy. Project Synergy is a 3-year program for the transformation of mental health services through the use of innovative technologies. JB is the Chair of the National Advisory Council for Open Arms, Veterans, and Families Counselling Service. She is a well-being and digital health consultant to Bupa, a member of the Veterans Mental Health Clinical Reference Group, and a Chief Investigator and author of the Defense and Veterans Transition and Wellbeing Study. She is the founder of and an equity shareholder in InnoWell. She is a Professor at the Social Innovation and Chair of the Centre for Mental Health at Swinburne University and Adjunct Professor of Social Impact and Entrepreneurship at Royal Melbourne Institute of Technology. The other authors have no conflicts of interest to declare.

Multimedia Appendix 1

Participant socio-demographics for the full sample and by sex.

[[DOCX File , 32 KB - mental_v7i9e18383_app1.docx](#)]

Multimedia Appendix 2

Participant socio-demographics by country.

[[DOCX File , 19 KB - mental_v7i9e18383_app2.docx](#)]

Multimedia Appendix 3

Frequency and experience of suicidal thoughts and behaviours.

[[DOCX File , 18 KB - mental_v7i9e18383_app3.docx](#)]

Multimedia Appendix 4

Odds and adjusted odds ratios for men and women's self-reported suicidal thoughts and behaviors by sociodemographic variables including social connection and transitional life events (Men n=2667; Women n=3826).

[[DOCX File , 17 KB - mental_v7i9e18383_app4.docx](#)]

Multimedia Appendix 5

Frequency of men and women's responses based on stressful transitional life event experience for participants who did and did not report suicidal thoughts and behaviours (PSFS).

[[DOCX File , 20 KB - mental_v7i9e18383_app5.docx](#)]

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Abbreviations

AOR: adjusted odds ratio

BMC: Brain and Mind Centre

EET: in education, employment, or training

LBOTE: language background other than English

LGBTQIA: lesbian, gay, bisexual, transsexual, queer, intersex, or asexual

NEET: not in education, employment, or training

PSFS: Psychiatric Symptom Frequency Scale

STB: suicidal thoughts and behaviors

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Original Paper

A Smartphone App to Monitor Mood Symptoms in Bipolar Disorder: Development and Usability Study

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Abstract

Background: There is considerable scientific interest in finding new and innovative ways to capture rapid fluctuations in functioning within individuals with bipolar disorder (BD), a severe, recurrent mental disorder associated with frequent shifts in symptoms and functioning. The use of smartphones can provide valid and real-world tools for use in measurement-based care and could be used to inform more personalized treatment options for this group, which can improve standard of care.

Objective: We examined the feasibility and usability of a smartphone to capture daily fluctuations in mood within BD and to relate daily self-rated mood to smartphone use behaviors indicative of psychomotor activity or symptoms of the illness.

Methods: Participants were 26 individuals with BD and 12 healthy control individuals who were recruited from the Prechter Longitudinal Study of BD. All were given a smartphone with a custom-built app and prompted twice a day to complete questions of mood for 28 days. The app automatically and unobtrusively collected phone usage data. A poststudy satisfaction survey was also completed.

Results: Our sample showed a very high adherence rate to the daily momentary assessments (91% of the 58 prompts completed). Multivariate mixed effect models showed that an increase in rapid thoughts over time was associated with a decrease in outgoing text messages ($\beta=-.02$; $P=.04$), and an increase in impulsivity self-ratings was related to a decrease in total call duration ($\beta=-.29$; $P=.02$). Participants generally reported positive experiences using the smartphone and completing daily prompts.

Conclusions: Use of mobile technology shows promise as a way to collect important clinical information that can be used to inform treatment decision making and monitor outcomes in a manner that is not overly burdensome to the patient or providers, highlighting its potential use in measurement-based care.

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KEYWORDS

bipolar disorder; momentary assessment; mood; mobile phone; mobile app

Introduction

Bipolar disorder (BD) is a severe, recurrent mental disorder that often has devastating effects on patient's everyday functioning. BD is characterized by intermittent episodes of depression and mania or hypomania, and it affects at least 2% of the general population, yet it is the sixth leading cause of disability worldwide in individuals aged 18 to 44 years [1] and the most costly mental health condition [2]. Taken together, this frequently shifting illness leads to substantial comorbidity, health care costs, and premature mortality [3,4]. Further, many patients with BD experience significant daily and weekly mood swings that are below the threshold for a full mood episode. It is typically this mood instability that can contribute to impairments in daily functioning [5]. Among those who seek or receive treatment, many do so within primary care [6-8], where precision in patient monitoring of problematic functioning is time and resource consuming.

Provider-administered assessments used in research or in clinical settings can be difficult to implement in routine clinical practice due to lack of clinical psychiatric training and time constraints, leading to the growing use of self-completed symptoms assessments. However, self-completed assessments of mood symptoms are dependent on retrospective reporting, which typically asks about symptoms experienced over the past week or two, which is subject to recall and response bias. Such assessments also require aggregation of mood-specific symptoms over days by the patient and the clinician, which is difficult to sustain in real-world clinical settings. Therefore, there is a need for more practical assessment of rapid fluctuations and symptoms in mood within BD.

In order to capture rapid fluctuations in functioning within individuals with BD, a more clinically useful measurement is needed to inform more personalized treatment options for this group and improve standard of care. The use of measurement-based care, a practice of basing clinical care on patient data that are continuously collected to inform treatment decision making and monitor outcomes [9], has not been widely adopted in mental health treatment due to the burden of assessments in routine practice. However, the advent of measurement-based care and precision medicine has created a potential for the development of valid and reliable methods to measure individual variation in symptoms and functioning, which could better inform treatments through improved diagnosis, predicted relapse, and insight into disease progression.

The use of mobile health technologies or remote measurement technology (ie, smartphone and similar technologies) has immense promise to not only capture reported symptom information but also provide data on phone behaviors (eg, information about number of phone calls or text messages being sent or received) that could indicate changes in functioning, both of which are ecologically valid ways of capturing behaviors in the real world [10,11]. Additionally, mobile technology offers a delivery method for assessment of what people are doing in real-world settings, a methodology known as ecological momentary assessment (EMA) [12]. Using EMA on smartphones can also provide a real-time clinical management

tool for psychiatric illness by providing an early warning sign of problematic shifts in mood or changes in behavior. EMA techniques are advantageous over retrospective reports, can be collected in the moment, and can be coupled with data on other smartphone usage behaviors to provide a unique way of accurately and efficiently monitoring changes in functioning and clinical phenotypes. Further, mobile technology can serve as a way in which patients can self-monitor their symptoms and functioning, which subsequently can allow them to take part in the medical decision making. Mobile technology can provide a quick and cost-efficient way to inform providers that patients are in the beginning stages of a mood episode relapse. Using mobile technology in this way can further push forward the feasibility of measurement-based care and help prevent disease progression, relapse, and treatment costs; however, this has not been rigorously tested.

There has been a surge of research examining the use of smartphones to monitor and capture symptoms and behaviors across a range of illnesses, including psychiatric illness [13-17], suggesting that there is considerable scientific interest in finding new and innovative ways of measuring illness parameters. Recent studies show mobile electronic devices to be useful in assessing and monitoring behaviors and severity of symptoms in both inpatient and outpatient settings [18,19]. Other studies have used mobile phone technologies to determine a relationship between psychiatric symptoms and phone behavior [20-22]. For example, Faurholt-Jepsen and colleagues [21] found that more depressive symptoms were associated with the phone's screen being on for longer periods, more incoming calls, fewer answered incoming calls, and less movement from the cell towers. In contrast, more manic symptoms were associated with more outgoing text messages and longer phone calls, suggesting that smartphones can generate objective data for behavioral activities that may be markers of illness activity.

Further examination of the feasibility and acceptance of using EMA on smartphones among those with BD illness is crucial. In addition, understanding if momentary assessment of mood is related to phone usage data, such as phone calls and text messages sent or received, is needed if the goal is to leverage technology for measurement-based care in a range of clinical settings. The aims of this study were (1) to examine the feasibility and acceptability of using a smartphone to capture daily mood symptoms in BD, using a custom, clinically informed smartphone app, and (2) to relate daily self-rated mood to smartphone use behaviors, such as phone calls and text messages, that may be proxies for psychomotor activity or symptoms of the illness. We hypothesized that patients with BD will find using smartphones a feasible and useful way of monitoring symptoms, based on metrics of how compliant they were with completing daily tasks. Further, we hypothesized that phone usage data would be related to aspects of self-reported mood collected over 28 days. Specifically, we hypothesized that higher depression scores would be negatively correlated with number of phone calls and text messages made and time spent on phone calls, based on the psychomotor retardation and anhedonia often accompanying depression, and increased activity during mania would be positively correlated with

number of phone calls, text messages, and time spent on phone calls [23,24].

Methods

Recruitment

Participants were recruited from the Heinz C Prechter Longitudinal Study of BD, an observational, naturalistic cohort study gathering phenotypic and biological data, at the University of Michigan [25]. A total of 36 individuals from the Prechter sample were enrolled into this current study (see “Results” section for breakdown). Recruitment and initial baseline evaluation procedures for the Prechter Longitudinal Study of BD have been described elsewhere [25], but to briefly summarize, all participants underwent an evaluation using the Diagnostic Interview for Genetic Studies (DIGS) [26], and a best-estimate process by at least two of the authors was used to confirm diagnoses. Participants were excluded if they had active substance use or neurological disease at enrollment. Both the longitudinal study and the present study were approved by the University of Michigan Institutional Review Board, and all participants provided signed informed consent.

Clinical information, such as age of onset for BD illness (DIGS), history of rapid cycling (based on having a history of 4 or more mood episodes per year) (DIGS), depression symptoms (Hamilton Depression Rating Scale-17 item) [27], mania symptoms (Young Mania Rating Scale) [28], and IQ (Wechsler Abbreviated Scale of Intelligence [29]), was taken from the initial baseline evaluation during enrollment into the larger longitudinal study. The number of lifetime mood episodes and psychiatric hospitalizations were obtained from the longitudinal data (DIGS) available in the Prechter Longitudinal Study. Inclusion criteria for the group with BD for this study included a history of rapid cycling or personal experience of mood fluctuations over the last couple months. Both BD and healthy control (HC) participants were included if they were currently smartphone users; all were provided with a study-specific smartphone. A total of 17 participants used iPhones at the time of enrollment but identified as being familiar with and having prior use with the Android operating system. We also selected participants who used their phones “regularly” and who were the primary users of their personal smartphones. Participants were excluded if they had vision or motor problems that would preclude them from using the smartphone study device or if they were not the primary or sole users of their smartphones ($n=3$). Participants received monetary compensation for their time participating in this study. They received US \$160 at the end of the first 2 weeks of cell phone data collection, regardless of how many cell phone engagements they chose to use, and US \$160 at the end of the study when they returned the issued smartphone.

Procedure

Description of Smartphone App

The smartphone app was custom built to use Android 5.1.1 operating system, downloaded by invitation from Google Play. Data were stored securely on the Google App Engine. No personal or identifiable information was stored on the App

Engine. The app was run continuously in the background of the phone with no indication to the participant that it was automatically collecting information about number and duration of phone calls and text messages. The app used minimal battery so battery drain was not readily apparent to the participant. Daily prompts to complete the app questions were sent in the morning and in the evening based on preselected times selected by the participants during study setup. They knew when these prompts would occur and they were prompted to complete app questions every 15 minutes for an hour until completed. No further prompts were sent after 1 hour. Notification of the prompts was visible by the study icon appearing at the top of the phone and accompanied by a unique prompting tone and message. Participants could swipe the screen message to launch the daily questions or delay for up to an hour. Participants responded to each question by using the visual analog scale ranging from 0 to 100 by positioning a marker on the touch screen (for mood questions, see “Smartphone Assessment” section below). The middle mark of 50 was the default position. During the training, participants were instructed that 0 and 100 represented the most extreme states they could imagine experiencing for each item and were provided examples to illustrate these points (ie, 0 on the impulsivity question was described as being the least impulsive in behaviors, so not reacting at all before thinking, and 100 was described as definitely acting or reacting without any forethought). After each response, participants pressed “Next” to continue to the next question. Time to complete the morning app questions was less than 5 minutes. Once they completed their session, the app responded with “Thank you for completing the survey” and automatically closed until the next scheduled prompt.

The app continuously and automatically collected phone usage information every day on (1) number of phone calls sent and received, (2) number of text messages sent and received, and (3) time spent on phone calls. The phones were set up to use wireless connectivity; data went to secure servers that could be checked by researchers at any time. No actual content within text messages was captured in order to maintain privacy.

Smartphone Assessment

At chosen prompt times in the morning and in the evening, participants answered 5 questions about their mood at that moment using a visual analog scale on days 1 to 14 and 28 to 56, for a total of 28 days. The rationale for the delivery of the daily prompts for 2 weeks with a 2 week gap was to decrease participant burden across 2 months but also to increase the chances that we collected some dynamic shifts in mood that may have occurred. These questions have been previously validated in a BD sample using a smartphone EMA study [30]. The 5 questions were (1) Rate your mood right now; (2) Rate your energy right now; (3) How fast are your thoughts right now? (4) How impulsive are your thoughts right now? and (5) How impulsive are your actions right now? These measures of symptomatology were selected based on correspondence to independent factors of mania shown through factor analysis: dysphoric mood (mood), psychomotor pressure (energy), psychosis (not conducive to self-report measure), increased hedonic function (impulsivity), and irritable aggression [31,32]. Further, mood, energy, and intellect (thoughts) were the 3 areas

noted through careful longitudinal study of phenomenology by Kraepelin [33] to cycle out of sync, producing mixed states [34].

Prestudy Assessment and Device Training and Postassessment

After consenting, participants completed a 15-minute training session led by trained research associates reviewing the use of an Android smartphone and learning how to respond to the daily app questions. Responses to the daily questions were demonstrated and participants were given an opportunity to practice the use of the responses and ask questions as needed.

All participants were given a Samsung Galaxy Note 4 (Samsung Electronics) smartphone running with the Android 5.1.1 operating system, a charger, and an abbreviated user manual (with a link to a full phone manual). The device was matched to the participant's personal cell phone carrier and their SIM card was placed into the study phone. Two participants chose not to use their current phone services (and personal cell phone numbers) and were provided with study phones with cellular data packages and new phone numbers. One participant did not participate because their personal SIM card was not compatible with the study phone and the participant did not want a different phone number. The device provided to each participant was preinstalled with the smartphone app. Participants' personal contacts, text messages, apps, photos, videos, and music were transferred to the study phones using the Wondershare program (Wondershare Software Co) [35]. Participants were instructed to respond to each of the app's twice-daily prompts to complete questions but to otherwise use the device as they normally would in their daily lives.

All individuals were reassessed at the end of 56 days of using the smartphone. This postassessment included completing a poststudy questionnaire that asked about their experiences and satisfaction using the smartphone, participating in the study, and responding to the daily prompts. Frequencies from this poststudy questionnaire were used as the main dependent variable in the feasibility and acceptability analyses.

Statistical Analyses

We used 2-tailed *t* tests and chi-square tests to describe demographic differences in our diagnostic groups. Bivariate correlations were used to describe the relationship between our adherence rates/app usage, demographics, IQ, clinical scales, and other descriptive variables. Frequency distributions were used to describe the outcomes from the postevaluation assessment results.

When examining the data collected from the smartphone app collapsed across both EMA collection periods, we conducted paired *t* tests to compare the 5 daily self-reported morning mood scores across 28 days—(1) Rate your mood right now; (2) Rate your energy right now; (3) How fast are your thoughts right now? (4) How impulsive are your thoughts right now? (5) How impulsive are your actions right now?—with the same 5 daily self-reported evening mood scores to examine acceptability of averaging these scores by day. These results showed no statistically significant differences between morning mood scores and evening mood scores for all 5 mood questions (all $P > .05$), indicating that each morning and evening mood question response was similar to combine into a single mood question mean score, creating 5 aggregated daily mood scores. We then used mixed effects linear regression models with random intercept to examine the associations of measurements of daily (1) number of phone calls sent and received, (2) number of text messages sent and received, and (3) time spent on phone calls with the 5 average daily mood scores over time (see 5 mood questions above) as outcomes, which took into account the clustering effect of multiple measures over the same participants. Average daily mood scores were used as predictors for phone patterns. All these models were run using just the BD sample adjusted for age, sex, and bipolar diagnosis type (ie, BD-I vs BD-II).

Results

Participant Characteristics

A total of 26 participants in this study had BD (BD-I=17, BD-II=8, BD not otherwise specified=1) and 12 were HC participants with no personal or family history of any psychiatric illness. Out of the 38 participants enrolled, 2 individuals did not complete postassessment measures due to personal or health reasons but completed the daily app prompts. One person was removed from the study due to losing the study phone twice. Due to technical problems with the prompts not appearing during the second survey period, 9 participants have some missing data points.

Descriptive statistics for participants by diagnostic group are in Table 1. The mean age of participants was 44.9 years (SD 9.0). There were no significant differences between the BD and HC participants in age ($t_{36} = -0.44$; $P = .66$), education ($t_{36} = 0.47$; $P = .64$), or IQ ($t_{36} = -0.04$; $P = .97$). The majority of our participants were female (27/38, 71%), with no difference in gender breakdown between BD and HC groups ($\chi^2_1 = 0.2$; $P = .71$).

Table 1. Demographics of participants.

Characteristic	BD ^a (n=26)	HC ^b (n=12)	Chi-square (<i>df</i>)	<i>t</i> test (<i>df</i>)	<i>P</i> value
Age (years), mean (SD)	46.46 (10.55)	44.92 (9.04)	N/A	-0.438 (36)	.66
Gender, n (%)	19 (73)	8 (67)	0.2 (1)	N/A	.69
Years of education, mean (SD)	15.88 (1.86)	16.17 (1.34)	N/A	0.470 (36)	.64
WASI IQ ^c , mean (SD)	108.96 (7.86)	108.83 (11.41)	N/A	-0.040 (36)	.97
HRDS ^d , mean (SD)	12.65 (6.49)	1.25 (1.87)	N/A	-5.933 (36)	<.001
YMRS ^e , mean (SD)	4.50 (4.92)	0.08 (0.29)	N/A	-3.086 (36)	.004
Clinical features for the BD group					
Type of BD (BD-I/BD-II/BD-NOS ^f), n	17/8/1	N/A ^g	N/A	N/A	N/A
Rapid cycling (yes), n (%)	15 (58)	N/A	N/A	N/A	N/A
Age of BD onset, mean (SD)	16.31 (8.06)	N/A	N/A	N/A	N/A
Compliance for full study (%), mean (SD)	92.20 (6.64)	90.63 (9.59)	N/A	-0.535 (31)	.60
Compliance for first 2 weeks of study (%), mean (SD)	92.32 (9.89)	91.83 (8.61)	N/A	-0.147 (36)	.88

^aBD: bipolar disorder.

^bHC: health control.

^cWASI IQ: Wechsler Abbreviated Scale of Intelligence.

^dHRDS: Hamilton Rating Scale of Depression.

^eYMRS: Young Mania Rating Scale.

^fNOS: not otherwise specified.

^gN/A: not applicable.

Study Adherence

Overall, our sample completed 91.5% of prompts sent. There was no difference in total completion rate between the BD and HC groups ($t_{31}=-0.80$; $P=.43$). Bivariate correlations (Table 2)

showed that full study adherence was positively related to IQ ($r=0.45$; $P=.008$), with those with higher IQ completing more app question prompts. However, no other demographics or clinical variables were related to adherence.

Table 2. Correlations between compliance rates, demographics, and mood ratings.

Variable	Compliance first ^a	Compliance total ^b	Age	Education	WASI IQ ^c	HDRS ^d	YMRS ^e
Compliance first							
<i>r</i>	1	0.77	-0.17	0.16	0.28	-0.08	-0.09
<i>P</i> value	— ^f	<.001	.32	.35	.35	.64	.58
Compliance total							
<i>r</i>	0.77	1	-0.23	0.01	0.45	0.21	0.02
<i>P</i> value	<.001	—	.21	.96	.008	.25	.92
Age							
<i>r</i>	-0.17	-0.23	1	-0.03	0.12	0.15	0.12
<i>P</i> value	.32	.21	—	.87	.49	.36	.47
Education							
<i>r</i>	0.16	0.01	-0.03	1	0.08	-0.25	-0.27
<i>P</i> value	.35	.96	.87	—	.62	.12	.11
WASI IQ							
<i>r</i>	0.28	0.45	0.12	0.08	1	0.07	0.05
<i>P</i> value	.35	.008	.49	.62	—	.67	.79
HDRS							
<i>r</i>	-0.08	0.21	0.15	-0.25	0.07	1	0.58
<i>P</i> value	.64	.25	.36	.12	.67	—	<.001
YMRS							
<i>r</i>	-0.09	0.02	0.12	-0.27	0.05	0.58	1
<i>P</i> value	.58	.92	.47	.11	.79	<.001	—

^aCompliance first: compliance rate for first 2 weeks of surveys.

^bCompliance total: compliance rate for all 4 weeks of surveys.

^cWASI IQ: Wechsler Abbreviated Scale of Intelligence.

^dHDRS: Hamilton Depression Rating Scale score (at baseline).

^eYMRS: Young Mania Rating Scale score (at baseline).

^fNot applicable.

Usability and Acceptability

Using the combined postassessment evaluation responses (Table 3), which 36 out of the 38 participants completed, 35 out of 36 participants (97%) did not have difficulties understanding the mood questions. While 15 out of 36 participants (42%) did not find the phone comfortable to carry, 33 out of the 36 participants (92%) did not have difficulties pressing response keys. When looking at evaluation responses for both BD and HC groups together, 34 out of 36 participants (94%) did not find that the

daily questions took too much time to complete, and 27 out of 36 participants (75%) indicated that answering the questions was helpful for them to monitor their moods. In addition, 26 out of 36 participants (72%) indicated that participating in this study had been helpful/beneficial, and 32 out of 36 participants (89%) did not believe participation in our study took up too much time. Overall, 34 out of 36 participants (94%) believed this experience was pleasant, and 33 out of 36 participants (92%) would recommend others participate in a similar study.

Table 3. Subject ratings on poststudy evaluation for 36 out of 38 participants.

Evaluation question	Strongly agree/agree, n (%)	Neutral, n (%)	Strongly disagree/disagree, n (%)
I had difficulties understanding the survey questions.	0 (0)	1 (3)	35 (97)
Answering the questions was helpful for me to monitor my mood/functioning.	27 (75)	4 (11)	5 (14)
The daily tasks or use of the Jawbone activity tracker changed my behavior in some way.	21 (58)	5 (14)	10 (28)
Participation in this study took up too much time.	2 (6)	2 (6)	32 (89)
Participating in this study has been helpful/beneficial.	26 (72)	6 (17)	4 (11)
Overall, this experience was pleasant.	34 (94)	1 (3)	1 (3)
Overall, this experience was challenging.	13 (36)	3 (8)	20 (56)
I would recommend others participate in a similar study.	33 (92)	0 (0)	3 (8)

Mixed Linear Effects Models

The multivariate mixed effect model for only the BD participants showed that an increase in text messages was associated with higher overall mood ratings ($\beta=.04$; $P=.04$). Decreased outgoing text messages was associated with an increase in rapid thoughts ($\beta=-.02$; $P=.04$). Total duration of calls was found to negatively associated with impulsivity ratings (impulsivity in thoughts and impulsivity in behavior) over time (thoughts: $\beta=-.29$; $P=.02$; behavior: $\beta=-.16$; $P=.05$).

Discussion

Principal Results

These results indicate that individuals who experience chronic and fluctuating changes in their mood are open to and respond adequately to twice-daily surveys about their mood using devices that they use on a regular basis, suggesting that this type of assessment could be acceptable to patients in practice. The completion rate of daily questions was similar to unaffected, healthy controls. Both diagnostic groups completed 91% of the questions sent to them. These findings suggest that this type of daily assessment is feasible to incorporate into measurement-based care initiatives and could provide a unique way of accurately and efficiently monitoring changes in functioning and clinical phenotypes. Further, our participants, including the individuals with BD, generally endorsed positive responses regarding use of the smartphone app. Using EMA on smartphones can serve as a way in which patients can self-monitor their symptoms and functioning, which subsequently could allow them to take part in the medical decision making. It could provide a quicker and cost-effective way to inform providers that patients are at risk or in the beginning stages of a relapse.

In line with our hypotheses, symptoms associated with increased energy and activation, including elevated mood, more impulsivity in thoughts and behaviors, and rapid thoughts, were associated with specific objective smartphone behaviors. Notably, higher mood was associated with more incoming text

messages, rapid thoughts were associated with fewer outgoing text messages, and impulsivity was associated with shorter call duration. There was not one pattern of increased objective phone behavior associated with increased self-reported activity and activation states, but rather symptom-specific relationships. Our findings suggest that increasing mania-like symptoms correlate with decreasing phone communication habits using text messages and phone calls. The more mania-like symptoms, the less the participants engaged in communication activities on their phone, despite receiving more text messages. These are promising results that suggest that smartphones could be an easy and objective monitoring tool to capture illness activity in bipolar disorder, particularly shifts in mania-like symptoms. Further work will examine if passive phone behavior patterns can be predictive of future mood symptoms within individuals or are correlated with mania-like symptoms that meet threshold for a full manic episode. For example, can passive phone behaviors the week or two before a mood episode be predictive of the impending mood episode? Additional research could also investigate if other smartphone activities using sensor data (eg, accelerometer, access to social media, etc) also change with increasing mania symptoms.

We did not find a relationship between smartphone behaviors and depression-like symptoms, in contrast to our hypothesis and some recent literature [21], suggesting that it is the increase rather than decrease in psychomotor activity that is likely reflected in phone usage patterns. This may reflect how mood was captured, as depressive symptoms were only assessed via 1 question (eg, rate your mood from low to high). In contrast to Faurholt-Jepsen and colleagues [21], who found that greater depression symptoms were associated with more incoming calls, we did not find a relationship between mood and number of incoming or outgoing calls. Further, Faurholt-Jepsen and colleagues found that higher mood was associated with more outgoing texts and longer duration of calls, but they captured mood ranging from “depressive to manic” using a scale from -3 to $+3$, whereas we divided mania-like symptoms into some of mania’s component parts (rapid thoughts, impulsivity). We found that faster self-reported thoughts and greater impulsivity

were associated with fewer outgoing texts and shorter call duration, respectively, indicating that mania-like symptomatology rather than global ratings of mood may have a differential effect on phone behaviors.

Limitations

Mobile health studies of this kind, particularly as studies now are focusing on chronic mental health disorder, are in their infancy. Limitations may impede overall interpretation of findings and will need to be addressed in future studies. Given our small sample size, our group of participants with bipolar disorder may not be reflective of the broader, heterogeneous nature of the bipolar disorder illness. The design of our study was targeting a narrow group of individuals with bipolar disorder (those with frequent mood fluctuations who were generally highly educated) who are likely more technology oriented, motivated to participate in research, and more willing to complete daily assessments than is the larger bipolar disorder population. For example, our sample was already actively engaged in a longitudinal study of bipolar disorder, so they were likely more willing to engage in other research studies and participate in daily activities than are other individuals who are not volunteering their time. Frequencies regarding usability may therefore be skewed compared with the general bipolar disorder population. In general, our findings may not be generalized to the broader bipolar disorder population or general population who use phone apps. Along the same lines, we may lack adequate power to find other meaningful relationships in the data. These results are preliminary and may not be capturing the smartphone behaviors that are reflective of mood states, and further replication is needed. Future studies should examine the feasibility in measuring mood over longer study periods, as there may be a period when individuals no longer are motivated to or see any benefit in measuring their own mood over time. Further validation analyses are underway to examine the validation of our single mood items, as they relate to the gold standard, clinician-administered measures of mood. These results are limited by use of only Android system users, and this may be a different subgroup of individuals. There may also be constraints of having our participants use study-issued phones that may inadvertently interfere with their normal use of the

phone. Lastly, we cannot state if a relationship exists between phone behaviors and subsequent emergence of a diagnosed manic episode because full mood episodes were not measured by a clinician rater.

Conclusions

Overall, our sample of individuals diagnosed with bipolar disorder showed a very high adherence rate to the daily momentary assessments, and they generally had positive evaluation responses, indicating that our smartphone app was acceptable and that this type of study design is feasible to use in individuals with BD who have frequent fluctuations in mood. Use of this type of mobile technology shows promise as a way to collect important clinical information that can be used to inform treatment decision making and monitor outcomes in a manner that is not overly burdensome to the patient or providers. It further highlights the feasibility of collecting these types of data for measurement-based care for patients who are already engaged in mental health treatment. Our participant evaluations of the app indicated that they did not find this type of assessment burdensome and that it made them think about their mood and behavior. Future studies based on further development of this app are aimed at investigating if engaging patients to assess their own symptoms and daily functioning may empower self-awareness and self-management of symptoms and help patients identify triggers, track their own disease progression, and learn when to seek out care.

Smartphones, which are ubiquitous within our culture and used by the majority of individuals, including those with chronic conditions, hold immense opportunities to study human behavior. For those with bipolar disorder, smartphones and specifically communicative behavior on smartphones (eg, how often one makes phone calls, number of text messages sent and received) show promise by providing proxy information about illness activity in bipolar disorder. Changes in communicative behavior may indicate an increase in mania-like symptoms and further be an indicator for a problematic mood shift towards a manic episode. This type of research is in its infancy for mental health researchers, but studies of this kind can help launch future work to investigate the potential that technology-related behaviors have on understanding disease.

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Conflicts of Interest

MGM has affiliations with Janssen Pharmaceuticals. AJL owns Apple stocks and has a family member who was an employee for Samsung Electronics until 2014. All other authors report no competing interests.

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Abbreviations

- BD:** bipolar disorder
DIGS: Diagnostic Interview for Genetic Studies
EMA: ecological momentary assessment
HC: healthy controls

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Original Paper

The VOICES Typology of Curatorial Decisions in Narrative Collections of the Lived Experiences of Mental Health Service Use, Recovery, or Madness: Qualitative Study

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Abstract

Background: Collections of lived experience narratives are increasingly used in health research and medical practice. However, there is limited research with respect to the decision-making processes involved in curating narrative collections and the work that curators do as they build and publish collections.

Objective: This study aims to develop a typology of curatorial decisions involved in curating narrative collections presenting lived experiences of mental health service use, recovery, or madness and to document approaches selected by curators in relation to identified curatorial decisions.

Methods: A preliminary typology was developed by synthesizing the results of a systematic review with insights gained through an iterative consultation with an experienced curator of multiple recovery narrative collections. The preliminary typology informed the topic guide for semistructured interviews with a maximum variation sample of 30 curators from 7 different countries. All participants had the experience of curating narrative collections of the lived experiences of mental health service use, recovery, or madness. A multidisciplinary team conducted thematic analysis through constant comparison.

Results: The final typology identified 6 themes, collectively referred to as VOICES, which stands for values and motivations, organization, inclusion and exclusion, control and collaboration, ethics and legal, and safety and well-being. A total of 26 subthemes related to curation decisions were identified.

Conclusions: The VOICES typology identifies the key decisions to consider when curating narrative collections about the lived experiences of mental health service use, recovery, or madness. It might be used as a theoretical basis for a good practice resource to support curators in their efforts to balance the challenges and sometimes conflicting imperatives involved in collecting, organizing, and sharing narratives. Future research might seek to document the use of such a tool by curators and hence examine how best to use VOICES to support decision making.

KEYWORDS

personal narrative; mental health recovery; decision making

Introduction

Background

Lived experience narratives are increasingly central to medical practice [1] and web-based mental health interventions [2], with a growing interest in the use of web-based mechanisms for delivering and accessing them [3]. They can be recorded and published in different ways, such as text, video, audio, art, or mixed media [4]. They can present narratives of a single author, such as *Madness Made Me* [5], or present groups of narratives edited by a curatorial team, such as *Living with Voices* [6]. Wide-scale public access to digital media hosting platforms is a relatively recent phenomenon, which now allows the presentation of a person's narrative to a worldwide audience [4]. Generic digital media hosting services now enable recorded versions of narratives to be shared directly with recipients on a mass scale, and thousands of lived experience narratives have been uploaded and are freely available to the public.

Narratives are *representations of a real or fictitious event or series of events* [7]. Lived experience narratives can explore events such as mental health service use or experiences of mental health problems, either grounded in a biomedical understanding of mental health or conceptualized as madness, which looks more widely at psycho-socio-political issues, emotional distress, and/or spiritual emergence [8]. Lived experience narratives may or may not be classed as recovery narratives. The term recovery narrative refers to a story told by a person about their journey of recovery. This includes elements of both adversity or struggle, and of strength, success, or survival related, at least in part, to mental health problems (ie, about recovery), and which refer to events or actions over a period of time (ie, a narrative) [9]. Recovery narratives have been studied as a mechanism for understanding how recovery happens [10] and as a recovery-promoting tool with potential benefits for the narrator, such as storytelling as a route to reframing emotional distress, as a part of narrative therapy practice [11]. Recovery narratives can also offer a source of knowledge and hope for the narrators and recipients [12].

There is disagreement and debate over the use and framing of what constitutes *recovery narratives*. Recovery in the Bin, which describes itself as a critical theorist and activist collective [13], has questioned the content and use of recovery narratives in that, for example, only *successful* or *acceptable* recovery narratives are promoted in services. They call for "a broader range of Survivor narratives to be recognised, honoured, respected and promoted that include an understanding of the difficulties and struggles that people face every day when unable to 'recover', not just 'successful recovery' type stories" [13]. Recovery began as a social justice movement led by survivors and service users with the aim to reform health services and promote patient-centered care defined as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all

clinical decisions" [14]. The movement rejected the notion of mental health diagnosis and called for a nonpathologizing and holistic treatment of mind and body, adopting a unified language of patient-centered care rather than perpetuating, through language and action, a division between physical and mental health [15]. The narratives of mental health service use, recovery, and madness have played a role in the personal and collective journeys of narrator emancipation from psychiatric judgment [16] and have been used to reshape clinical and scientific responsibilities [6], challenge conceptualizations of biomedical paradigms [17], and inform policy change [18] or as tools of resistance, opposition, collective action, and social change [19].

As narratives about recovery or madness inherently incorporate discussions of personal distress or trauma, there are challenges in the design of curatorial processes such as personal, legal, or ethical dilemmas linked to the identification of narrators or third parties. They also include broader ethical and political issues related to the representation and dissemination of distressing and difficult material, which might affect those exposed to recovery narratives and those producing them [20]. In addition, there are unresolved questions about what it means to reinscribe the identity of the service user or survivor, through the use of recovery narratives, as one closely associated with distressing events or experiences. Moreover, issues around power and control are especially relevant in curation processes owing to the existing inequalities of power, status, or assumed credibility of service users, providers, and professionals [21]. All these issues are made more complex when one considers them intersectionally and attends to gender, ethnicity, sexuality, gender identity, and disability as well as the experience of distress.

Some guidelines for the curation of recovery narratives based on experience and expert judgment have been published, for example, guidelines by the Scottish Recovery Network [22]. However, there is no research leading to a comprehensive typology of curatorial decisions for recovery or madness narratives. There is a need to outline all the critical considerations for the curation of narratives, including those that individual curators may not automatically consider without guidance. Previous guidance may be organizationally or culturally specific and may not be relevant across different contexts. A typology might support the work of future curators of recovery or madness narrative material, for example, by informing the design of a decision aid tool [23].

Initial insights into curatorial practices have been developed in a systematic review and qualitative evidence synthesis [20]. The review included 1 research publication and 22 informal documents providing evidence of curation. These were synthesized to develop a preliminary typology that described 9 curatorial issues and choices: (1) purpose of the collection, (2) audience for the collection, (3) safety (of narrators, recipients, and third parties), (4) narrative collection process, (5) narrative

selection process, (6) narrative editing process, (7) narrative presentation choices, (8) ethical and legal considerations, and (9) the societal positioning of the collection. The review only included publicly available documents. Their accuracy in reflecting decisions made around curation could not be verified and therefore may not have provided full information about all curatorial decisions made because curators may not have discussed some decisions publicly.

Aims and Objectives

The aim of this study is to extend the prior review by directly consulting expert curators about the work of curation. The objectives of this study are to develop a typology of curatorial decisions involved in curating narrative collections of the lived experiences of mental health service use, recovery, or madness and to characterize existing approaches used in relation to identified curatorial decisions.

Methods

Study Approvals

The study was conducted as part of the Narrative Experiences Online (NEON) Programme [24], which is a program of work investigating whether engagement with mental health recovery narratives can influence an individual's recovery journey (ISRCTN1152837). The study was reviewed and given a favorable opinion by the Nottingham 2 Research Ethics Committee (reference 17/EM/0401) and was approved by the UK Health Research Authority. In line with the approved protocol, all participants gave verbal consent, which was recorded on a paper consent form by the researcher. The findings will inform a future trial (ISRCTN1152837).

Participants

The inclusion criterion for participants was experience of curating 1 or more narrative collections of the lived experiences of mental health service use, recovery, or madness. Collections were considered relevant if the majority of narratives in the collection matched any of those 3 categories, or if the curator identified the collection with any of them. The meaning of the term madness was as discussed in Mad studies [25], which challenges the biomedical interpretations and language of mental health discourse. This usage has emerged through the psychiatric survivor and peer support movement.

To maximize heterogeneity, maximum variation sampling [26] was used across the dimensions of (1) the country of publication of the collection to capture country-specific social, cultural, and political contexts and (2) the presence or absence of curator lived experience of using mental health services (ie, non-mental health service user, primary care service user, secondary care service user, voluntary hospital admission, or involuntary hospital admission) to capture service user curator perspectives. Deviant case sampling was used to illuminate both unusual and typical decision-making strategies [27].

Procedures

A semistructured interview was conducted with an expert curator. The expert curator played a lead role over 12 years in the development of an extensive recovery narrative repository

containing multiple collections, the development of guidelines for narrative collection, the conduct of narrative-based research, and the development of a recovery narrative-based online intervention. Data from the interview were used to develop an initial list of curatorial decisions and approaches. This was refined through 6 consultations with the expert curator. A preliminary typology of curatorial decisions and approaches was developed by synthesizing the initial expert curator list with material presented in an earlier systematic review [20]. The preliminary typology, which had 11 themes, can be found in [Multimedia Appendix 1](#) [1].

Semistructured interviews were then conducted with 30 other curators, either in person (n=4) or by phone (n=17), video call (n=8), or, if no other option was available, by email (n=1). Each participant was given a unique identifier. A demographics form was used to capture the curator background. The interview schedule was initially derived from the preliminary typology using open questions relating to each of the 11 themes, and then refined over the course of the interviews as new themes emerged. Participants were asked to comment on a recent collection they had curated and whether they had considered each of the 11 themes in the process of curation and what decisions they had made with respect to these. Interviews lasted 60 to 90 min and were audiotaped and transcribed using pseudonymization.

Analysis

The analyst team consisted of 10 researchers from a range of disciplinary (survivor research, sociology, philosophy, social anthropology, digital research, organizational development, health research, and youth work) and clinical professional (mental health nursing and clinical psychology) backgrounds. A thematic analysis of transcripts by constant comparison was conducted [28] using NVivo 12 Pro (QSR International) for coding work. First, 2 analysts (CY and LHD) coded the same 6 transcripts to establish a shared understanding of the data in the form of a preliminary coding framework. This consisted of a range of superordinate themes and subthemes describing the issues considered by curators, with subthemes selected to describe specific curatorial considerations and superordinate themes selected to provide a higher-level structure. Thereafter, 3 analysts (CY, LHD, and KP) coded a further 3 transcripts to check for consistency of coding and to refine the coding framework. The remaining transcripts were then coded by CY and LHD to further develop the coding framework. The wider analyst team met every 5 to 10 transcripts to discuss newly transcribed elements and generate a set of suggested updates to interim versions of the coding framework, such as adding, splitting, or relabeling superordinate themes, or adding or splitting subthemes. Once the analysis work was complete, the coding framework was tabulated. An illustrative question was chosen to represent each subtheme, and text coded against each subtheme was examined to identify example approaches chosen by a curator. Tables are presented in the *Results* section with illustrative transcripts fragments, each accompanied by the participant identifier, for example, [#30] for the participant allocated identifier 30. We also summarize the preliminary typology and present a descriptive analysis of participant demographics.

Results

Preliminary Typology

The preliminary typology ([Multimedia Appendix 1](#)) offered considerations and strategies relating to 12 themes: context, purpose, curatorial team, audience, legal and copyright, collection, selection, editing, safety and well-being, presentation, language, and ordering.

Participants

A total of 30 interviews were conducted with curators of art exhibitions (8/30, 27%) and book or online narrative collections (22/30, 73%), with collections published in 7 countries: the United Kingdom (18/30, 60%), the United States (6/30, 20%), Canada (2/30, 7%), Brazil (1/30, 3%), Hong Kong (1/30, 3%), India (1/30, 3%), and Italy (1/30, 3%). Overall, 60% (18/30) curators had used mental health services, comprising primary care (1/30, 3%), secondary care (6/30, 20%), voluntary hospitalization (8/30, 27%), and involuntary hospitalization (3/30, 10%). [Table 1](#) presents the additional sociodemographic characteristics collected.

Table 1. Sociodemographic characteristics of participants (N=30).

Characteristics	Participants, n (%)
Gender	
Female	19 (63)
Male	11 (37)
Ethnicity	
White	24 (80)
Asian	3 (10)
Black	1 (3)
Multiple ethnic groups	1 (3)
Prefer to self-describe	1 (3)
Age (years)	
<25	2 (7)
25-34	4 (13)
35-44	13 (43)
45-54	5 (17)
55-64	5 (17)
>64	1 (3)
Sexual orientation	
Heterosexual	22 (73)
LGBTQ+ ^a	4 (13)
Prefer to self-describe	2 (7)
Prefer not to say	2 (7)
Educational level	
Higher degree	23 (77)
Bachelor's degree	7 (23)
Employment status	
Full-time paid employment	18 (60)
Part-time paid employment	5 (17)
Self-employed	2 (6)
Student	2 (6)
Volunteer	2 (6)
Retired	1 (3)
Did the participant declare a disability?	
No	23 (77)
Yes	7 (23)
Income, £ (US \$)	
<10,000 (<13,000)	4 (13)
10,000-15,000 (13,000-19,500)	1 (3)
15,001-20,000 (19,501-26,000)	3 (10)
20,001-35,000 (26,000-45,500)	6 (20)
35,001-50,000 (45,501-65,000)	6 (20)
50,001-100,000 (65,001-130,000)	5 (17)
>100,000 (>130,000)	1 (3)

Characteristics	Participants, n (%)
Prefer not to say	2 (6)

^aLGBTQ+: lesbian, gay, bisexual, transgender, queer.

The VOICES Typology of Curatorial Decisions

The final coding framework identified 6 superordinate themes relating to the process of curation: values and motivation,

organization, inclusion and exclusion, control and collaboration, ethical and legal, and safety and well-being. These themes are collectively referred to as VOICES. These are listed in [Textbox 1](#), with all identified subthemes.

Textbox 1. Themes and subthemes identified in the VOICES typology of curatorial decisions.

<p>Values and motivation</p> <ul style="list-style-type: none"> • Guiding values • Purpose • Audience • Context <p>Organization</p> <ul style="list-style-type: none"> • Identification • Collection process • Presentation • Impact and Evaluation <p>Inclusion and exclusion</p> <ul style="list-style-type: none"> • Selection and inclusion • Exclusion • Editing • Language <p>Control and collaboration</p> <ul style="list-style-type: none"> • Role of curator • Curatorial team • Power dynamics • Working together <p>Ethics and legal</p> <ul style="list-style-type: none"> • Anonymization • Consent process • Data security • Funding • Payments • Copyright and ownership • Withdrawal process <p>Safety and well-being</p> <ul style="list-style-type: none"> • Safety and well-being • Distress • Trigger warnings

Theme 1: Values and Motivations

The values and motivations theme detailed in Table 2 included participants' guiding values (how they conducted their work) and their purposes (why they conducted their work), the audience they aimed their collection at, and the external factors that influenced how their collections were built. The purpose of building a collection could be at an individual level, for example, giving a narrator a place to tell their story, or at a collective level, such as building an evidence base for a rights movement, or both:

She contrasted writing to self-harm...So rather than carving you know, symbols on her body, she felt that writing her story was an alternative to self-harm...and you know write in a more public fashion rather than on her body because she felt that by harming herself she was actually complicit in her own abuse and subjugation, so there was a lot of social impact there. [#30]

It was to start...a human rights movement so I thought okay there's been a black rights movement, a gay rights movement, and we need a mental health rights movement. [#19]

Table 2. Values and motivations in creating a collection.

Subthemes	Illustrative question	Identified approaches
Guiding values	What values will guide curatorial work?	<ul style="list-style-type: none"> • Values defined collectively (eg, community-based, political, societal) • Values defined organizationally (eg, by the mental health trust that has commissioned the collection) • Personal values (eg, those of the curators, narrators, or publishers)
Purpose	What are the intended purposes of the collection?	<p>Individual purposes:</p> <ul style="list-style-type: none"> • Generating artistic acclaim or academic success • Generating personal economic gain • Enhancing the personal recovery of curators, narrators, and/or recipients <p>Collective purposes:</p> <ul style="list-style-type: none"> • Building a narrative collection to act as an evidence base for rights movement • Building capacity among service users, survivors, and allies • Facilitating emancipatory action • Enabling re-evaluation of values • Improving mental health and social care services from youth to old age • Opening dialogue between different voices • Educating or critiquing organizational, community, societal, or political aspects or structures • Supporting organization, peer support, and solidarity • Enabling the definitions of mental illness to be reconceptualized • Enabling the voices of recovery or madness to act as agents of change
Audience	Who are the desired audiences?	<ul style="list-style-type: none"> • Specific subgroups (eg, activists, artists, mental health workers, people with mental health issues, problems or distress, users of mental health services, their families, and/or carers, or people with a BAME^a ethnicity) • General public • Governments or political bodies
Context	What external factors influenced curation?	<ul style="list-style-type: none"> • Economic perspectives • Cultural perspectives • Organizational perspectives (eg, if the collection is curated within a mental health trust) • Political perspectives • Societal perspectives

^aBAME: Black, Asian, and Minority Ethnic.

Theme 2: Organization

The organization theme shown in Table 3 describes the practical organizational processes of building a collection and curating. These include the identification of narrators, the collection

processes used to capture narratives, communication methods with the narrator, the curatorial resources required, how narratives were presented, and how they aimed to measure the impact of the collection.

Table 3. Organizing and presenting collections.

Subthemes	Illustrative question	Identified approaches
Identification	How to identify and recruit narrators for the collection?	<ul style="list-style-type: none"> • Placement of advertising (eg, social media, posters, leaflets) • Working with charities • Working with health services • Engaging with existing community groups • Use of existing contacts of the curator • Engaging with recovery education programs • Targeting specific communities • As part of a wider research or arts project
Collection process	How to capture and/or produce the narratives?	<ul style="list-style-type: none"> • By email or post • Through an interview • Through one-on-one creative activities • Through a video call • Through group workshops (sometimes scheduled alongside other training activities)
	How to communicate with the narrator?	<ul style="list-style-type: none"> • Email • Face-to-face • Phone • Video call
	What resources are required?	<ul style="list-style-type: none"> • Clinical support • Funding • Peer support • People • Time
Presentation	How will the narratives be presented?	<ul style="list-style-type: none"> • Exhibits at an art exhibition • Book • Booklet • Event • Film • Forum • Online collection • Song • Video
Impact and evaluation	How do you measure the impact of the collection?	<ul style="list-style-type: none"> • Analysis of feedback forms • Popularity of the collection as determined by the audience size • Through a research project evaluation

Theme 3: Inclusion and Exclusion

The inclusion and exclusion themes shown in [Table 4](#) include the decisions relating to the selection and inclusion or exclusion of narrators or narratives and editing of narratives and language. Some participants described their power in the process of curation as they aimed to ensure that certain voices and narratives were not ignored or silenced owing to their social or political dimensions:

It is real life stories, it is truth, it is from the underground, it is the untold stories, it is for people who are on the margins of society, it is those who do not have a voice, so you know I think it is hugely important and it is giving value to their voice and you know, it is a whole world really that is not seen in the mainstream, so I think it has got huge political relevance. [#24]

Table 4. Selection, inclusion and exclusion of narratives, narrators, and language.

Subthemes	Illustrative question	Identified approaches
Selection and inclusion	On what basis should narrators be selected for inclusion?	<ul style="list-style-type: none"> • Clinically defined diagnosis of the narrator • Demographic factors (eg, narrator is a member of a BAME^a community) • Place of residence (eg, in a collection focused on a particular country) • History of narrator service usage • Narrator's personal philosophy, values, or views
	On what basis should narratives be selected for inclusion?	<ul style="list-style-type: none"> • Content of the narrative • Curator-defined quality of writing • Sociopolitical standpoint of the narrative • Trajectory of the narrative (eg, narrative ends hopefully) • Nature of the experience described, such as in a collection focused on presenting spiritual experiences
Exclusion	On what basis should narrators be excluded?	<ul style="list-style-type: none"> • Conflict of personal philosophy, values, or views between the curator and the narrator • Legal concerns around the narrator's current status • Presence of safeguarding concerns in relation to the narrator • Sociopolitical standpoint of the narrator • No basis—narrators should not be excluded
	On what basis should narratives be excluded?	<ul style="list-style-type: none"> • Defined quality of writing • Legal concerns around the content of the narrative • Modality of narrative • Presence of safeguarding concerns in relation to the content of the narrative • Sociopolitical standpoint of the narrative • Narrative length • Narrative structure • Narrative subject • No basis—narratives should not be excluded
Editing	What characteristics will a narrative be edited for?	<ul style="list-style-type: none"> • Content • Length • Language • No editing • Style
Language	How does language need to be changed?	<ul style="list-style-type: none"> • Alter grammar or spelling • No change • Remove discriminatory language • Remove expletives

^aBAME: Black, Asian, and Minority Ethnic.

Inclusion and exclusion occurred at either the narrator or the narrative level. At the narrator level, inclusion by both the curator and the narrator could be either conscious or unconscious. Some groups may not be actively approached owing to oversight or the curator may lack time, motivation, knowledge, skills, or resources to engage with certain communities or marginalized groups. In some instances, the needs that would enable inclusion were not met owing to a number of factors. These factors included a lack of funding for the narrator's payment, not providing sufficient reasonable adjustments for people with physical or mental health disabilities, such as British sign language interpreters or wheelchair-friendly venues, or owing to misunderstanding around benefits situations. Some potential narrators self-excluded owing to the fear of different kinds of reactions, including punitive actions:

...because of the benefits situation, they preferred just to have their travel expenses and food reimbursed

and things like that...there was so much fear associated with benefits and in claiming benefits that it's just not worth it...there's one person that wouldn't take part because they thought that if somebody saw it they would think oh well you are well enough to be in that video and tell your story so therefore you are fit for work. [#25]

At the narrative level, the inclusion and exclusion of both content and style, including vocabulary language and grammar, raised issues around maintaining the narrator's voice and meaning and ensuring the ethical representation of cultures in which narrators were embedded. Standardization of language and grammar may be seen as exerting class power or diminishing certain communities:

We have a made up word in here and I had a lot of wrangling with the publisher because he didn't want me to use a made up word and I was fairly insistent

that the made up word said more than any real word ever could...It was her word. It was hers, it was her way of expressing herself in a story that is full of really long words actually and a really expressive story. [#16]

There were issues around some people's language as their first language was not English, I corrected their English and made it grammatically correct. I don't think I captured that person's voice. [#01]

Theme 4: Control and Collaboration

It's important people have their own voice not their voice filtered through my voice. [#02]

The control and collaboration themes shown in [Table 5](#) include the types of roles adopted by participants in the curatorial process, the desired skills and experience of the curatorial team, how issues of power were considered in the process, and how different parties worked together. Participants described how they approached the role of the curator either in a distant editorial role with very limited contact with narrators, a controlling role, or in a collaborative role of varying degrees.

Table 5. Control and collaboration in the curation of collections.

Subthemes	Illustrative question	Identified approaches
Role of the curator	What type of role should be adopted by the curators?	<ul style="list-style-type: none"> • Artist • Coproducer • Editor • Facilitator • Guide • Inspiration • Interviewer • Leader • Partner • Peer • Supporter • Writer
Curatorial team	What skills and experience are needed on the curatorial team?	<ul style="list-style-type: none"> • Academic • Activism • Community engagement • Curatorial experience • Experience as an artist • Lived experience of the subject of the collection • Mental health professional training
Power dynamics	How will issues of power within the curatorial team and between the curator and the narrator be addressed?	<ul style="list-style-type: none"> • Coproduced guidelines • Curator-produced guidelines • Individual discussion • Group discussion • Not addressed or considered
Working together	How will the curatorial team work with the narrators?	<ul style="list-style-type: none"> • Collaborative approach • Coproduction • Curator-led process • Narrator-led process • Participatory approach

Participants either worked alone or as part of a curatorial team, as an independent, employed by, for example, a mental health trust or charity, or unpaid. Curatorial teams were made up of people from a variety of backgrounds, such as clinical, art, or academic backgrounds and with varying degrees of lived experience of mental health service use. Some team members who were also service users stated that they felt that other team members had taken advantage of their naivety, enthusiasm, and passion, or played on their anxiety or feelings of paranoia. An example of this was with 1 participant who had worked with their former social worker and had felt unable to oppose the decision to employ this person on the curation project:

I think it's a kind of general thing among the survivor service user community that we really want to help

one another and we really want to be positive and we really want to give, to volunteer, to be involved and I think a lot of time that is taken advantage of. [#01]

Theme 5: Ethics and Legal

The ethics and legal themes shown in [Table 6](#) includes decisions around narrative anonymization, consent processes, data storage and security processes, project funding, payments to different parties, copyright and ownership issues, and withdrawal processes. Some participants struggled with ethical dilemmas. An example of this was a participant who considered that the withdrawal of stories may affect the collective cause of the website. They had an official policy of not allowing withdrawal; however, in certain instances, this rule was broken owing to safety concerns:

Sometimes people get cold feet or they just get nervous about stigma, and they don't have like a real immediate threat to their livelihood or wellbeing...our official policy...we don't take down any published content on the site at all for any reason, but realistically we do if someone has a safety concern, or there was a situation where an author became psychotic...journalism is sort of sacred...you don't just unpublish an article because someone is upset...it's part of the ongoing conversation...If

everyone had second thoughts about their story and asked for it to be taken down, if you said 'yes' to all those, we would have a lot less content on the site and sometimes the stories that we do sometimes end up taking down...they were very powerful and important stories and now they are not out there, now no-one will ever read them...it's kind of like balancing the needs of the individual writers with the needs of the movement or society. [#30]

Table 6. Ethical and legal considerations in the curation of collections.

Subthemes	Illustrative question	Identified approaches
Anonymization	How will narratives be anonymized?	<ul style="list-style-type: none"> • Anonymize all names and details that would make anyone identifiable • Anonymize narrator name and/ or details • Anonymize third parties • Offer each narrator choice as to what to anonymize • No anonymization
Consent process	How will consent for narrative inclusion be gained?	<ul style="list-style-type: none"> • Use of consent forms • No consent process • Verbal consent in person or by phone
Data storage and security	What data security procedures will be used?	<ul style="list-style-type: none"> • Use of data encryption when storing material • Use of a locked room and/or storage for data • None
Funding	How will the project be funded?	<ul style="list-style-type: none"> • Charity donation or independent funding body • Crowd funding • Individual sponsor • Government funding • Self-funded
Payments	What will be the payment processes for different parties?	<ul style="list-style-type: none"> • Employment contract • Expenses paid • Fixed sum paid • Royalties paid • Unpaid
Copyright and ownership	Who will own the copyright to the narratives?	<ul style="list-style-type: none"> • Curators • Joint ownership • Narrators • Publishers
Withdrawal process	What process will be put in place for the withdrawal of narratives?	<ul style="list-style-type: none"> • No withdrawal allowed • Withdrawal permitted at any point until publication • Withdrawal after publication possible

Theme 6: Safety and Well-Being

The safety and well-being theme shown in [Table 7](#) includes the types of support the curators, narrators, recipients, and third parties received during the curation process, the participant's approach to uncertainty and distress, and if and how trigger warnings were used. Participants used different approaches to deal with distress. Some participants decided to avoid the discussion of difficult subjects or to not *press* on triggering subjects such as experiences of abuse, as they considered this to be damaging. Other participants believed in tolerating the uncertainty of possible negative consequences by delving deeper into a challenging narrative and that taking risks can be beneficial to the narrators and the recipients:

Most people expect their stories to be, I don't want to say raped, that's not the right word, but taken advantage of for the use of other people...they were afraid that I was going to try and twist and portray their story into a harmful light or into one that would make them re-experience trauma and so I had to assure them that it was safe and that I also was not going to be damning them through my editing of their stories. [#18]

Art making is risk taking...and there is benefits to the artists, the benefits then to the visitors to the public that come and really art for them is asking them questions, it is giving them different perspectives on

the world, sometimes is around mental illness...art is a great space for kind of breaking down barriers

between...the public and asylum and public and hospital. [#10]

Table 7. Safety and well-being in the curation of collections.

Subthemes	Illustrative question	Identified approaches
Individual safety and well-being of the curators, narrators, recipients, and third parties	What support will be offered to the curators, narrators, recipients, and third parties?	<ul style="list-style-type: none"> • None • Online group • Peer or group support • Supervision • Support of clinician • Support of family or friend • Support pack including items such as coloring books, mindfulness exercises, and support group contact details
Uncertainty and distress	How to approach uncertainty and distress?	<ul style="list-style-type: none"> • Avoidance of difficult subjects • Avoid pressing on triggers • Tolerate different levels of uncertainty in times of distress and if deemed safe delve deeper
Trigger warnings	How will trigger warnings be used?	<ul style="list-style-type: none"> • Broad trigger warning for whole collection • Not used • Used on all individual narratives • Used on a select number of narratives

Discussion

Principal Findings

This study collected and analyzed the experiences of curators of collections of the lived experiences narratives of mental health service use, recovery, or madness. The resulting VOICES typology identifies 6 curatorial decision-making themes: values and motivations, organization, inclusion and exclusion, control and collaboration, ethics and legal, and safety and well-being. Our work addresses a knowledge gap related to curatorial decision making that is not available in public documents [20]. Drawing on potentially unpublished insights collected through interviews with curators, it provides a richer understanding of the intended purpose of these collections than the previous work and a richer understanding of how curators collaborated with narrators and worked to control the process of building collections. The identification of 26 subthemes and more than 100 approaches taken by the existing curators may provide the future curators with knowledge to guide their curation process.

Relationship With Existing Work

Values and Motivations

It has been argued that to understand and facilitate processes of resilience and recovery, there is a need "to end the silence imposed on people with psychiatric disabilities" and value and honor the personal and collective voices of their lived experience [12]. The operationalization of the concept of recovery within mental health systems has come under increasing criticism for shifting from a collective social responsibility to a private, individual responsibility [29]. Within this general critique, the use of the recovery narrative has been criticized as positioning both the problem and its potential solution at the level of individuals [30].

Woods et al [31] posed the following question in relation to the recovery narrative: "What might be opened up, revealed, or foreclosed in telling a recovery narrative in the first-person plural?" as they argued that the recovery narrative is bound to and by the first-person singular and its efficacy is indexed to the individual. Although some participants in our study have built collections of narratives for individual purposes, others have aimed to bring together narratives united in a collective purpose or voice, to be used as a means to impact at an organizational, community, social, or political level. The curation of recovery narrative collections for a collective purpose might therefore be seen as a mechanism for addressing the criticism of the use of individual recovery narratives. Future research might evaluate the collective impact of recovery narrative collections.

Organization

In museums studies, the practical organizational work of curating exhibitions has been explored [32], and there is a growing interest in conceptualizing collaborative and participatory approaches, including in relation to the curation of mental health materials [33]. Research has also begun to document the complex reactions of those visiting or receiving difficult mental health materials [34]. The VOICES typology offers curation knowledge grounded in specific experiences of curating collections of narratives addressing madness, mental distress, and recovery, and hence extends this knowledge base. Further exploration of the VOICES typology is warranted as a potential decision-making tool to build collections of narratives in ways that incorporate health care values such as person-centeredness [35], inclusivity [36], and collaboration [37], and being ethically and legally sound [38] and safe [39].

Inclusion and Exclusion

A narrative collection brings together different voices and different narratives, and the curator holds a position of power as they make decisions on the inclusion or exclusion of different

people and discourses. It has been argued that certain discourses shape and create meaning systems that gain the status of the *truth* and dominate how we define and organize both ourselves and our social world by marginalizing and subjugating alternative discourses [40]. In this instance, questions arise as to whose version of *truth* should be told in a collection and for what reason or agenda? Exclusion of narratives from a collection might contribute to a narrowing of views on how recovery can happen, potentially resulting in a disempowering discourse that acts as an antithesis to humanistic, individualized patient-centered care, which could place a greater emphasis on social and political factors in mental distress [41]. Likewise, if particular representations of recovery are considered too difficult or challenging for recipients and are therefore excluded, then that risks making certain perspectives and/or certain kinds of people invisible. Future work could evaluate the voices and messages present in particular collections and hence identify the collective message created by these collections. It might consider the opportunities and barriers to using such resources in clinical mental health practice and identify the principles for curating collections to be used for this purpose.

Control and Collaboration

In relation to exclusion and colonization, it has been argued that “those who have been ‘experts’ ...traditionally, as researchers, academics, social and political commentators, need to think through their role. Rather than making devalued groups’ narratives merely another subject of their enquiries, or a new field under their direction, they have a chance to ‘authenticate’ service users’ experience through adding their ‘authority’, helping give it credence and legitimacy. The former represents an extension of the devaluing of outsider narratives; the latter offers the prospect of supporting their growth and empowerment” [42]. One of the core values of antioppressive practice is to give voice to and validate the experiences of oppressed people [43], and one might ask if this can be possible if their voice is filtered through a curator’s voice? Relationship parallels may be drawn between the curator and the curated and the clinician and the service user, as some participants acted with a heavy-handed editorial style, which may be viewed as oppressive, whereas others acted with the aim of not filtering the voices of the narrator through their own.

Ethics and Legal

A previous systematic review identified the anonymization of narratives as an ethical issue for which there is no ideal solution [20], and this study confirmed this finding, with questions raised around the best approach to take in relation to the needs of the curator, narrator, recipient, and third parties and the agenda of the collection. Curators debated the balance between their safeguarding duties and censorship and considered issues such as how to respond if the narrator was deemed too unwell to tell their story, who decides if a person has the capacity to make

decisions and for what reason; what are the rights of narrators to claim their stories; and what if any protection should be given to the narrators for *their best interests* such as protecting from future stigma or prejudice in employment opportunities or relationships? These questions are pertinent in the discussion of mental health treatment around risk and safeguarding. Future work could explore parallels between the experiences of mental health treatment and the handling of the narratives of mental health treatment.

Safety and Well-Being

Storytelling is an act of uncertainty for the different parties involved, as what will happen during and after a narrator shares their narrative is unknown. This is especially the case where digital technologies are involved, for example, owing to the ease of access to a person’s narrative online [44]. Some approaches to health treatment, such as Open Dialogue, argue for tolerating uncertainty to enable a deeper examination of the trauma or distress in a person’s narrative [45]. These approaches state that uncertainty can only be tolerated if an individual feels safe and that safety can be established by hearing and responding to each person’s voice and point of view and legitimizing them and their narratives. The safety and well-being of the narrators, curators, recipients, and third parties was a concern for every participant interviewed. The VOICES typology highlights the participants’ curatorial approaches to uncertainty and dealing with distress, with examples of how they tried to make different parties feel safe. Future work could explore the safety and well-being of different parties after publication and the impact collections have on the lives of the narrators, curators, recipients, and third parties.

Limitations

More participants came from the United Kingdom than any other country, which might limit the generalizability of the findings. For all collections other than one, only 1 curator per collection was interviewed, and hence only 1 perspective on the curation of each collection was collected. Interviews with multiple members of a curatorial team might reveal contrasting or even conflicting views on the process of curation.

Conclusions

The VOICES typology identifies key decisions to consider when curating narrative collections about the lived experiences of mental health service use, recovery, or madness. The VOICES typology might be used as a theoretical basis for a good practice resource to support curators in their efforts to balance the challenges and sometimes conflicting imperatives involved in collecting, organizing, and sharing narratives. Future research might seek to document the usage of such a tool by curators and hence examine how best to use VOICES to support decision making.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Preliminary typology of curatorial decisions.

[[PDF File \(Adobe PDF File\), 40 KB - mental_v7i9e16290_app1.pdf](#)]

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Abbreviations

NEON: Narrative Experiences Online

NIHR: National Institute for Health Research

VOICES: values and motivations, organization, inclusion and exclusion, control and collaboration, ethical and legal, safety and well-being

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Original Paper

Detection of Behavioral Anomalies in Medication Adherence Patterns Among Patients With Serious Mental Illness Engaged With a Digital Medicine System

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Abstract

Background: Adherence to medication is often represented in the form of a success percentage over a period of time. Although noticeable changes to aggregate adherence levels may be indicative of unstable medication behavior, a lack of noticeable changes in aggregate levels over time does not necessarily indicate stability. The ability to detect developing changes in medication-taking behavior under such conditions in real time would allow patients and care teams to make more timely and informed decisions.

Objective: This study aims to develop a method capable of identifying shifts in behavioral (medication) patterns at the individual level and subsequently assess the presence of such shifts in retrospective clinical trial data from patients with serious mental illness.

Methods: We defined the term *adherence volatility* as “the degree to which medication ingestion behavior fits expected behavior based on historically observed data” and defined a contextual anomaly system around this concept, leveraging the empirical entropy rate of a stochastic process as the basis for formulating anomaly detection. For the presented methodology, each patient’s evolving behavior is used to dynamically construct the expectation bounds for each future interval, eliminating the need to rely on model training or a static reference sequence.

Results: Simulations demonstrated that the presented methodology identifies anomalous behavior patterns even when aggregate adherence levels remain constant and highlight the temporal dependence inherent in these anomalies. Although a given sequence of events may present as anomalous during one period, that sequence should subsequently contribute to future expectations and may not be considered anomalous at a later period—this feature was demonstrated in retrospective clinical trial data. In the same clinical trial data, anomalous behavioral shifts were identified at both high- and low-adherence levels and were spread across the whole treatment regimen, with 77.1% (81/105) of the population demonstrating at least one behavioral anomaly at some point in their treatment.

Conclusions: Digital medicine systems offer new opportunities to inform treatment decisions and provide complementary information about medication adherence. This paper introduces the concept of *adherence volatility* and develops a new type of contextual anomaly detection, which does not require an a priori definition of *normal* and allows expectations to evolve with shifting behavior, removing the need to rely on training data or static reference sequences. Retrospective analysis from clinical trial data highlights that such an approach could provide new opportunities to meaningfully engage patients about potential shifts in their ingestion behavior; however, this framework is not intended to replace clinical judgment, rather to highlight elements of data that warrant attention. The evidence provided here identifies new areas for research and seems to justify additional explorations in this area.

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KEYWORDS

digital medicine; mobile phone; entropy rate; Markov chains; medication adherence; contextual anomaly; psychiatric disorders

Introduction

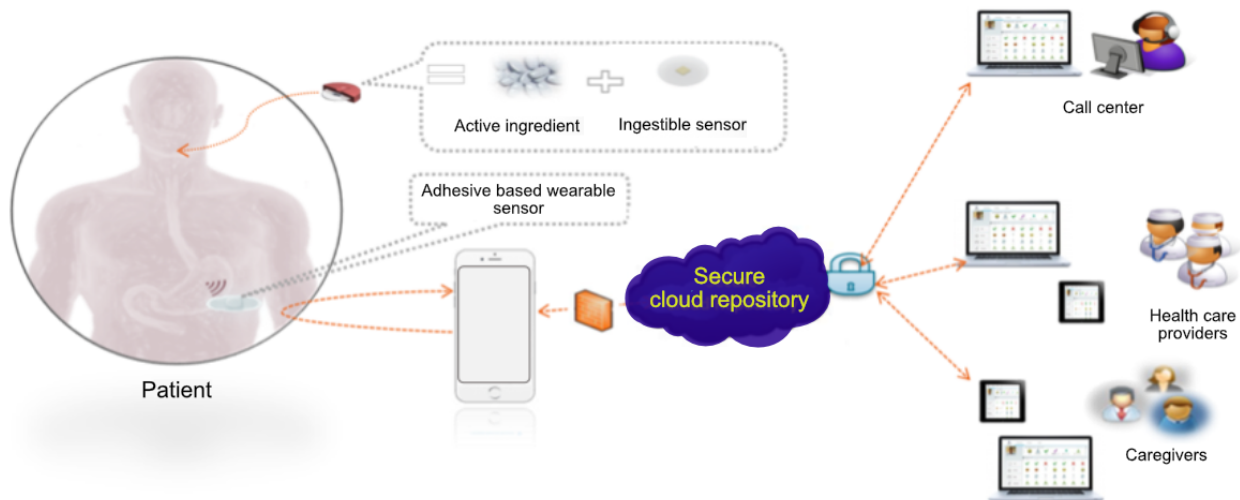
Lack of adherence to medication is a major issue, contributing to increased health care utilization and less favorable outcomes [1-3]. Common methods of measuring medication adherence such as the proportion of days covered or the medication possession ratio rely on claims data. Although useful for many applications, these methods do not provide objective evidence that the medication was ever taken. More objective measures such as electronic cap systems and electronic blister packs provide more granular observations at the event level but capture an interaction with the packaging, not the ingestion. Recently, the Food and Drug Administration approved the first ever digital medicine system (DMS) [4] to track medication ingestion in patients with serious mental illness (SMI). This system comprises an electronic sensor embedded in an active pharmaceutical, a wearable sensor (a patch), and a mobile application to collect and share data as appropriate (Figure 1). Systems such as the recently approved DMS hold promise for improving objective information available to patients, clinicians, and care teams, enabling better decision making. In this study, we sought to evolve the framework by which medication adherence information is leveraged in clinical decision making.

Adherence to medication is often represented in the form of a success percentage over a period of time, where success may refer to observations such as *prescription refills*, *bottle openings*, or, in the case of digital medicine, the detection of medication ingestions by the DMS. However, a single success rate over a period of time, regardless of the objectivity of the measure, may not—by itself—be sufficient to adequately assess a patient's treatment adherence behavior. Although noticeable changes to aggregate adherence levels are certainly indicative of unstable medication-taking behavior, a lack of noticeable changes in these levels over time does not necessarily indicate stable, interpretable, medication adherence values. As demonstrated in the *Results* section, it is possible for anomalous shifts to be identified in day-to-day ingestion patterns in the absence of noticeable changes to the aggregate success rate. For instance, although a patient may be missing the same number of doses across defined intervals, one interval could have regularly interspersed misses whereas the other interval could have a single series of consecutive misses. Although the immediate clinical consequences of such differences would likely be dependent on compound properties such as half-life and therapeutic index, they could also indicate a more significant (potentially ongoing) behavioral change that is yet to manifest in an observable difference in the aggregate adherence value. Timely knowledge of such (potentially subtle) shifts in medication behavior may provide early opportunities for discussions and interventions.

One potential approach to detecting behavioral shifts in medication data is to apply contextual (or behavioral) anomaly detection. Anomaly detection, change point detection, or outlier detection refers to the task of identifying some part or pattern of data that is meaningfully different in some respects [5,6]. In general, there are 3 types of anomalies [5]: (1) point anomalies

are individual points in the data that can be considered anomalous to the others, (2) contextual anomalies (also called conditional anomalies [7]) require the anomaly to be defined within a construct specific to the data, and (3) collective anomalies are extensions of point anomalies in that the presence of a set of points, which may not be individually anomalous, constitutes an anomaly when present together. Developing methodologies for anomaly detection typically requires specific consideration of the application at hand to frame the problem appropriately [5]. In the field of mental health, new and existing anomaly detection methods have begun to appear as an appealing option for a variety of applications, including relapse prediction [8-10], detection of illness [11,12], worsening cognitive impairment [13], motor skills [14], and anomalous traveling patterns [15,16]. For instance, by leveraging passively collected smartphone sensor data and digitally delivered patient surveys, Barnett et al [9] identified increases in the rate of anomalous behavioral patterns in 3 schizophrenia patients up to 7 days before a relapse. This study represents an important step in demonstrating the feasibility and applicability of individual-level anomaly detection for clinically relevant outcomes, albeit on a small sample size. Barnett et al [9] appropriately included in their discussion that the relapses "... quantified in the three subjects may not have reflected other potential trajectories and mechanisms that can lead to relapse," supporting the value in developing other characterizations of behavioral anomalies from additional data sources. Using a natural language approach, Birnbaum et al [10] enrolled patients with recent onset psychosis and retrospectively combined social media data with medical records to identify anomalous linguistic patterns across monthly periods of relative health or relapse. Similar to Barnett et al [9], Birnbaum et al [10] note "Going forward, integrating multiple sources of digital data (sensors, social media, online searches) to predict mental health outcomes in clinical settings, could change the way clinicians diagnose and monitor patients ...," again speaking to the value of expanding the scope and depth of anomaly detection in the mental health space to inform links between behavioral changes and clinically meaningful outcomes at the individual level. Specific to the space of medication adherence, anomaly detection has been employed in patients with Parkinson disease, where observable changes in treatment pharmacodynamics (eg, gait patterns) were leveraged as a surrogate for medication compliance [17]. However, this approach cannot provide information on daily medication behavior, and when there are temporal lags between medication ingestion and effect (as is common in the mental health space), this type of approach may not provide an optimal alert window for detected anomalies. Although we are unaware of any similar studies validating specific behavioral anomalies to an intended clinical outcome, these initial studies demonstrate a growing ability to identify correlations in behavioral changes (anomalies)—at the patient level—to clinically meaningful observations, suggesting that further evidence and methods on novel data sources such as digital medicine will be of value to the clinical and research communities.

Figure 1. An overview of the digital medicine system (DMS). From left to right: Patient takes medication embedded with an ingestible sensor, which is activated in the stomach. The ingestible sensor is detected by a wearable sensor, which sends its collected information (including additional sensors not depicted) to the patient's smartphone. The information is passed on to a secure cloud infrastructure where it can be made available to appropriate members of the patient's care team. Image reproduced under creative commons license from the article published in [18].



Previously published work has demonstrated that a first-order Markov model could describe digital medicine ingestion data at the population level [18]; however, this work did not address the temporal evolution of Markov chains at the individual level or provide a mechanism by which such information might be used proactively by clinicians, patients, or their support teams to aid in treatment decisions. This study addresses these 2 additional components. Furthermore, we defined the concept of *adherence volatility* as “the degree to which medication ingestion behavior fits expected behavior based on historically observed data.”

Adherence volatility is formally represented as the longitudinal evolution of the entropy rate of a single (in this case binary) Markov chain generated from a patient's medication ingestion data across treatment, where the success state indicates an observed ingestion on a given day (1) and an unobserved ingestion on a given day represents the unsuccessful state (0). The entropy rate has been utilized previously for characterizing behavioral data in rodents and can be thought of as “a quantification of the predictability of the next observation given the history of observations that occurred before it” [19]. When viewed longitudinally, the entropy rate metric can provide information as to shifts in both the marginal (stationary) and conditional dependence structures simultaneously, making it a promising measure by which to detect contextual (behavioral) anomalies.

On the basis of the aforementioned logic, an anomaly detection system was built that is computationally nonintensive and can be leveraged in real time to identify contextual behavioral anomalies, and shifts, at the individual level. Although we are aware of entropy rates previously explored for anomaly detection in complex dynamic systems [20,21], the current application differs in a critically distinct way: there is no *baseline truth* or external stimuli required in this system. A patient's own evolving behavior (adherence volatility) is used to construct the expectation bounds for each future interval,

eliminating the need for training or relying on a difference from a particular static reference sequence.

The results of this study provide some basic simulations to highlight behavioral anomalies and shift detection by leveraging the concept of adherence volatility. We also demonstrated the existence of such anomalies and behavioral shifts in previously collected clinical data. Although this is a retrospective analysis, we believe that knowledge of this approach, as well as its application and evolution, will be valuable to the medical and informatics communities as digital and objective medication adherence data become more prevalent in clinical practice. Finally, although the application of this approach is conceived based on medication ingestion data, there is no fundamental reason why the methods presented here could not be leveraged to implement the concept of *contextual anomaly detection* in any data that can be adequately represented as a stationary, irreducible Markov process.

Methods

Clinical Study Data

Ingestion data from two 8-week clinical trials (NCT02722967 and NCT02219009) of patients with SMIs (schizophrenia, major depression, and bipolar 1) being treated with a DMS was used. In this system (Figure 1), a patient-worn patch detects a signal from a digitized medication that contains an ingestible sensor. The patient-worn patch then transmits data to a mobile device and subsequently to a secure cloud infrastructure where it can be made available to clinical (and nonclinical) care teams to aid in decision making. We have previously provided descriptions of these studies [18] but recapitulated below for clarity.

Both of these studies provided smartphones with the appropriate DMS software preloaded and required male and female patients to be on stable, once-daily doses of oral aripiprazole. It was required that patients were deemed capable of using a DMS. During these studies, patients received only the digital versions of their stable oral aripiprazole dose. Both studies received

human subject approvals from the Copernicus Group Institutional Review Board (One Triangle Drive, Suite 100, Research Triangle Park, North Carolina, United States), and subjects provided informed consent. Future use of clinical trial data for research was included in the consent for both studies, and no additional ethical approvals were required to leverage the data.

Study 1 was a multicenter, 8-week, open-label study with a primary objective of capturing the usability of the DMS by adult subjects with a diagnosis of schizophrenia with regard to their ability to independently (and successfully) replace their patch by the end of week 8 (NCT02219009). Patients were expected to perform 5 site visits following the screening period: baseline and weeks 1, 2, 3, and 8.

Study 2 was a multicenter, 8-week, open-label, single-arm, exploratory trial with the primary objective of assessing the functionality of an integrated call center for the DMS by adult subjects with primary diagnoses of schizophrenia, major depressive disorder, or bipolar 1 disorder (NCT02722967). This study consisted of 2 phases: a 2-week prospective phase and a 6-week observation phase. To progress to the 6-week observation phase, patients were required to have at least 50% patch data capture for the 7 days before the week 2 visit. Subjects who met this criterion were eligible to continue into the 6-week observation phase and would be expected to complete 4 total site visits (baseline and weeks 2, 4, and 8).

We leveraged data from patients (either study) who had more than 10 days of ingestion data (see the *Anomaly Detection from Adherence Volatility* section below: $n=105/119$) and defined Time on System as the difference between the minimum patch record or mobile application login and the maximum record from the same data sources. In some cases, the time on system may exceed the availability of patch and medication (eg, if last visit after 60 days and mobile application is still accessed in that timeframe), which will be annotated in the *Results* section where appropriate.

Entropy Rate of a Markov Chain and Adherence Volatility

For a binary Markov chain (assumed to be stationary and irreducible), the entropy rate [19] is defined as

$$-\sum_{q \in \{0,1\}} \pi_q \log \pi_q$$

where π_q is the stationary distribution of each state $q \in \{0,1\}$ representing \square . The logarithm term in this implementation refers to the natural logarithm. For a subject i on day T , the observed data are represented as \square , where $x_t \in \{0,1\}$ represents whether an ingestion was observed (1) or not (0) on day t . From the observed transition count data, $n_{q,r}$ representing the counts of transitions $q \rightarrow r$ ($q,r \in \{0,1\}$), the transition probabilities (TPs) are empirically estimated at any point in time using the maximum-likelihood definition of \square [19]. The 2-state Markov chain for this subject, up to day T , is then represented by the transition matrix

$$\begin{bmatrix} \square & \square \\ \square & \square \end{bmatrix}$$

capturing the observed probabilities of ingestion successes and failures to be followed by success or failure. An estimate of the entropy rate of this Markov chain under these conditions is

$$-\sum_{q,r \in \{0,1\}} \pi_q P_{q,r} \log P_{q,r}$$

The stationary distribution \square is estimated using the eigenvalue decomposition method on \square [19,22]. Adherence volatility for subject i is represented as the longitudinal evolution of \square .

The relatively short duration of data sets encountered in the current digital medicine application (generally around 60 days or less) makes it difficult to truly verify or explore the assumption of stationarity, and our assumption of irreducibility is based on the assertion that when applied to human behavior, no observed event eliminates the possibility of other events, provided that the behavior is observed over a sufficiently long timeframe. However, at short durations, it is possible for individual data sets to appear absorbing: for example, after 8 days, one patient's data may be *11100000*, which has the illusion that the unsuccessful event may be absorbing. The accurate estimation of the entropy rate at this relatively short duration, even when the true order of the system is known (assumed first order in this case), has been shown to be challenging for multiple estimation methodologies [19]; however, the precision of estimation accuracy at any one point is not required to carry out contextual anomaly detection in this sense (discussed in the following section).

Anomaly Detection From Adherence Volatility

It is acknowledged that individual alert systems could alternatively be constructed by directly tracking the occurrence rate of each particular sequence of interest in the data, for example, detecting an increasing number of consecutive missed doses. However, we propose to leverage the entropy rate for the evolving Markov chain as an ideal base candidate by which to identify anomalous behaviors in these data sets because it is a parsimonious metric that encompasses information on both the stationary and conditional distributions simultaneously.

The lack of ground truth (*normal*) makes leveraging existing anomaly detection systems challenging for application in this space. The expected behavior here should be allowed to shift over time to accommodate the actual shifting patterns in patient behavior, that is, anomalous behavior during one period should shift expectations for the future; no a priori assumptions are made about what *normal* behavior looks like, nor how many different shifts in behavior may occur over the (relatively short) observed sequences. These aspects of digital medicine ingestion data compromise the ability of existing techniques to identify anomalous shifts in the data from natural shifts.

Contextual anomaly detection in this study is built with an approach that could be classified as adaptive outlier detection. Figure 2 displays the pseudocode for the algorithm. Briefly, after an initial observation period (to allow for some TPs to be generated), the central tendency of the entropy rate observations

for the next n days is calculated as a weighted average of all possible entropy rates n days into the future. For a binary Markov chain and an n -day observation window, there are 2^n possible future states: The weights are calculated as the probability of each event given the historically observed data to that point. In this work, the expectation boundaries around the central tendency are set to 1 SD calculated from the observed weighted variance. Although there are existing methodologies and research around generating standard error bounds on estimates of entropy rate for a stochastic process [19], the intention here is to generate boundaries for the expected central

tendency and variation in the empirical entropy rate over the next n days, simultaneously. After the expectation boundaries have been set for the observation window, the next n days are observed, logging an anomaly if the observed entropy rate goes outside the boundaries. At the end of each observation window, the boundary conditions are updated to include recent data; this process repeats until the treatment is completed. In this study, an initial period of 10 days was used, with a subsequent observation window of 5 days. These choices were made from practical and intuitive considerations so as to evenly divide a 1-month (30-day) treatment cycle.

Figure 2. Contextual (behavioral) anomaly detection algorithm pseudocode.

VARIABLES	PSEUDOCODE
$\mathcal{X}^t \leftarrow$ observed data of length t $c \leftarrow$ Initial observation duration $n \leftarrow$ anomaly observation window length $S = \{s_i\}; i \leq 2^n \rightarrow$ Set of 2^n possible futures $\mathcal{X}_{s_i}^t \leftarrow$ concatenation of \mathcal{X}^t and s_i $W^t = \{w_i^t\}$ where $w_i^t = P(s_i \mathcal{X}^t)$ (NB: It follows directly that $\sum_{W^t} = 1$)	initialize ↓ observe data to obtain $\mathcal{X}^D = \{\mathcal{X}_i^D\}; D > c$ $\text{win_bounds} = \text{dict}()$ $\text{win_num} = 0$ for i in $c:D$: calculate $h = \hat{H}(\mathcal{X}^i)$ if $(i - c) \bmod n == 0$: # border point: window bounds for next window $\text{win_num} += 1$ $\text{win_min}, \text{win_max} = \text{window_bounds}(\mathcal{X}^i, 1)$ $\text{win_bounds}[\text{win_num}] = [\text{win_min}, \text{win_max}]$ if $(h > \text{win_bounds}[\text{win_num}-1])$ or / $(h < \text{win_bounds}[\text{win_num}-1])$: register anomaly else: if $(h > \text{win_bounds}[\text{win_num}])$ or / $(h < \text{win_bounds}[\text{win_num}])$: register anomaly
FUNCTIONS	
def $\text{window_bounds}(\mathcal{X}^D, m)$: calculate W^D $\text{win_avg} = \sum_{i=1}^{2^n} w_i^D * \hat{H}(\mathcal{X}_{s_i}^D)$ $V2 = \sum_{i=1}^{2^n} (w_i^D)^2$ $\text{win_sd} = \sqrt{\frac{1}{1-V2} * \sum_{i=1}^{2^n} w_i^D * (\hat{H}(\mathcal{X}_{s_i}^D) - \text{win_avg})^2}$ return $(\text{win_avg} - m * \text{win_sd}), (\text{win_avg} + m * \text{win_sd})$	

To demonstrate proof of concept, this study highlights only one possible way in which the central tendency and boundary conditions can be set for the observation windows; however, the approach could be modified for specific use cases or as evidence suggests better alternatives. Further, we acknowledge that the full set of statistical properties of the weighted entropy rate distribution for each of the observation windows have not been described, but given that we define contextual anomaly detection here relative to observed data only, this formal characterization is not a prerequisite for application of the proposed approach.

From the definition outlined above (and in Figure 2), we define a *behavioral anomaly* as an observation window where the observed entropy rate goes outside the expectation range for any duration within that window and a *behavioral shift* as at least two consecutive anomalous windows. Although the aforementioned *behavioral anomalies* may provide potential indicators, the above definition may result in anomalous windows arising from a single missed ingestion; therefore, for the Results section, the majority of the focus will be on identifying *behavioral shifts*, as these are more robust indicators of change.

Results

The salient results presented in this paper are observational and based on case studies. The intent is to highlight the presence and identification of behavioral anomalies and shifts, regardless of the level of aggregate adherence observed or the directionality of the anomaly with respect to ingestion success. Examples from simulations, as well as real clinical data, are provided and attempt to demonstrate the concepts with a broad range of observed adherence rates. Although these results have been generated retrospectively, the observations (anomalies and shifts) are reported in the moment for real-time access to clinical and care teams.

Simulation Results

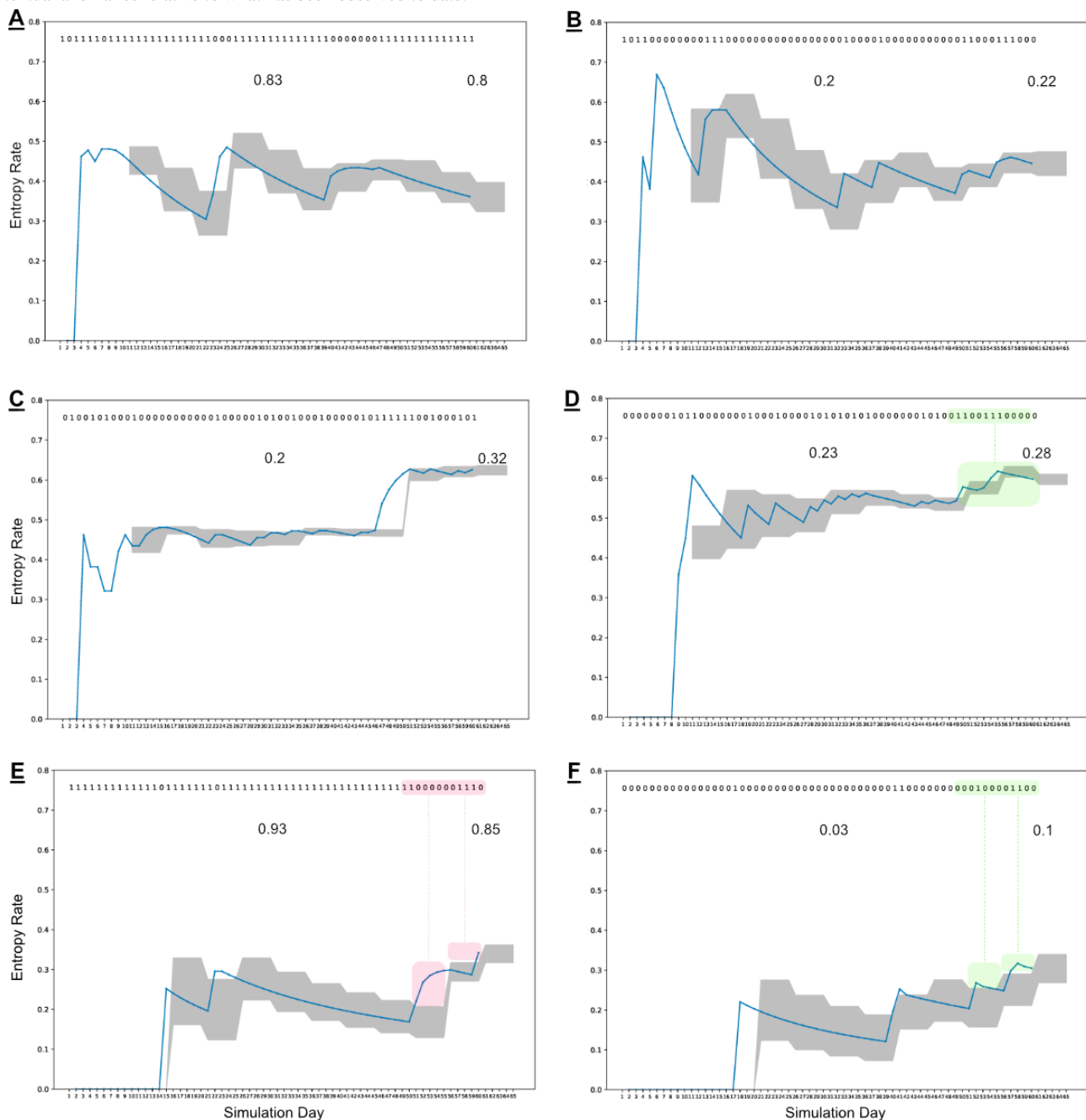
Figure 3 highlights 6 different simulated Markov chains, their resulting adherence volatility traces (blue lines), and their corresponding expected boundaries across 5-day observation windows (the gray-shaded region). Simulation durations of 60 days were chosen to mirror the available clinical data. For each of the simulations, the underlying TP matrix remains constant—the selected use cases represent only a few representative high- and low-adherence scenarios. This simplistic setup is presented for 2 primary reasons: (1) to

demonstrate that even when the underlying behavior is not changing, there are noticeable shifts that can occur relative to historically observed data and (2) conversely, to highlight that an anomaly in this setting could arise for multiple reasons and does not inherently need to indicate a shift in the underlying system. For instance, simulations E and F both end treatment during an identified behavioral shift despite no change in the TPs. If these were observed in a clinical setting, additional data may be desirable before making a decision regarding the consistency of medication adherence. Simulations A and B, however, present stable ingestion patterns—demonstrated by the overlapping trace plots with the expectation boundaries over time (with the exception of an early anomaly)—despite very different levels of aggregate adherence.

All behavioral shifts (at least two consecutive anomalies) in the figures are identified by green or red boxes, with the

corresponding sections of observed data highlighted. The green and red colors indicate if the driving factors for the detected shifts are anomalous patterns of dosing successes or unobserved doses, respectively. The behavioral shift in [Figure 3 \(D\)](#) is driven by increasing the frequency of dosing successes clumped together at shorter intervals than historically observed. In [Figure 3 \(E\)](#), the concentrated patches of zeros at the end are very irregular for that simulation to that point, and the presence of (at least) one more unobserved dose after only 3 consecutive observed doses is also irregular. These 2 instances in combination drive each of the last 2 windows to be tagged as anomalies, leading to its classification as a possible shift in behavior. Similar to simulation D, simulation F demonstrates successful events moving closer and appearing more frequently, albeit still at a very low rate.

Figure 3. Adherence volatility plots for 6 simulated—representative—binary Markov chains over 60 days. The binary string at the top represents the underlying simulated data (0=unsuccessful, 1=successful). The 2 numeric values on the insets represent the observed aggregate adherence rates at 30 and 60 days, respectively. The blue line in the figures represents the calculated empirical entropy-rate based on the observed transition probability (TP) matrix to that day, whereas the shaded gray area represents the defined expected boundary across 5-day windows. Anomalies (single windows with deviations) are not highlighted in this figure; however, observed behavioral shifts (at least two consecutive windows with deviations) are identified in the data and trace plots by the green and red boxes. (A) Underlying TPs $p_{01}=0.3$, $p_{10}=0.1$ (expected success rate, $ADH_{exp}=0.75$). The simulation has high observed adherence rates and 2 identified anomalies from observation windows 1 and 3. (B) Underlying TPs $p_{01}=0.1$, $p_{10}=0.5$ ($ADH_{exp}=0.17$). The simulation has low aggregate adherence and only one anomaly identified from observation window 2. Both simulations (A) and (B) represent what could be considered as a stable observed ingestion behavior. (C) Underlying TPs $p_{01}=0.3$, $p_{10}=0.5$ ($ADH_{exp}=0.38$). The simulation again has low observed aggregate ingestion success, but a dramatic anomaly at observation window 8, which seemingly restabilizes. (D) Again has underlying TPs $p_{01}=0.3$, $p_{10}=0.5$. Despite only 5% change in observed ingestion success rate, a behavioral shift is identified across observation windows 8-10 being driven by tighter groups of successes. Both (E) and (F) display behavioral shifts at the end of the simulations, with TPs $p_{01}=0.5$, $p_{10}=0.1$ ($ADH_{exp}=0.83$) and $p_{01}=0.1$, $p_{10}=0.3$ ($ADH_{exp}=0.75$) respectively. Groupings of unobserved events are driving the behavioral shift in (E), whereas groupings of successful events are driving the shifts in (F). In the last 2 examples, there is only a 5% to 7% change in observed success rates. These simulations are illustrative but provide insights that anomalies and shifts in this methodology are not required to represent shifts in the underlying system parameters, rather it detects contextual anomalies relative to what has been observed to date.



Clinical Data Results

Figure 4 highlights selected patients across 2 clinical studies who were enrolled for 8 weeks of digital medicine treatment. These patients were selected to loosely recapitulate what was highlighted in the simulated data sets: the top 2 patients (A-B) had generally stable ingestion patterns at different ends of the adherence spectrum, and the middle 2 patients (C-D) end with stable behaviors but demonstrated behavioral shifts from the perspective of their day-to-day ingestion patterns: of note for Patient C, only the 60-day treatment window in which patches and medication were available is summarized in this analysis (identified up to the dashed line). Finally, the last 2 patients (E-F) demonstrated ongoing behavioral shifts with respect to their historical data, without much change in the aggregate adherence values. All behavioral shifts are identified in the plots as red or green boxes along with the corresponding subsequences in the observed data. Patient A demonstrates a behavioral shift driven by increasingly concentrated missed doses relative to historical observations. However, after this behavior is observed, the information is incorporated into future bounds, and when a similar pattern occurs again (light orange box over the observed data), it no longer results in an anomaly. Patient C demonstrates a behavioral shift starting around day 37, which is driven by the presence of unobserved doses appearing more tightly clumped together, including consecutive unobserved doses appearing for the first time. Patient D demonstrates a strong behavioral shift across 3 observation windows (15 days): in this

scenario, sequences of 3 and 4 missed doses begin to surface. Of particular interest in the clinical data is Patient F. Despite successfully registering 87% (47/54) of prescribed ingestions across the treatment period, when viewed from the perspective of the adherence volatility plots, the last 30 days of treatment suggest a continuing shift in ingestion behavior that has not stabilized by the time treatment is over. It is unclear whether the ingestion patterns would have continued to shift in this direction, but this is a very clear example from the available clinical data of where this approach can add a unique perspective to clinical intuition: a medication adherence rate of 87% is considered high, but the adherence volatility data suggest that there are significant changes occurring in the patient's observed ingestion behavior.

Table 1 shows the count distribution of observed behavioral shifts in each patient included in the analysis: 22.8% (24/105) of patients had no behavioral shifts observed during treatment, 71.4% (75/105) of patients had only 1 behavioral shift observed, and 5.7% (6/105) of patients had 2 behavioral shifts observed across their treatment (NB: these counts include total *Days on System*, not just the treatment window as is discussed in Figure 4). This table is included to provide information on the current scale of identified behavioral shifts across patient data; however, given the relatively small sample size for this analysis and the current inability to provide context around these behavioral shifts, no comparisons are made across demographics.

Table 1. Count distribution of observed behavioral shifts in clinical data.

Number of shifts	Participants, N	Fraction pop
0	24	0.23
1	75	0.71
2	6	0.06

Discussion

Medication adherence is an important issue in chronic conditions. Although tools for monitoring adherence to medication have seen dramatic improvements—including the first approved DMS for patients with SMI—there have not been parallel advances in data products and algorithms to accompany them. In this study, we present the concept of *adherence volatility* and provide a complementary anomaly detection system that focuses on contextual *behavioral anomalies*. Anomaly detection in this framework does not require an a priori definition of what normal means and allows expectations to evolve with shifting behavior such that observing an anomaly in one observation period informs the expectations of subsequent observation periods. Further, this framework is not intended to replace clinical judgment: anomalous data patterns detected here are intended to highlight elements of data that may warrant attention from the patient's clinical and support teams who would determine the best course of action (if any) when identified in real time.

The DMS leveraged in this study requires compliance with both a wearable and an ingestible component to generate a successful signal. Thus, although a successfully observed signal is a robust, objective indicator of ingestion, an unobserved ingestion may arise from multiple scenarios. Although this makes the exact interpretation of anomalies difficult here, the current iteration represents when ingestion behavior, at the system level, is momentarily different or shifting, which we believe is a beneficial starting point given that future iterations could become more specific as to which component is driving a detected anomaly, or collect patient feedback in the moment if an anomaly is detected.

We leveraged the entropy rate of a Markov chain as the basis to build the proposed anomaly detection system. Despite its *catch all* nature in terms of what types of anomalous patterns can be detected, observing the evolution of this metric over short durations will undoubtedly contain both expected and anomalous shifts in observed values: deciphering the expected from the anomalous shifts in this metric, and at these scales, is not a task for which current standard anomaly detection systems are equipped to succeed. We also frame the anomaly detection problem as a contextual problem, which is not dependent on accurate point estimates of the entropy rate. Rather, the approach is concerned with the magnitude of relative changes at a given point. This change alleviates the downstream complexity of generating accurate point estimates of the entropy rate for short durations [19].

From an interpretation standpoint, a detected anomaly or shift does not directly indicate either a true shift in the underlying

system or a change in aggregate adherence levels per se. However, this indicates that the current observed patterns are not consistent with expectations based on data generated up to that point. The simulated sequences presented in this paper (Figure 3) highlighted this by demonstrating anomalies and shifts from evolving Markov chains with stable underlying transition matrices. The choice to adopt a weighted average and variance approach was used to highlight the initial system and demonstrate the proof of concept; however, this framework and approach may evolve over time as additional data and evidence become available to support other measures, or boundary conditions, which may be more effective at detecting certain types of clinical scenarios. The same would also apply for the choice of observation window duration: as clinical outcomes and observations are collected in conjunction with digital medicine data, optimal observation window durations may arise beyond the currently displayed 5-day duration.

Data available for this study were from once-daily dosing of a single medication (aripiprazole) for patients who were already on stable doses. The homogeneity of the patient population from a stability and dosing regimen standpoint and a lack of in-the-moment feedback or clinical exploration into observed behavioral shifts are clear limitations to the generalizability of this study. Formal exploration of how these methods and concepts interact with more complicated underlying dynamics and clinical outcomes are additional opportunities for future research. Despite the current inability to provide insight into the clinical relevance of detected anomalies and shifts in the presented data, we believe this study demonstrates that focusing solely on aggregate adherence levels misses opportunities to effectively interact with patients and make the most informed treatment decisions. It was particularly interesting to find examples of both stable and shifting adherence volatility behaviors at high- and low-adherence levels despite the lack of heterogeneity in the available data.

DMSs, such as the one leveraged in this study, offer new opportunities to inform treatment decisions and provide complementary information about medication adherence. The anomaly detection framework that has been developed identifies one way of leveraging such information to improve patient care by identifying potentially meaningful changes in medication behavior over time. This unique approach to medication behavior also opens the door to new areas of potential research. Although much work remains to be carried out to determine (and validate) how and when to leverage such information to inform clinical care, the evidence provided here, along with the growing body of evidence supporting the potential for applying anomaly detection to advance the goal of personalized care, seems to justify continued explorations.

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Authors' Contributions

JK drafted the manuscript, and all authors provided comments and revisions. JK was involved in the collection of clinical data. All authors provided input to the methodology.

Conflicts of Interest

JK, ZH, and JC are all the employees of Otsuka Pharmaceutical Development and Commercialization.

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Abbreviations

DMS: digital medicine system

SMI: serious mental illness

TP: transition probability

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Original Paper

Exploring Suicidal Ideation Using an Innovative Mobile App-Strength Within Me: The Usability and Acceptability of Setting up a Trial Involving Mobile Technology and Mental Health Service Users

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Abstract

Background: Suicide is a growing global public health problem that has resulted in an increase in the demand for psychological services to address mental health issues. It is expected that 1 in 6 people on a waiting list for mental health services will attempt suicide. Although suicidal ideation has been shown to be linked to a higher risk of death by suicide, not everybody openly discloses their suicidal thoughts or plans to friends and family or seeks professional help before suicide. Therefore, new methods are needed to track suicide risk in real time together with a better understanding of the ways in which people communicate or express their suicidality. Considering the dynamic nature and challenges in understanding suicide ideation and suicide risk, mobile apps could be better suited to prevent suicide as they have the ability to collect real-time data.

Objective: This study aims to report the practicalities and acceptability of setting up and trialing digital technologies within an inpatient mental health setting in the United Kingdom and highlight their implications for future studies.

Methods: Service users were recruited from 6 inpatient wards in the north west of England. Service users who were eligible to participate and provided consent were given an iPhone and Fitbit for 7 days and were asked to interact with a novel phone app, Strength Within Me (SWiM). Interaction with the app involved journaling (recording daily activities, how this made them feel, and rating their mood) and the option to create safety plans for emotions causing difficulties (identifying strategies that helped with these emotions). Participants also had the option to allow the study to access their personal Facebook account to monitor their social media use and activity. In addition, clinical data (ie, assessments conducted by trained researchers targeting suicidality, depression, and sleep) were also collected.

Results: Overall, 43.0% (80/186 response rate) of eligible participants were recruited for the study. Of the total sample, 67 participants engaged in journaling, with the average number of entries per user being 8.2 (SD 8.7). Overall, only 24 participants created safety plans and the most common *difficult emotion* to be selected was feeling sad (n=21). This study reports on the engagement with the SWiM app, the technical difficulties the research team faced, the importance of building key relationships, and the implications of using Facebook as a source to detect suicidality.

Conclusions: To develop interventions that can be delivered in a timely manner, prediction of suicidality must be given priority. This paper has raised important issues and highlighted lessons learned from implementing a novel mobile app to detect the risk of suicidality for service users in an inpatient setting.

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KEYWORDS

mobile applications; smartphone; mobile phone; mHealth; mental health; suicide; social media

Introduction

Background

Suicidality has been defined as any suicide-related behavior, including completing or attempting suicide (intent), suicidal ideation (thoughts), or communications [1]. Suicide is a growing public health concern, with 6507 suicides registered in the United Kingdom in 2018 [2]. However, it has been suggested that suicide rates are often underestimated [3], raising questions about the reliability and accuracy of statistics related to suicide [4]. A recent report examined the current trends in suicide rates in the United Kingdom and reported that suicide is more prevalent among men aged 45–49 years, with men 3 times more likely to take their own lives than women [5]. The rate of suicide among young people between the ages of 15 and 24 years has risen since 2013, with the suicide rate for young women now at its highest on record (9.5 per 100,000). It is argued that many suicide deaths can be prevented [6].

However, although the global prevalence of mental health disorders in the general population is high, the use of mental health services is comparatively low [7]. Research has identified barriers, including stigma, lack of time, and pragmatic issues of accessing services which often prevent people who have mental health problems and who are at an increased risk of suicide from seeking help and support from services [8,9]. However, the demand for National Health Service (NHS) psychological services has been increasing [10]. Inadequate resources, both staffing and financial, have resulted in 1 in 10 patients experiencing a wait of over 1 year before receiving any form of treatment [11,12]. One in 6 of those on a waiting list for mental health services is expected to attempt suicide [11]. In addition, it has been highlighted that these services often fail to provide effective, timely interventions at the point of crisis, and their traditional methods (clinical) to identify suicide risk have been criticized for lacking accuracy [8,13,14]. A systematic review revealed that risk assessments can lack validity and are not always able to predict suicidality in high-risk populations [15]. Such assessments are time consuming and may not add value to either the patient or the clinician [16].

Currently, approximately 95% of households in the United Kingdom own mobile phones, a figure that has remained constant since 2015 [17]. It is not surprising that the use of smartphone apps for research and clinical care in mental health has become increasingly popular [18]. The use of smartphones to support mental health has the potential to reach and engage with those groups of people who might find it hard to attend services [19] and has the potential to provide immediate support. Effective mental health apps may, therefore, have the ability to improve patient outcomes [20–22]. Logically, mental health apps are seen as a cost-effective and scalable solution to the gap in mental health services [23]. Unfortunately, the pace of research has not kept up with the advances in mobile technology [24], with the majority of mental health apps available for

download not supported by evidence-based research and perhaps not even following treatment guidelines [25].

A review of mobile health apps for the most prevalent mental health conditions [26] identified that, of the 1500 depression-related apps in the market, only a small proportion (2%) had been tested. There is a clear need for more research to be conducted on the use, reliability, and efficacy of apps in the field of mental health [27]. Researchers interested in conducting studies focusing on suicide risk or prevention are also faced with additional methodological constraints such as ethical or safety issues [1,28]. It has been highlighted that individual-based naturalistic studies are the best for identifying prognostic factors of suicide risk [29]. Although suicidal ideation has been shown to be linked to a higher risk of death by suicide [30], not everybody openly discloses or communicates their suicidal thoughts and/or plans to friends and family or seeks professional help before suicide [9,31]. Therefore, new methods are needed to track suicide risk in real time [32], together with a better understanding of the ways in which people communicate or express their suicidality [31].

Considering the dynamic nature of and challenges in understanding suicide ideation and suicide risk, mobile apps could be better suited to prevent suicide as they have the ability to collect real-time data, thus offering support at the time of crisis [22]. Research indicates that changes in mental health symptoms can be identified by analyzing certain patterns of smartphone use [33]. Machine learning (ML) is potentially one way to expand our understanding of people's thoughts, feelings, and behavior and to improve the monitoring of suicide risk in real time. ML uses computational methods to analyze past information to make accurate predictions [34]. A pilot study using data from 144 patients with mood disorders suggests that ML algorithms using previous clinical data were successful in distinguishing between people who attempted suicide and those who did not, with a prediction accuracy between 65% and 72% [13]. Similarly, a study that used ML from unstructured clinical notes was able to estimate the risk of suicide with an accuracy consistently $\geq 65\%$ [16].

Social media is another means of collecting real-time information. It has been reported that social media has the potential to prevent suicide or identify suicide risk based on an individual's self-expression by analyzing their status updates through the use of ML [34], thus providing clinicians with timely information for early intervention. Another study demonstrated the utility of social media blog post analysis in classifying individuals with a high suicide risk in China [35]. Sleep problems have also been identified as a risk factor for individuals with suicidal tendencies [36,37]. Specifically, a shorter sleep duration on weekdays and a longer sleep duration on weekends predicts a high risk of suicidality [38]. Unfortunately, most studies rely on self-reported measures of sleep [39], which do not provide reliable, real-time information. The use of connected sensors (wearables) offers the opportunity to collect data during sleep, producing real-time information.

This study adds to the literature by introducing external, user-generated input and smartphone data and combining them with clinical data. For the focus of this paper, we report the practicalities of implementing a study designed to test the feasibility of using ML algorithms to identify suicidal ideation and eventually predict suicide risk in acute inpatient mental health settings in the United Kingdom using a novel smartphone app—Strength Within Me (SWiM). The results of the multiple ML algorithms that were tested were reported in a previous paper [40]. The SWiM feasibility study aimed to (1) determine the degree to which participants accept and engage with the SWiM app; (2) collect sufficient data to inform the development of risk algorithms; and (3) gather participants' feedback regarding the SWiM app, risk assessments, and participation in the study.

The SWiM App

SWiM is a novel phone app that has been developed to provide clinicians with additional information that would otherwise not be available to them. It should be emphasized that the SWiM app is not a therapeutic intervention and was developed to improve the understanding and identification of suicide risk and, in the long term, potentially contribute to a reduction in suicide rates.

The app allows service users to journal at any time of the day using free text only; this may include a short note about what the user did that day or longer entries about their thoughts, feelings, and experiences. Participants were encouraged to record at least one journal entry per day, but the number of journal entries they could input was unlimited. When a service user completes a journal entry, there is an automatic prompt to rate their current mood using emoticon faces.

When participants sign up at baseline and when they stop using the app or are discharged from the study, they are asked to answer 4 questions about their mood and sleep during the past 7 days; these include feeling depressed, feeling hopeless, unable to fall asleep, and waking up frequently at night.

In addition, the SWiM app enables service users to create a safety plan using a 3-step process. Step 1 involves self-soothing activities that they can perform on their own; step 2 involves activities they can perform with a friend or caregiver if step 1 does not help; and step 3 involves identifying a professional they can contact, such as their doctor or clinician, if the first 2 steps do not help. Participants can choose from 4 emotions with which they may struggle (sad, angry, lonely, and worried) to create a safety plan. They also have the 'other' option so that they can develop a safety plan for additional emotions. Safety plans can be adjusted to reflect what is working for each participant and what is not (Figure 1).

Figure 1. Screenshot to illustrate the front screen of the Strength Within Me app.



Development of the SWiM Algorithm

For building the model, both active and passive data were gathered. Active data (where the user engaged with the SWiM app; the data included journaling, safety plans, and rating mood) complemented the passive data collected (where the user did not actively engage with the app; the data included social media [Facebook posts], sleep monitoring [sleep quality], and daily activity [number of steps], as recorded by the participant wearing a Fitbit). Unfortunately, social media data were excluded from the model because of the low number of participants who consented to the use of Facebook data. The data were analyzed to train the ML algorithms to produce a risk score that deduced

the likelihood of suicide, which was analyzed using natural language processing (NLP). This involved extracting language patterns to make inferences about people's thoughts and feelings [41,42]. A study demonstrated that NLP analysis using language from social media posts could identify people at risk of suicide [43]. In addition, clinical data using assessments conducted by trained researchers looking at suicidality, depression, and sleep enabled comparisons to be made generating a risk score were collected.

Aim of the Paper

This study aims to report the practicalities and acceptability of setting up and trialing digital technologies within an inpatient

mental health setting in the United Kingdom and to highlight the implications of these for future studies.

Methods

Recruitment Procedure

As the SWiM app was novel and untested, it was important to first introduce and test it in a controlled environment for the safety of participants—in this case, vulnerable service users presenting with acute mental health difficulties. This enabled the research team to monitor for any possible side effects. It also enabled researchers and data scientists to monitor the data, keep track of equipment, and determine whether service users would actually engage with the app. Service users were recruited from 6 NHS acute adult mental health wards in the north west of England in the United Kingdom.

Service users were eligible to participate in the study provided they had the capacity to give informed consent and possessed a good command over written and spoken English. Exclusion criteria included service users who were unwell at the time of recruitment (experiencing psychosis or significant agitation), those unable to use an iPhone, those undergoing detoxification, anyone with visual or other physical impairments that would impede their use of a mobile phone or app, and service users who had been readmitted within the study time frame.

To facilitate recruitment, researchers discussed any new admissions (admitted within the last 7-10 days) with nursing staff in each participating ward and went through the inclusion and exclusion criteria. Those people who were considered by the clinical care team to be eligible to participate in the research were referred to the research team. The researchers went through the participant information sheet with each participant and recorded their written informed consent. Eligibility was continuously assessed by researchers throughout the recruitment procedure. Participants were also asked whether they would allow the study to access their Facebook data via a secondary opt in app, SMiLE. This was to allow patterns in their social media content and activity to contribute to the development of the risk algorithm(s). Participants could opt in or out of this aspect of the study without affecting their overall participation.

It had been established in the pilot work that this particular service user population did not routinely have access to an iPhone or a Fitbit; therefore, participants were loaned an iPhone and a Fitbit device. They were also asked to sign a contract form agreeing not to purposefully damage the equipment and to return it at the end of the study period. These documents were photocopied and the copies included in the patient's health record.

Between January and November 2018, there were 810 admissions across 6 wards, yielding 186 eligible service users. Furthermore, 105 service users declined to participate, resulting in 81 who consented to participate in the study. Unfortunately, 1 service user who had consented to participate was excluded because of the recruitment website not working. This resulted in 43.0% (80/186 response rate) participants taking part in the study, with 66 included in the analysis based on the completion of at least two follow-up clinical assessments. Reasons for

noncompletion of assessment tools at all time points were as follows: declined, not available at the time of follow-up, or discharged from the ward.

Procedure

After obtaining informed consent, participants were given a study iPhone and Fitbit for use during the following 7 days. The setup for participation in the study involved a series of technical and time-consuming procedures. One of the researchers created a new private SWiM and Fitbit account for the service user. In addition, the researcher recorded demographic data for every participant, including age, gender, weight, and height. The SWiM and Fitbit apps were configured for the service user on the iPhone and participants were shown how to access and use them.

When this was being done, the other researcher asked participants to complete a number of clinical assessments. The baseline assessments comprised 3 questionnaires that recorded the presence and severity of depression (Patient Health Questionnaire-9) [44], suicidal thoughts and behavior (Columbia Suicide Severity Risk Scale [C-SSRS]) [45], and sleep difficulties (Insomnia Severity Scale) [46]. Questionnaires were completed on 2 additional occasions: at follow-up 1 (approximately 3 days later) and at follow-up 2 (approximately 3 days after follow-up 1 or at the end of the study). The expectation was that service users would participate in the study for a maximum period of 7 days. If they were discharged within the 7-day study period from the ward, the staff collected the iPhone and Fitbit, and the researchers aimed to collect their final questionnaire data. At each time point, a copy of the C-SSRS was given to the staff if they had scored above 0 to ensure that each patient's suicide risk was documented. An additional setup process was required if service users consented to the monitoring of their Facebook accounts. Service users had to input their Facebook credentials into a secure website (SMiLE).

In recognition of their involvement, shopping vouchers valued at £25 (US \$32) were given to participants following completion of the assessments at baseline and at the end of the study. Participants were given the researchers' study telephone number so that they could contact if they had any questions, problems, or required technical support. Once a participant had completed their time in the study, the researchers synced the Fitbit data, terminated their SWiM app account, and then reset both iPhone and Fitbit, which resulted in deleting all participant data from the study devices.

Some qualitative data were also obtained via a brief informal exit interview. Questions related to what participants thought of the study and the SWiM app, including likes or dislikes and improvements for future research, were asked. Notes were taken during this discussion and were analyzed thematically to illustrate their views.

Participant Characteristics

Of the 80 participants who were recruited to the study, 35 (44%) were male and 45 (56%) were female. The mean age was 36.8 years (SD 11.6) and the age range was from 18 to 61 years.

A total of 79 participants completed the C-SSRS at baseline and all reported that they had experienced suicidal thoughts at some point in their life. There were 68 participants who reported having made at least one previous suicide attempt.

Results

Acceptability and Engagement of the SWiM App

Journaling

Overall, 653 journal entries were recorded. Of the total sample (n=80), there were 67 (84%) participants who engaged in journaling, with an average number of entries per user being 8.2 (SD 8.7). The total number of journal entries per user ranged from 1 to 43. Interestingly, the average number of journal entries for female participants was 7.2 (SD 7.1; range 1-32), whereas male participants had an average of 9.4 (SD 10.4; range 1-43)

Table 1. Number of journal entries for each age category.

Age category (years)	Participants per age category, n	Average number of journal entries	Range of journal entries
18-29	24	10	1-32
30-39	22	7	1-24
40-49	22	12	1-43
50-59	10	11	3-21
60-64	1	1	1

Safety Plan

Overall, only 30% (24/80) participants created safety plans. A total of 61 safety plans were completed, with an average of 2.5 plans per person (SD 1.4; range 1-5). The most common emotion that participants completed a safety plan for was feeling sad (n=21). Within the safety plans, 113 helpful activities were recorded by participants, for example, talking to someone, participating in exercises, and listening to music.

Participant Feedback About the SWiM App

One of the main themes that emerged was how helpful the SWiM app had been. The ability to write-out thoughts suited those people who might otherwise have had to *struggle to voice these verbally* (Participant number 901127). One participant reported a preference for writing their thoughts into the journaling feature of the app as opposed to talking to staff face-to-face about their feelings. Many service users reported that they liked having the ability to openly express their thoughts in the SWiM app without having the staff always assume that they would act on their thoughts. From their reported experience, expressing their suicidal thoughts to a member of staff often resulted in the removal of privileges such as time off from the ward. The potential implications of this will be discussed later in this paper. In addition, several participants identified the ease of using an app on a phone; you “don’t always have pen and paper, but you always have your phone” (Participant number 902113). This enabled participants to engage with the app at any time of the day.

The app required participants to complete a journal entry before being given the option to rate how they were feeling. Many

journal entries each. Participants aged between 40 and 49 years completed more journal entries on average than other age groups (Table 1).

Participants used the journaling facility on the SWiM app to report a wide range of situational and emotional factors that affected their everyday lives in the inpatient setting. The journal entries varied from a couple of words to an extensive narrative:

Feel low [Participant number 901122]

Today has been mostly spent in bed. I had a injection forced upon me today which I refused several times but they left me with no choice. I have now been prescribed meal replacement drinks which I’m refusing to have. I’ve had a lot of teary moments today as I have asked for some of my personal belongings yet I was refused. [Participant number 901127]

participants found the journal entry component of the app difficult to write, reporting that it required a level of motivation that they did not always possess. They reported that they would have preferred to have the option of rating their mood separately. It was not possible to discern, however, whether mood fluctuations acted as a trigger for accessing the app and recording those thoughts and feelings. Although the app did allow participants to review previous journal entries, which were perceived by some as being useful to monitor any progress they had made, some participants reported that this actually opened up negative thoughts again. Moreover, 1 participant commented that they were bored using the app after a few days as they had begun to feel well again and did not feel the need to use it anymore. Participants also commented on improvements they would like to see in the app, such as changing the color scheme, including uplifting quotes, having self-help links, and an SOS (an abbreviation for distress) button for helpful contact numbers.

Participant Feedback in Relation to Fitbit

Fitbit’s primary purpose in this study was to support the data obtained from the SWiM app by providing information regarding the participants’ sleep and daily activity. The majority of participants (n=69) provided positive responses about using Fitbit, which included increased self-awareness of levels of physical activity, goal setting, and peer motivation. Participants also reported changing their behavior, in particular, increasing their activity levels and adopting activity goals as a result of wearing Fitbit. They also reported interacting with other Fitbit wearers participating in the study to increase their activity. The use of Fitbit, therefore, had some unforeseen positive benefits. This is in line with previous findings indicating that mental

health service users found Fitbit a useful and accessible form of technology [47-49].

Practicalities of Using the SWiM App

Technological Issues

When service users were recruited to the study, researchers had to input their SWiM and Fitbit credentials into a secure website. This website provided participants with their own private SWiM and Fitbit accounts. There were several occasions in which researchers were unable to access this site because of updates and modifications being done, which meant that some eligible service users could not be recruited at that time, delaying recruitment. However, only 1 service user (who had consented) could not be recruited because of this issue as they were being discharged when the recruitment site was operational again. In addition, there were times when the app was not functioning correctly (ie, journals not getting saved and mood ratings not working), resulting in loss of data. Overall, this issue affected 12 participants.

The staff at the participating sites expressed concerns about giving service users iPhones and Fitbits for the duration of the study, suggesting that the equipment would either be stolen or damaged. They were also concerned about who would be responsible for monitoring the devices. However, out of 18 iPhones and Fitbits, only 1 phone and 1 Fitbit were lost and 1 phone was accidentally damaged. All other devices were returned intact.

Relationships and Gatekeeping

We found that the relationships researchers had formed with staff at the wards were crucial for recruitment. Moreover, it was common to find that when senior staff were committed to the study (consultants, ward managers), the ward staff seemed to be more interested and proactive.

In areas of high staff turnover, the proportion of staff who did not know about the study increased and the initial stage of recruitment to the study was more difficult. The visibility of researchers at the wards increased awareness of the study and helped retain the momentum of recruitment.

Although considerable effort was expended in ensuring that the nursing staff understood the eligibility criteria, there were instances where service users who were identified by the nursing staff as eligible could not consent to the study when approached by the researchers. This was most often because of fluctuations in their mental health.

Facebook Use

The original plan was to monitor the use of social media by looking at Facebook usage with the participants' consent. However, during the course of the study, Facebook changed their approach to data sharing. This meant that not all participants could be offered the opportunity to access their Facebook data. Of the 61 participants who were asked, only 13 agreed to allow their data to be accessed. Reasons for not consenting to sharing Facebook data included: not having a Facebook account (n=27), not using Facebook at the time of recruitment (n=10), unable to remember Facebook password

(n=3), or simply declining (n=8). Importantly, some participants explained that they attributed their emotional distress to the use of Facebook, and other people reported that using Facebook while experiencing a deterioration in their mental health accentuated their distress. Others reported negative thoughts about themselves when they compared their lives with those of their family and friends as depicted in their Facebook posts. These reports echo those of many other researchers who report a complex, mixed, and uncertain association between social media and mental health [50,51]. The Facebook data collected were excluded from any analysis because of the low response rate.

Discussion

Summary

Being able to identify individuals at imminent risk of suicide is a major challenge because of the high prevalence of varying risk factors [52]. Therefore, detecting suicide risk in real time is an important part of reducing suicides [32] and understanding how people communicate or express their suicidality [31]. One way to address this is through the development of digital apps [53]; although they may have the ability to transform mental health care [23], integrating them into mental health settings for research studies can be complex and often underestimated. As demonstrated in this study, when mobile technologies are used in the context of mental health, there are some challenges. In this paper, we have reported some aspects of the study involving the development of an innovative mobile app, SWiM, that worked well and some issues that created difficulties for the study. In the following sections, we examine the implications of these findings and considerations for future research.

Technological Issues, Technology Damage, and Associated Costs

One of the advantages of using digital technology is that it has the potential to be an efficient and cost-effective approach to treating mental illness [20]. In general, apps are openly accessible and the use of an app by 1 individual does not prevent another from using the same service at the same time [10]. They provide constant availability and greater access to support [25]. However, there are cost issues that might hinder the adoption of health apps within services such as access to smartphones, connectivity, development and regular updates of apps, and the maintenance of the technology [23].

This study found that 4G connectivity was essential for reliable and continuous access to the SWiM app. An important element in this study was capturing people's thoughts in real time and fluctuations in mood. This required participants to be able to journal at any time without the worry of connectivity and journal entries not being saved. Future studies using mobile apps should strive for as much connectivity as possible to allow for consistent functionality [54]. Although this may have financial implications for research budgets, it is a vital consideration for future research not only to ensure continued participation in studies, particularly if the app is to be used in people's homes in the community, but also for security reasons. This is particularly important when the connectivity cost of

downloading an app is charged to the user. This was highlighted in a study that suggested that some patients may not be able to afford the cost of the required internet connection to run an app, which may act as a deterrent to its use [55]. In addition, the requirement to update apps may also pose a significant burden in both time and effort on service users.

Of the total sample, 12 participants were affected by technological issues, with 1 service user being unable to take part. This study illustrates the importance of having the research team available in participating wards to trouble shoot issues in a timely manner. It also demonstrates the significance of having positive working collaborations within the research team, including data scientists and technicians, to ensure a continuous flow of data. This is supported by previous research that emphasizes the importance of collaborative partnerships between researchers, clinicians, app developers, and service users [56].

The initial cost of the devices and the possibility of having to replace them were concerns in this study that proved to be unfounded. A concern raised by staff in the context of this study was that smartphones would be broken, lost, or stolen [57]. Clear policies about responsibilities and implementation could help avoid these issues [49]. In this study, a contract with the service user placed the responsibility for the iPhone and Fitbit on the participant. The extent to which the contract influenced how a participant took care of the devices is unclear. It is possible, in general, that people are more responsible about other people's equipment than we give them credit for.

Relationships and Gatekeeping

In general, research within the NHS is highly reliant on ward staff and clinician support, and the design of this study required staff to identify eligible patients for the researchers to approach and consent. When the clinical care teams are already busy and their role in research is seen as an addition to their work, it is likely that recruitment might not always happen in the same way over time [58,59]. Staff may be too busy to prioritize research and may not see participation as integral to their role [60,61]. Likewise, previous research has reported that clinicians have expressed difficulty in maintaining enthusiasm for research with other responsibilities they had [62].

Establishing good working relationships between research and clinical staff before commencing recruitment and then maintaining them is vital to building enthusiasm for study trials [61]. In line with this, the value of developing positive working relationships with frontline workers is equally important. Although having an initial set-up meeting was critical for the study to begin, having constant negotiations with the staff maintained the profile of the study with staff. It has been suggested that key engagement strategies should be employed with frontline staff in the design and rollout of a study to improve engagement [53]. Similarly, it has been reported that positive relationships are crucial for effective recruitment [63]. Future research should consider the most effective ways of engaging with the wider clinical team to enhance recruitment to studies.

Apps Versus Face-to-Face Contact

The use of phone apps within mental health care is on the rise, with more people preferring to communicate in this manner [18,23]. However, 1 recent study surveyed college students and found that only 26% reported that they would use mental health apps, with the majority (81%) preferring to talk to a person [64]. It has also been suggested that digital apps can help reduce barriers to face-to-face help-seeking, such as stigma and discomfort about discussing one's own mental health [65]. Feedback from the current study suggested that some participants enjoyed using the SWiM app because they were able to write their thoughts down without the feeling of being judged or misinterpreted. It also enabled some participants to express thoughts and emotions that they did not feel comfortable discussing with the staff.

There are important questions about how the data derived from digital apps compare with those elicited using face-to-face contacts. In this study, several participants reported that they experienced suicidal thoughts on which they had no intention of acting. This raises the question of whether in clinical practice there is a tendency to over-rely on personal expression of suicidal thoughts, which may lead to premature and unnecessary intervention in the lives of service users. In 2017, Facebook reported using artificial intelligence to detect the part of a Facebook post or video that matched suicide risk patterns. Anyone expressing thoughts of suicide in any type of Facebook post would trigger a response by prevention-trained human moderators [66]. Given the findings of the study reported in this paper, careful consideration needs to be given to the ways in which people think and feel in the context of suicide if digital apps are to be designed to accurately predict the risk of suicide.

Suicidal Risk and Facebook Use

Social networking has become embedded in the everyday lives of a large proportion of the population [67]. Facebook remains the largest and most popular web-based social networking site worldwide and has been estimated to have over 2.4 billion active members [68]. With this consideration, there was an assumption that the majority of eligible participants for the study would actively use Facebook. In reality, this was not the case. A study exploring the difficulties experienced by 28 people with depression and anxiety when using the internet and social media sites such as Facebook found just over one-third of the sample reported Facebook to be the site with which they had most difficulty, similar to this study [69]. Reasons included exposure to unexpected, inappropriate content that caused them to feel upset and frustrated, exposure to content that might trigger negative memories, social comparison cues including comparing their present with the past, difficulties with direct contact, and the pressure to maintain social networking. As the number of service users actually using Facebook in our study was low, there needs to be careful consideration for further research regarding other potential markers that use real-time information that might add to the prediction of suicide risk.

Age and Mental Health Apps

Previous research on mobile health apps [18,70] found that there seems to be a strong emphasis on younger adults' mental health

because of the high prevalence of ownership and access to smartphones in this age group. Furthermore, it has been suggested that older people in particular may have a lack of knowledge, discomfort, and difficulty in operating new technology devices [71-73].

In contrast to previous research that suggests older people may have difficulties with mental health apps, this study included people aged 18 to 61 years, and there were no reports from participants about difficulty in using iPhones or Fitbits. In a study of US veterans [70], it was found that although age can represent a barrier to owning a smartphone, once a person has access to a device, age was not correlated with interest in or usage of mental health apps. Older people were not less interested or involved with the apps than their younger counterparts.

Furthermore, the findings from this study report positive feedback about the usability of the SWiM app from participants across all ages. As age does not appear to be a factor that affects a participant's interest or ability to use mental health apps, research in digital apps should therefore not assume that older people will not be interested in participating. Given the aging population, research, using mobile phone apps should allow for the participation of adults across a wide range of age groups and should not just focus on younger people.

Limitations

Although many of the issues raised by participants in this study may have wider applications, the inpatient context restricts the extent to which the findings can be applied to other settings, such as community settings. During our study, there were reports from participants that the SWiM app had helped them occupy their time during their stay in the hospital. The presence of researchers at the wards also provided a means of keeping the study in the minds of the participants. In this context, it may not be surprising that the majority of participants engaged with the SWiM app. In the community, however, with the distractions of everyday life and the absence of a research team to act as a reminder, it is not clear whether engagement would be so high.

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Conflicts of Interest

None declared.

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These are aspects of the SWiM app that would have to be assessed if the app were to be used in community populations.

The SWiM app is currently configured to operate on an iPhone only. During the initial planning phase of the study, it was assumed that service users who agreed to participate would be able to use their own iPhone to download and access the SWiM app. However, there were concerns from clinicians based at the recruitment sites that the majority of patients would not own an iPhone. Taking this into consideration, the research team completed a small, snapshot survey at one time point to establish the number of patients who owned an iPhone and found that only 9 patients across 3 wards had access to an iPhone. As a result, a decision was made to purchase iPhones to loan to the participants. If the SWiM app is to become available for download in the future, app versions catering to a range of smartphones will be required.

During the study period, there were 810 admissions across all 6 participating wards. Only 80 participants were recruited, with the majority of service users meeting the exclusion criteria. Although the sample size was sufficient for this study, the very nature of the target population may indicate that recruitment to digital trials takes longer than in other settings. The inpatient context also restricted participation to people in the age range of 18 to 64 years. More work is required to assess the acceptability of the SWiM app with younger and older populations as well as with people living in the community.

Conclusions

The need to intervene precisely during a critical moment of potential suicidality could reduce the loss of life. However, to develop interventions that can be delivered in a timely manner, the prediction of suicidality must be given priority [39]. This paper has highlighted and raised important issues and lessons learned from trying to understand how service users express their suicidality using a novel phone app in an inpatient setting. Although our findings are restricted to an inpatient population, the practical components of trialing a novel phone app within health services may be valuable for future research and health care organizations.

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Abbreviations

C-SSRS: Columbia Suicide Severity Risk Scale

ML: machine learning

NHS: National Health Service

NLP: natural language processing

SWiM: Strength Within Me

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Original Paper

Mental Health Professional Consultations and the Prevalence of Mood and Anxiety Disorders Among Immigrants: Multilevel Analysis of the Canadian Community Health Survey

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Abstract

Background: There is a significant body of evidence on the link between migration and mental health stressors. However, there has been very little research on the use of mental health services by immigrants in Canada. The prevalence of mental health professional consultations among immigrants, as well as its correlations, are not well understood and remain largely unknown.

Objective: This study aims to examine how specialist mental health visits (to a psychiatrist) differ from general mental health visits (to a family doctor or general practitioner) from immigrants, when compared to visits from those born in Canada, in a nationally representative sample of Canadian adults. This study also examines which group—immigrant or Canadian-born—suffers more from depression or anxiety, 2 of the more common mental health conditions.

Methods: We used data from the Canadian Community Health Survey (CCHS) between the years 2015 and 2016. The outcome variables included consultation with any mental health professional, consultation with a specialist (psychiatrist), and the prevalence of mood and anxiety disorders. The independent variable was immigrant status. Other variables of interest were adjusted for in the analyses. Multilevel regression models were developed, and all analyses were performed with Stata IC statistical software (version 13.0, StataCorp).

Results: The prevalence of mood and anxiety disorders was significantly lower among immigrants compared with individuals born in Canada; the prevalence of mood disorders was 5.24% (389,164/7,422,773) for immigrants vs. 9.15% (2,001,829/21,885,625) for individuals born in Canada, and the prevalence of anxiety disorders was 4.47% (330,937/7,410,437) for immigrants vs. 9.51% (2,083,155/21,898,839) for individuals born in Canada. It is expected that individuals with a lower prevalence of mood or anxiety disorders would use mental health services less frequently. However, results show that immigrants, while less likely to consult with any mental health professional (OR=0.80, 95% CI 0.72-0.88, $P<.001$), were more likely to consult with a psychiatrist (OR=1.24, 95% CI 1.04-1.48, $P=.02$) for their mental health visits when compared to individuals born in Canada.

Conclusions: The results of this study reveal an unusual discord between the likelihood of mental health professional consultations with any mental health professional and mental health visits with psychiatrists among immigrants compared to nonimmigrants in Canada. Mental health initiatives need to be cognizant of the differences in the associated characteristics of consultations for immigrants to better tailor mental health services to be responsive to the unique needs of immigrant populations in Canada.

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KEYWORDS

immigrants; immigrant mental health; mental health consultations; mood disorders; anxiety disorders; mental health visits; Canadian Community Health Survey

Introduction

There is an extensive amount of published literature on mental health conditions in Canada. However, there is a paucity of research on mental health among immigrant populations [1]. A literature review on mental health concerns among Canadian immigrants showed varying trends and patterns. One study noted that immigrants have fewer episodes of mood disorders compared with their native-born counterparts [2]. Contrarily, 2 peer-reviewed articles reported an increased prevalence of mental health conditions such as emotional problems, stress, and increased psychotic disorders among Canadian immigrants [3,4]. Enabling factors identified to potentiate mental health problems among immigrants include racial discrimination and immediate difficulties with settling [4,5]. These situations are made worse by the barriers (ie, poverty, experiences of discrimination, stigma, language) faced by immigrants trying to access mental health services [2].

Access to mental health services significantly impacts immigrants, who have been currently identified as one of the most underserved in the Canadian healthcare system [4]. Studies have shown that only 50% of Canadians with mood disorders and anxiety disorders receive adequate care, in addition to long wait times for counseling and therapy services [6,7]. Specifically, immigrant communities in Canada underutilize mental health services in comparison to national and provincial averages [6,8]. For example, immigrant populations in Toronto utilized mental health services significantly less than Canadian-born participants (6% for recent immigrants, 7% for longer-term immigrants, and 10% for Canadian-born participants) [6]. With the increasing influx of immigrants to Canada, addressing gaps in the provision of and access to mental health services, including mental health professionals, among immigrants presents a rapidly emerging challenge.

An understanding of the relationship between mental health professional consultation and its association with immigrant status is largely unknown. The 2015 pan-Canadian survey on mental health services highlighted that 91% of survey respondents indicated that increasing access to mental health care professionals was a top priority for government action [9]. Examining this relationship is essential to identify potential gaps that need addressing within the mental health care system. Furthermore, understanding the relationship between mental health professional consultations and immigrants could give rise to strategies that would mitigate mental health-induced burdens associated with immigrant transition and assimilation into Canadian culture. More assuredly, a better understanding of immigrant mental health consultation patterns and mental health outcomes encourages patient-centered care in delivering mental health services to Canada's booming immigrant population. The purpose of this study is two-fold and aims to answer the following research questions: (1) What is the variation of past-year mental health consultations (with general health practitioners and with psychiatrists) among immigrants compared to individuals born in Canada? (2) What is the prevalence of mood and anxiety disorders (2 of the most common mental health conditions) among immigrants compared to individuals born in Canada?

Methods

Data Source

We obtained data for the study from the 2015-2016 Canadian Community Health Survey (CCHS) [10]. The CCHS is an ongoing, national, cross-sectional survey that collects information on health status, health care utilization, and health determinants for the Canadian population. CCHS employs a cross-sectional study design to collect information related to health status and covers approximately 98% of the Canadian population aged 12 years and over. The CCHS data structure consists of individuals nested within health regions nested within provinces. CCHS data are collected using computer-assisted in-person and telephone interviewing. Further details on the methodology utilized by the CCHS and its measures can be found on the Statistics Canada webpage [10]. The CCHS uses a multistage stratified cluster design to sample household dwellings of the Canadian population aged 12 years and older living in private households. Excluded from the sampling frame were individuals living on First Nations reserves, institutions, remote regions, and full-time members of the Canadian Forces.

Independent Variable

The immigrant sample, categorized as a binary variable (*yes* or *no*), is defined by Statistics Canada as “persons residing in Canada who were born outside Canada, excluding temporary foreign workers, Canadian citizens born outside Canada, and those with student or working visas” [11]. Participants in the CCHS were asked if they were born in Canada. Those that answered “no” to this question were considered immigrants. Nonimmigrants in this study refer to persons who were born in Canada.

Outcome Variables

We assessed and analyzed 4 different outcomes related to self-reported responses to past-year mental health consultations. The questions included the following: (1) In the past 12 months, that is, from (date, one year ago) to yesterday, have you seen or talked to a health professional about your emotional or mental health? (*yes* or *no*) (2) Whom did you see or talk to? (Psychiatrist? *yes* or *no*) (3) Do you have a mood disorder such as depression, bipolar disorder, mania, or dysthymia? (*yes* or *no*) (4) Do you have an anxiety disorder such as a phobia, obsessive-compulsive disorder, or a panic disorder? (*yes* or *no*). Respondents were to self-report conditions diagnosed by a health professional; however, they were not asked to elaborate on the type of mood disorder diagnosis or the time when the diagnosis occurred. All missing values for the outcome variables were dropped from the dataset during the statistical analyses.

Other Covariates

Other covariates of interest adjusted for in the analysis include sex (male, female), age, marital status (married/common-law, not married/never married), sense of belonging (strong, weak), working status (not employed, employed), income adequacy (low income, income adequate), highest level of education (high school graduate or less, some post-secondary or more), owned or rented home, cultural or racial origin (Caucasian, visible minority), physical activity level (active, inactive), current

smoking status (smoker, nonsmoker), and the number of chronic conditions present (zero, 1 or more).

Statistical Analysis

Individuals were nested within health regions, which were further nested within provinces. Multistage analyses consisting of both descriptive statistics and multilevel logistic regression models were employed to identify relationships among variables measured at the individual level as well as the amount of variation of the effect at the group level (provinces and health regions). Tests of model fit using Akaike information criterion values were done to identify the level of multilevel logistic regression modeling that best fits the data. The estimated prevalence rates of the 2 mental health consultations associated outcomes were calculated for immigrant populations. Multilevel logistic regression modeling was carried out on each of the outcomes. The covariates outlined were assessed as potential characteristics of “any past-year mental health consultation,” “past-year psychiatrist consultation,” “self-reported diagnosis of mood disorder,” and “self-reported diagnosis of anxiety disorder.” The confounding effects of control variables on the study outcome variables were assessed at each stage of the model building process; any variable that caused a change of 20% or more on the regression coefficient of the primary covariates of interest was considered a confounder and was hence retained in the model. We calculated an intraclass correlation coefficient to measure the amount of variation shared by members of the same geographical area and to help us quantify the heterogeneity between the health regions and provinces.

We applied population sample weights to the effect size estimates to make inferences to the Canadian population. We used bootstrap weights provided by Statistics Canada in the CCHS data file to account for the complex sampling design used to calculate the 95% confidence intervals or the prevalence estimates. Bootstrapping is a technique used to estimate the

variance of a statistic. The level of significance was set at 5%, with two-way analyses in reporting odds ratios and 95% confidence intervals as well. All analyses were performed using Stata IC (version 13.0, StataCorp) [12].

Results

Descriptive Statistics

In the CCHS 2015-2016, 25.33% (weighted percentage; 7,438,691/29,372,184) of the Canadian population surveyed (N=29,372,184) identified themselves as immigrants, with 25.30% (1,659,753/6,561,120) being recent immigrants and 74.70% (4,901,367/6,561,120) being nonrecent immigrants. The results of the descriptive analysis in the CCHS 2015-2016 are displayed in Table 1. The results show that 8.78% (624,617/7,110,919) of immigrants consulted any mental health professional in the past 12 months, 20.00% (124,559/622,661) had consulted with a psychiatrist, 5.24% (389,164/7,422,773) had mood disorders, and 4.47% (330,937/7,410,437) had anxiety disorders. The immigrant sample was 49.07% (3,649,845/7,438,691) male and 50.93% (3,788,846/7,438,691) female. The majority of the immigrants were 60+ years old (2,017,299/4,662,122, 43.27%), married (4,807,589/7,405,342, 64.92%), had a strong sense of belonging in the local community (4,860,802/6,988,638, 69.55%), were employed (4,451,118/6,718,851, 66.25%), earned an adequate income (5,571,604/7,434,459, 74.94%), had some post-secondary education or more (4,932,147/7,306,626, 67.50%), owned their home (4,991,492/7,395,539, 67.49%), were a visible minority (4,732,248/7,340,648, 64.47%), were physically active (5,345,682/7,016,883, 76.18%), were nonsmokers (6,565,496/7,430,428, 88.36%), and had no chronic conditions (5,283,483/7,387,161, 71.52%). Sensitivity analyses showed that there were no significant differences between outcome responses retained for analysis and those excluded by listwise deletion.

Table 1. Summary statistics for mental health professional consultation, mental health outcomes, sociodemographic, socioeconomic status, and behavioral variables by immigrant status (N=29,372,184).

Outcome variables, n (%) ^a	Canadian born, n=21,933,493 (74.67%)	All immigrants, n=7,438,691 (25.33%)	<i>P</i> values
Consulted any mental health professional in the past year?			< .001
Yes	3,434,221 (16.07)	624,617 (8.78)	
No	17,936,177 (83.93)	6,486,302 (91.22)	
Consulted a psychiatrist in the past year?			.38
Yes	573,903 (16.77)	124,559 (20.00)	
No	2,847,760 (83.23)	498,102 (80.00)	
Prevalence of self-reported mood disorders?			< .001
Yes	2,001,829 (9.15)	389,164 (5.24)	
No	19,883,796 (90.85)	7,033,609 (94.76)	
Prevalence of self-reported anxiety disorders?			< .001
Yes	2,083,155 (9.51)	330,937 (4.47)	
No	19,815,684 (90.49)	7,079,500 (95.53)	
Sex			0.73
Male	10,849,193 (49.46)	3,649,845 (49.07)	
Female	11,086,248 (50.54)	3,788,846 (50.93)	
Age category in years			< .001
<20	2,609,211 (16.98)	422,982 (9.07)	
20-39	3,407,653 (22.18)	1,007,521 (21.61)	
40-59	3,802,799 (24.75)	1,214,320 (26.05)	
60+	5,545,249 (36.09)	2,017,299 (43.27)	
Marital status			< .001
Married/common-law	12,089,338 (55.22)	4,807,589 (64.92)	
Not/never married	9,805,033 (44.78)	2,597,753 (35.08)	
Sense of belonging in the local community			.65
Strong	14,398,157 (68.09)	4,860,802 (69.55)	
Weak	6,748,070 (31.91)	2,127,836 (30.45)	
Working status last week			.67
Employed	13,217,420 (67.66)	4,451,118 (66.25)	
Not employed	6,318,019 (32.34)	2,267,733 (33.75)	
Income adequacy			< .001
Low income household	4,454,184 (20.32)	1,862,855 (25.06)	
Income adequate	17,465,194 (79.68)	5,571,604 (74.94)	
Highest level of education			< .001
High school grad or less	9,285,274 (42.86)	2,374,479 (32.50)	
Some post-secondary/more	12,376,542 (57.14)	4,932,147 (67.50)	
Home rented or owned			< .001
Owner	16,559,806 (75.81)	4,991,492 (67.49)	
Rented	5,283,586 (24.19)	2,404,047 (32.51)	
Cultural or racial origin			< .001
Caucasian	19,164,163 (92.69)	2,608,400 (35.53)	

Outcome variables, n (%) ^a	Canadian born, n=21,933,493 (74.67%)	All immigrants, n=7,438,691 (25.33%)	<i>P</i> values
Visible minority	1,510,714 (7.31)	4,732,248 (64.47)	
Physical activity level			< .001
Active	16,216,008 (82.30)	5,345,682 (76.18)	
Inactive	3,486,779 (17.70)	1,671,201 (23.82)	
Current smoking status			< .001
Yes	4,207,071 (19.19)	864,932 (11.64)	
No	17,717,523 (80.81)	6,565,496 (88.36)	
Chronic conditions			.004
No conditions	15,363,198 (70.53)	5,283,483 (71.52)	
1 or more conditions	6,418,787 (29.47)	2,103,678 (28.48)	

^aCanadian Community Health Survey (CCHS) frequency weights have been applied to sample prevalence rate calculations.

From the stratified analysis shown in Table 2, the 2 immigrant groups (recent and nonrecent) were significantly different in the distribution of the outcome variables and all covariates ($P < .001$). Of note is the fact that nonrecent immigrants consulted mental health professionals more frequently (8.95% vs. 8.32%; $P = .02$), consulted a psychiatrist more frequently (21.77% vs. 16.64%; $P = .51$), and had a higher prevalence of mood (5.96% vs. 3.43%; $P < .001$) and anxiety disorders (4.92% vs. 3.18%; $P < .001$).

Table 2. Summary statistics for mental health professional consultation and mental health outcomes by recency of immigration.

Outcome variables, n (%)	All immigrants, N=7,438,691 (25.33%)	Recent immigrants (0-9 years), n=1,659,753 (25.30%)	Nonrecent immigrants (10+ years), n=4,901,367 (74.70%)	<i>P</i> values ^a
Consulted any mental health professional in the past year	624,617 (8.78)	135,096 (8.32)	416,307 (8.95)	.02
Consulted a psychiatrist in the past year	124,559 (20.00)	22,396 (16.64)	90,359 (21.77)	.51
Prevalence of self-reported mood disorders	389,164 (5.24)	56,854 (3.43)	291,501 (5.96)	< .001
Prevalence of self-reported anxiety disorders	330,937 (4.47)	52,702 (3.18)	239,839 (4.92)	< .001

^aChi-square test for differences between recent (0-9 years) and nonrecent (10+ years) immigrant groups.

Multilevel Logistic Regression Analysis

Tables 3 and 4 show the multilevel logistic regression results with their respective odds ratios and 95% confidence intervals, adjusted for the primary predictor and other covariates.

Table 3. Final multivariate multilevel models A and B for immigrant status and mental health professional consultations and psychiatric consultations among respondents in the Canadian Community Health Survey (CCHS) 2015-2016.

Variable	Model A outcome: any mental health professional ^a			Model B outcome: specialized mental health professional (psychiatrist) ^a		
	OR	95% CI	P value	OR ^b	95% CI	P value
Immigrant status						
No	Reference	Reference	—	Reference	Reference	—
Yes	0.80	0.72-0.88	<.001	1.24	1.04-1.48	.02
Sex						
Male	Reference	Reference	—	Reference	Reference	—
Female	2.08	1.97-2.20	<.001	0.85	0.76-0.96	.006
Age in years						
<20	Reference	Reference	—	Reference	Reference	—
20-39	1.07	0.93-1.23	.36	1.03	0.85-1.27	.74
40-59	0.96	0.83-1.11	.56	1.24	1.02-1.50	.03
60+	0.45	0.39-0.52	<.001	0.94	0.77-1.15	.56
Marital status						
Married/common-law	Reference	Reference	—	Reference	Reference	—
Not/never married	1.43	1.35-1.52	<.001	1.40	1.22-1.59	<.001
Sense of belonging to the local community						
Strong	Reference	Reference	—	Reference	Reference	—
Weak	1.46	1.38-1.54	<.001	1.39	1.24-1.55	<.001
Working status last week						
Employed	Reference	Reference	—	Reference	Reference	—
Not employed	1.36	1.28-1.45	<.001	—	—	—
Income adequacy						
Income adequate	Reference	Reference	—	Reference	Reference	—
Low income household	1.19	1.12-1.27	<.001	0.79	0.70-0.91	.001
Highest level of education						
High school grad or less	Reference	Reference	—	Reference	Reference	—
Some post-secondary/more	1.23	1.17-1.31	<.001	—	—	—
Home rented or owned						
Owned	Reference	Reference	—	Reference	Reference	—
Rented	1.26	1.18-1.34	<.001	1.21	1.06-1.38	.004
Cultural or racial origin						
Caucasian	Reference	Reference	—	Reference	Reference	—
Visible minority	0.54	0.48-0.61	<.001	—	—	—
Physical activity level						
Active	Reference	Reference	—	Reference	Reference	—
Inactive	0.92	0.86-0.99	.03	—	—	—
Current smoking status						
No	Reference	Reference	—	Reference	Reference	—
Yes	1.26	1.18-1.35	<.001	1.25	1.10-1.42	.001
Chronic conditions						

Variable	Model A outcome: any mental health professional ^a			Model B outcome: specialized mental health professional (psychiatrist) ^a		
	OR	95% CI	<i>P</i> value	OR ^b	95% CI	<i>P</i> value
No conditions	Reference	Reference	—	Reference	Reference	—
1 or more conditions	1.40	1.32-1.48	<.001	1.15	1.02-1.29	.03

^aIntraclass correlation coefficient for Model A is 1.08% and Model B is 1.91%.

^bAdjusted for employment status, highest level of education, physical activity, and chronic conditions.

Table 4. Final multivariate multilevel models C and D for immigrant status and the prevalence of mood disorders and anxiety disorders among respondents in the Canadian Community Health Survey (CCHS) 2015-2016.

Variable	Model C outcome: mood disorders ^a			Model D outcome: anxiety disorders ^a		
	OR ^b	95% CI	P value	OR ^c	95% CI	P value
Immigrant status						
No	Reference	Reference	—	Reference	Reference	—
Yes	0.79	0.71-0.89	<.001	0.73	0.65-0.83	<.001
Sex						
Male	Reference	Reference	—	Reference	Reference	—
Female	1.88	1.76-1.99	<.001	1.93	1.81-2.06	<.001
Age in years						
<20	Reference	Reference	—	Reference	Reference	—
20-39	1.21	1.05-1.39	.009	1.04	0.92-1.18	.48
40-5	1.59	1.39-1.82	<.001	0.79	0.70-0.89	<.001
60+	0.77	0.67-0.88	<.001	0.40	0.36-0.45	<.001
Marital status						
Married/common-law	Reference	Reference	—	Reference	Reference	—
Not/never married	1.39	1.29-1.49	<.001	1.19	1.11-1.28	<.001
Sense of belonging to local community						
Strong	Reference	Reference	—	Reference	Reference	—
Weak	1.95	1.83-2.08	<.001	1.66	1.56-1.77	<.001
Working status last week						
Employed	Reference	Reference	—	Reference	Reference	—
Not employed	1.61	1.50-1.72	<.001	1.60	1.49-1.72	<.001
Income adequacy						
Income adequate	Reference	Reference	—	Reference	Reference	—
Low income household	1.55	1.44-1.67	<.001	1.39	1.29-1.50	<.001
Highest level of education						
High school grad or less	Reference	Reference	—	Reference	Reference	—
Some post-secondary/more	1.08	1.01-1.15	.02	—	—	—
Home rented or owned						
Owned	Reference	Reference	—	Reference	Reference	—
Rented	1.44	1.33-1.54	<.001	1.39	1.29-1.50	<.001
Cultural or racial origin						
Caucasian	Reference	Reference	—	Reference	Reference	—
Visible minority	0.51	0.44-0.59	<.001	0.63	0.54-0.72	<.001
Physical activity level						
Active	Reference	Reference	—	Reference	Reference	—
Inactive	—	—	—	—	—	—
Current smoking status						
No	Reference	Reference	—	Reference	Reference	—
Yes	1.67	1.55-1.79	<.001	1.74	1.62-1.87	<.001
Chronic conditions						
No conditions	Reference	Reference	—	Reference	Reference	—

Variable	Model C outcome: mood disorders ^a			Model D outcome: anxiety disorders ^a		
	OR ^b	95% CI	P value	OR ^c	95% CI	P value
1 or more conditions	1.74	1.63-1.86	<.001	1.73	1.61-1.85	<.001

^aIntraclass correlation coefficient for Model C is 2.31% and Model D is 1.34%.

^bAdjusted for physical activity level.

^cAdjusted for the highest level of education and physical activity level.

Consulted Any Mental Health Professional (Model A)

Immigrants had lesser odds of consulting any mental health professional than nonimmigrants (OR 0.8, 95% CI 0.7-0.9). Even when predisposing (age groups and sex) and enabling characteristics (owned home, employment status, etc) were taken into account, the association between immigrant status and any mental health professional consultation persisted (Table 3, Model A). The sociodemographic variables showed that the odds of consulting any mental health professional were almost twice as high for females when compared to males (OR 2.1, 95% CI 2.0-2.2). However, not married and never married respondents had significantly higher odds of consulting any mental health professional than married individuals (OR 1.4, 95% CI 1.4-1.5). Interestingly, individuals that felt a very weak sense of belonging to their local communities (OR 1.5, 95% CI 1.4-1.5), individuals between the ages of 20-44 years (OR 1.1, 95% CI 0.9-1.2), individuals from low-income households (OR 1.2, 95% CI 1.1-1.3), individuals that lived in rental accommodations (OR 1.3, 95% CI 1.2-1.3), smokers (OR 1.3, 95% CI 1.2-1.4), and individuals with 1 or more chronic conditions (OR 1.4, 95% CI 1.3-1.5) all had significantly higher odds of consulting any mental health professional in comparison with their respective reference groups.

Consulted a Psychiatrist (Model B)

Immigrants had higher odds of consulting with a psychiatrist than their nonimmigrant counterparts (OR 1.2, 95% CI 1.0-1.5). When predisposing (age groups and sex) and enabling characteristics (marital status, owned home, employment status, etc) were taken into account, the association between immigrant status and consultation of a psychiatrist persisted (Table 3, Model B). The sociodemographic variables showed that females had lesser odds of consulting a psychiatrist than males (OR 0.9, 95% CI 0.8-1.0). In addition, not married and never married individuals had significantly higher odds of consulting with a psychiatrist than their married and common-law counterparts (OR 1.4, 95% CI 1.2-1.6). Similarly, individuals that felt a very weak sense of belonging to their local communities (OR 1.4, 95% CI 1.2-1.6), those that lived in rental accommodations (OR 1.2, 95% CI 1.1-1.4), current smokers (OR 1.3, 95% CI 1.1-1.4), those with 1 or more chronic conditions (OR 1.2, 95% CI 1.0-1.3), and those aged 45-64 years (OR 1.2, 95% CI 1.0-1.5) all had significantly elevated odds of consulting with a psychiatrist compared to their respective reference groups. Individuals from low-income households had lower odds of consulting a psychiatrist (OR 0.8, 95% CI 0.7-0.9).

Presence of Mood or Anxiety Disorder (Model C and Model D)

In examining 2 of the most common psychiatric disorders, Table 4 shows that the immigrants had significantly lesser odds of having mood disorders (OR 0.8, 95% CI 0.7-0.9) and anxiety disorders (OR 0.7, 95% CI 0.7-0.8). Females, younger age groups, not married and never-married individuals, individuals with a weak sense of belonging to the local community, unemployed individuals, current smokers, and those with 1 or more chronic conditions also had increased odds of having mood or anxiety disorders. Individuals from visible minority groups had lesser odds of having both a mood disorder (OR 0.5, 95% CI 0.4-0.6) and an anxiety disorder (OR 0.6, 95% CI 0.5-0.7). These associations were both significant ($P < .001$).

Significant results between health region and provincial variation were identified for all outcome variables. After completing all 4 final models, it was found that the proportion of group-level variability explained by the health region level and provincial factors included in the models ranged from 1-2% for the odds of positively consulting any mental health professional, consulting a psychiatrist, and the presence of either a mood or anxiety disorder. We used 2-tailed Wald tests with statistical significance set at $P = .05$ to determine the statistical significance of the determinants in the final models, and only statistically significant variables were included in the final models shown in Tables 3 and 4. Model diagnostics were assessed using the Akaike information criterion at each stage of the model building process to ensure model fit and to check for outliers. All residuals were shown to be within acceptable levels.

Discussion

Principal Findings

The main objective of this study is to examine differences in any mental health professional consultation and psychiatrist consultations among immigrant and nonimmigrant groups in Canada. This study also examines the prevalence of mood and anxiety disorders among immigrants to Canada compared to those born in Canada.

The study results revealed that Canadian-born populations were more likely to suffer from self-reported diagnoses of mood and anxiety disorders compared with immigrant populations in Canada. This finding is consistent with other Canadian studies [13,14] and studies done in the United States [15-17]. Ideally, it would be expected that individuals with a more significant burden of mood or anxiety disorders would use mental health services more often. However, we found that immigrants, when compared to Canadian-born populations, were less likely to consult with any mental health professional (eg, psychologists,

social workers, general physicians) and were more likely to consult with a psychiatrist for their mental health visits. This suggests an apparent primary care gap in the services received by immigrants and could be an indication of the reported severity of mental health issues immigrants commonly face [18,19]. The implication of this gap is a delay in the reception of care, leading to further deterioration of mental health with increasing cost implications to the individual and health care system.

It is common knowledge that psychiatrists typically tend to handle more severe cases of mental health issues than family physicians or other health care providers. Additionally, there is evidence in the literature showing how challenges with language, stigma, and other difficulties prevent immigrants from promptly accessing the mental health care they need [20-23]. These observations, taken into considerations with our findings of increased use of psychiatrists' services, give further credibility to our position of a visible primary care gap, which could be mitigated by promoting support for the mental health of immigrants at an early stage of illness through primary health care services.

An alternative explanation for the frequent use of psychiatrists over other primary care providers could be that immigrants are more aware of the services that psychiatrists provide based on traditional knowledge from their home countries, in comparison to mental health services offered by psychologists, social workers, and family physicians. It is also possible that our findings might have been skewed to the individual preference for specialist care (ie, psychiatrists) [24]; however, a closer look at this study attributed its findings to the local presence of a psychiatric hospital and an extensive network of community-based organizations involved in mental health.

Interestingly, when respondents were stratified by self-reported diagnosis of mood and anxiety disorders, immigrants were more likely to consult a psychiatrist for their mental health than any other mental health professional as compared to Canadian-born populations. These findings—along with the identified effect of a sense of belonging, marital status, living arrangement, and being from a visible minority immigrant group—provide additional support for the need to explore mental health service utilization. The observed risk factors associated with mental health professional consultations in this study overlapped with many of the determinants found in other literature [25-27]. This study found that immigrants from a visible minority population (ie, racialized immigrants) were much less likely to report mental health consultations. The stressors of migration and resettlement have profound mental health implications, including mental health professional consultations. Long wait times, language barriers, lack of culturally safe care, the proximity of mental health services and difficulties with transportation, challenges in finding timely child care, and lack of suitable e-mental health technology implementation have been cited as primary reasons for unmet mental health care needs [7,21,28]. More importantly, a number of cultural factors (ie, differences in language and ethnicity of care providers) related to shame, stigma, and preference for help-seeking from family members have been cited as possible reasons for why Chinese populations in Canada persistently report the lowest levels of mental health

service utilization [1]. These gaps warrant further research inquiry.

A few studies have reported gender differences in mental health-related consultations to be often nonexistent [29-31]. In our study, we found that female immigrants were more likely to consult with any mental health professional and with a psychiatrist as compared with male immigrants. However, men were more likely to have an inadequate number of mental health consultations compared with women, which could be due to gender differences in accessing health care (ie, women being more likely to have and keep to regular medical appointments with their family physician) [32-34]. This could imply that the mental health of immigrant men may be worse than that of immigrant women; nonetheless, further research is necessary to corroborate this claim further.

Our study provides additional insight into the type of mental health professional consultation an immigrant is more likely to seek. It is also insightful in offering education about alternative sources of mental health care to immigrant populations in Canada. Additionally, this could be useful for policymakers and service providers in targeting mental health funds and programs to vulnerable groups. Ultimately, addressing this issue could lead to increased health-related quality of life, improved productivity in the workforce, and decreased cost of medical resources targeted towards immigrant mental health care. More research is warranted to explore further and to understand better the discordance between mental health professional visits and psychiatric visits in general among immigrant and Canadian-born populations in Canada. Even so, a more comprehensive version of the CCHS is needed, especially one that takes into account immigrant-specific measures of variables such as language barriers in accessing mental health care, mental health stigma, level of mistrust of mental health services, the availability of culturally safe mental health care, and preferred immigrant help-seeking behaviors for mental health. These will help researchers and clinicians to better assess how mental health promotion programs can be tailored to address the specific mental health needs of immigrant populations in Canada.

Study Limitations

Limitations of this study were, for the most part, related to the use of CCHS data. First, there were a limited number of mental health-specific variables in the dataset. This fact, in addition to the dichotomy of almost all variable responses, made it impossible to explore some other factors (for example, the sex of mental health professionals, and reasons for not consulting any mental health professional). Second, the CCHS data, although almost representative of the Canadian population, does not have data for on-reserve Aboriginal populations. Further research of this highly vulnerable group could have been explored and contrasted to findings among immigrant groups, as both groups face similar barriers in accessing culturally appropriate health and mental health care services in Canada. Third, as with all epidemiological studies employing cross-sectional data, we cannot make inferences about the temporality of events. Fourth, diagnostic tests for all models showed residuals within acceptable levels, hence implying the absence of outliers and increasing the reliability of the model.

However, caution should be applied due to the limitations in the CCHS publicly available dataset. Lastly, the CCHS has the potential for recall bias as it requires participants to remember past events rather than corroborating with medical records. In addition, the outcome variables of mental health consultation (any and psychiatric) were based on a single survey item.

Despite these highlighted limitations, the use of the CCHS for this analysis provided comparative data from a large Canadian sample, which allowed for inferences to be made about the Canadian population as a whole. These findings could be further explored in future research with adjustments to the survey tools over time, especially as it relates to the inclusion of culturally specific variables.

Conclusions

This study found that the majority of immigrants who seek mental health care consult the specialist services of a psychiatrist. As psychiatrists are known to deal with more complex cases of mental health, there is a crucial need for open conversations on mental health between family doctors and

immigrants, as this is usually their first contact with the Canadian health care system. An expansion of the care role of family doctors may be a possible avenue to pursue to improve mental health service access for immigrant populations. A weak sense of belonging was strongly associated with past-year mental health consultation for immigrant populations. Mental health initiatives and policies need to be embedded in immigrant settlement initiatives to ensure that immigrants are better connected to their local communities. These could help immigrants get the right information about mental health in a timely manner and ultimately improve overall health and wellbeing. Cross-sectoral and holistic approaches are thus needed to move towards the comprehensive provision of timely and culturally safe mental health care delivery. This study examined conventional mental health professional consultation. Further research is required to understand how immigrant populations use other unconventional mental health supports as they relate to help-seeking behaviors for mental health; these can include social support networks, faith-based support, family or friend support, and spiritual or cultural services.

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Authors' Contributions

This study was conceptualized and designed by CN, who acquired the data, analyzed and interpreted the data, and drafted the manuscript. CN had full access to all the data in the study and had final responsibility for the decision to submit for publication. UO and HB contributed to the data interpretation, writing, critical review, and revision of the manuscript. All authors provided intellectual content, reviewed, edited, and amended the manuscript. All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

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Abbreviations

CCHS: Canadian Community Health Survey

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Original Paper

Utilizing Machine Learning on Internet Search Activity to Support the Diagnostic Process and Relapse Detection in Young Individuals With Early Psychosis: Feasibility Study

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Abstract

Background: Psychiatry is nearly entirely reliant on patient self-reporting, and there are few objective and reliable tests or sources of collateral information available to help diagnostic and assessment procedures. Technology offers opportunities to collect objective digital data to complement patient experience and facilitate more informed treatment decisions.

Objective: We aimed to develop computational algorithms based on internet search activity designed to support diagnostic procedures and relapse identification in individuals with schizophrenia spectrum disorders.

Methods: We extracted 32,733 time-stamped search queries across 42 participants with schizophrenia spectrum disorders and 74 healthy volunteers between the ages of 15 and 35 (mean 24.4 years, 44.0% male), and built machine-learning diagnostic and relapse classifiers utilizing the timing, frequency, and content of online search activity.

Results: Classifiers predicted a diagnosis of schizophrenia spectrum disorders with an area under the curve value of 0.74 and predicted a psychotic relapse in individuals with schizophrenia spectrum disorders with an area under the curve of 0.71. Compared with healthy participants, those with schizophrenia spectrum disorders made fewer searches and their searches consisted of fewer words. Prior to a relapse hospitalization, participants with schizophrenia spectrum disorders were more likely to use words related to hearing, perception, and anger, and were less likely to use words related to health.

Conclusions: Online search activity holds promise for gathering objective and easily accessed indicators of psychiatric symptoms. Utilizing search activity as collateral behavioral health information would represent a major advancement in efforts to capitalize on objective digital data to improve mental health monitoring.

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KEYWORDS

schizophrenia spectrum disorders; internet search activity; Google; diagnostic prediction; relapse prediction; machine learning; digital data; digital phenotyping; digital biomarkers

Introduction

Schizophrenia can be associated with significant impairment [1]. Although early intervention services have demonstrated the potential to improve outcomes [2], several challenges persist, limiting the established benefits of effective care. These include lengthy delays to early and accurate diagnostic ascertainment [3,4], as well as high rates of relapse, particularly during the early course of illness [5]. Under-recognized or misdiagnosed symptoms contribute to poorer outcomes such as social isolation, unemployment, and comorbid depression, anxiety, and substance abuse [6]. Furthermore, each new relapse can be associated with costly emergency room visits, psychiatric hospitalizations, family burden, medical complications, and suicide [7].

These challenges are compounded by the fact that psychiatry is still nearly entirely reliant on patient self-report. In contrast to all other areas of medicine, there are no reliable tests, biomarkers, or objective sources of collateral information available to inform diagnostic procedures or to assess mental health status [8-10]. Clinicians must therefore rely on subjective information, collected through patient and family interviews, to support diagnoses and make treatment recommendations. Technology offers the opportunity to collect objective digital data to complement self-reports and facilitate more informed treatment decisions [11-13]. Online search activity is a source of objective data with great potential.

Google search is one of the most popular websites worldwide, managing over 3 billion searches daily across over 600 million daily visitors [14]. Moreover, searching online has become a primary resource for youth seeking mental health-related information [15-20]. This is particularly true for stigmatized illnesses such as schizophrenia as the internet provides an easy and anonymous setting to gather information about symptoms and treatment options [21]. Importantly, online search engines store search activity as time-stamped digital records, offering a reliable source of objective, easily accessed, and detailed collateral information about an individual over an extended period of time.

Prior work has highlighted opportunities to utilize large-scale anonymized search logs to detect signals associated with the emergence and progression of medical illnesses [22]. For example, search activity, including content and patterns of use, has been used to identify individuals with lung cancer, Parkinson disease, and pancreatic cancer with high degrees of accuracy up to a year in advance of the diagnosis [23-25]. The success of these algorithms may lead to the development of a new generation of digital tools designed to assist in the screening and early identification of individuals at risk for medical conditions. Similar methods have been employed successfully in psychiatry using digital data extracted from social media sites [26-33]. However, few studies to date have explored the use of computational approaches to detect search patterns associated with psychiatric disorders [34]. Furthermore, while promising, online activity research thus far has been limited by the fact that it has been conducted primarily utilizing data extracted from anonymous individuals online who self-disclose having a particular diagnosis [35], and has yet to be carried out in

real-world clinical settings using participant-contributed search data with clinically validated diagnoses.

Toward the goal of improving early diagnostic accuracy and relapse detection, we sought to conduct one of the first ecologically valid investigations into the relationship between online search activity and behavioral health. Specifically, we aimed to develop computational algorithms designed to accurately identify individuals with schizophrenia spectrum disorders (SSD) and to predict psychotic relapse based on internet search activity. We hypothesized that significant differences in the timing, content, and pattern of online search activity would differentiate participants with SSD from healthy volunteers, and that changes in these features would accurately predict a psychotic relapse in individuals with SSD.

Methods

Participants and Data Collection

Participants between the ages of 15 and 35 years were recruited from Northwell Health's inpatient and outpatient psychiatry departments. Individuals with SSD were recruited primarily from the Early Treatment Program, Northwell Health's specialized early psychosis intervention clinic (N=37). Additional participants diagnosed with SSD (N=7) were recruited from a collaborating institution located in East Lansing, Michigan. Recruitment occurred between March 2016 and December 2018. The study was approved by the Institutional Review Board (IRB) of Northwell Health (the coordinating institution) as well as by the local IRB at the participating site. Written informed consent was obtained for adult participants and legal guardians of participants under 18 years of age. Assent was obtained for participating minors. Healthy volunteers were approached and recruited from an existing database of eligible individuals who had already been screened for prior research projects at Zucker Hillside Hospital and had agreed to be recontacted for additional research opportunities (N=58). Additional healthy volunteers (N=21) were recruited from a southeastern university via an online student community research recruitment site. Healthy status was determined either by the Structured Clinical Interview for DSM Disorders [36] conducted within the past 2 years or the Psychiatric Diagnostic Screening Questionnaire [37]. If clinically significant psychiatric symptoms were identified during the screening process, participants were excluded.

Participants requested their search archive (known as "takeout") through a simple process supported by Google. Participation involved a single visit during which all historical search activity was downloaded and collected. Each archive included a time-stamped record of search terms and browser history. Using hospitalization dates pulled from participants' medical records, each participant's search data was segmented into 4-week periods immediately before and after each hospitalization. A 4-week period was selected as it represents an interval of time long enough to identify symptomatic changes [38,39] and also to contain sufficient online data required to train an algorithm [33,40]. For healthy participants (who did not have a hospitalization date), we randomly selected 4 weeks' worth of search data to serve as a control.

Diagnostic Classifier

A diagnostic classifier was built utilizing 4 weeks' worth of search data immediately preceding the first psychiatric hospitalization. Data prior to the first hospitalization were selected to reduce the potential confounding influence of receiving a psychiatric diagnosis, being hospitalized, and receiving psychiatric interventions (such as therapy or prescriptions for psychiatric medications) on search activity. Concurrently, we built the diagnostic classifier using data closest to the time when the diagnosis is typically made (at the point of initial hospitalization) [41] to enhance the classifier's potential clinical utility as a diagnostic support tool. A 4-week period before hospitalization was selected as it represents a period of time when psychotic symptoms would likely be most prominent. To match the data extraction period for both groups, we randomly selected 4 weeks' worth of search data from each healthy participant to serve as a comparison group. This strategy also reduced possible effects of seasonality on search behavior. Participants diagnosed with SSD who did not have any search data in the 4-week period before their first hospitalization were excluded from this classifier. For healthy volunteers, if no search data existed in the randomly selected 4-week period, that participant was excluded.

Relapse Classifier

A relapse classifier was built by segmenting the search data into 4-week periods of "relative health" and "relative illness." Periods of relative illness were defined as the 4 weeks immediately preceding each relapse hospitalization, as it represents a period of time prior to hospitalization during which psychiatric symptoms are typically the most prominent. When less than 1 month existed between two consecutive hospitalizations, these data were not included in the classification model. Healthy periods were defined as the 4-week period immediately following discharge from a relapse hospitalization, as this represents a period of time when symptoms are typically better managed and less pronounced. If less than 2 months' worth of search data existed between consecutive hospitalizations, these data were not included in the classifier, as we did not expect this period to represent a true period of relative health. Search data prior to the first hospitalization were not included in the relapse classifier. In total, 38 participants were included in the relapse classifier

consisting of 51 periods of relative health and 42 periods of relative illness.

Defining Features

We defined features of search content and search behavior using linguistic and temporal parameters. For linguistic features, we used linguistic inquiry and word count (LIWC) [42]. LIWC is a language analytic tool designed to capture and count the frequency of 51 different word categories, with established psychometric properties, including emotions, mood, cognition, thinking styles, and social concerns. A rich body of literature has identified associations between the use of LIWC categories and psychological health and illness [42,43]. We concatenated the Google search streams for the selected periods before passing them to LIWC as the input text for computing features. For the search behavioral features, we constructed histograms of length and frequency of queries using 1-hour bins as well as 4-day bins. This was done to explore search features that might accompany changes in circadian patterns associated with SSD. The 1-hour bin histogram helped to model finer changes in the length and frequency of search behaviors throughout the day, whereas the 4-day bin histogram was used to model broader changes in search behaviors. The 1-hour bin histograms were computed by creating 24 bins corresponding to each hour of the day and aggregating (through summation) each participant's data across the 28 days. We chose hourly bins as this approach has been successfully implemented in prior research [27,44-46] exploring fluctuations in mood.

In addition, we included the total number of queries and the average query length for the 4-week period. We also included the standard deviation of the 4-day bin histograms (length and frequency) to represent the variation in search behaviors. Finally, we included directional changes in search behavior by computing first- and second-order statistics on the derivative of the 4-day histograms. All LIWC features were normalized based on the number of words in all searches concatenated for each participant, whereas the other features were normalized by subtracting the mean and dividing by the standard deviation. This process controls for any discrepancies in the feature values (ie, differences in the number of searches). A summary of all feature types along with the dimension of each feature is shown in [Table 1](#).

Table 1. Feature categories along with the dimensionality of each feature type.

Feature type	Dimensions
24-hour histogram of length of queries with 1-h bin	24
24-hour histogram of frequency of queries with 1-h bin	24
32-day histogram of length of queries with 4-day bin	8
32-day histogram of frequency of queries with 4-day bin	8
SD of 4-day frequency of queries bins	1
SD of 4-day length of queries bins	1
Average of the derivative of 4-day frequency of queries bins	1
Average of the derivative of 4-day length of queries bins	1
SD of the derivative of 4-day frequency of queries bins	1
SD of the derivative of 4 day length of queries bins	1
Linguistic inquiry and word count	51
Total number of queries in 1 month	1
Average query length in 1 month	1

Classifier Analyses

For both the diagnostic classifier and relapse prediction, we tested three classifiers: random forest (RF) [47], support vector machine (SVM) [48], and gradient boosting (GB) [49]. We used the standard python-based scikit-learn [50] library for evaluating classification performance. We performed hyperparameter tuning using a held-out validation dataset, which resulted in selection of optimal hyperparameters for the classifiers. For example, for SVM, we selected the radial basis function kernel over the standard linear kernel. Each classifier was validated using a 5-fold crossvalidation technique to avoid overfitting. To prevent bias in selection of healthy volunteer data, we tried 10 different iterations of randomly selected 4-week periods and found that the results were consistent. We calculated the average F1 score, average accuracy, and average area under the receiver operating characteristic curve (AUC) across 5 folds for each classifier. Since both diagnostic and relapse classifiers were trained on unbalanced datasets, we chose to evaluate the classifiers based on the AUC since it is a parameter that is agnostic to class imbalance [51].

Feature Importance

A total of 123 features were used for each classifier. We used the permutation feature importance [52] method to compute the rank-ordered feature importance for each classifier. Under this method, feature importance is defined by the difference in the

model's score when the feature is randomly shuffled. Feature importance is proportional to the drop in the model score when the feature is shuffled. We used the AUC value as the model score. The feature importance was calculated on the validation set in 5-fold crossvalidation and the average score was computed across the 5 folds. We used this method as it is model-agnostic and enabled comparison of three different classifier models in an unbiased manner.

Results

A total of 123 search archives (44 individuals diagnosed with SSD and 79 healthy volunteers) were available for analysis, and 116 (42 individuals with SSD and 74 healthy volunteers) met the inclusion criteria. Of these, 38 participants with SSD were available for the relapse classifier. An overview of the final dataset is shown in Table 2.

With respect to the diagnostic classifier (Table 3), the RF was selected for further feature analysis given its superior AUC compared to that of the other models. Figure 1 shows the receiver operating characteristic curves of the RF diagnostic classifier for each of the 5 folds. To explore consistency, this process was repeated 10 times with differing randomly selected 4-week periods of healthy volunteer data. Classifier performance remained consistent. Table 4 shows the quantity of search data provided per group for the diagnostic classifier.

Table 2. Participant demographics (N=116).

Characteristic	Value
Age (years), mean (SD)	24.38 (5.18)
Sex, n (%)	
Male	51 (44.0)
Female	65 (56.0)
Race, n (%)	
Asian	18 (15.5)
African American	32 (27.6)
Caucasian	60 (51.7)
Mixed/Other	6 (5.2)
Hispanic, n (%)	11 (9.5)
Diagnosis, n (%)	
Schizophrenia	16 (13.7)
Schizophreniform	13 (11.2)
Schizoaffective	2 (1.8)
Unspecified SSD ^a	11 (9.5)
Healthy volunteers, n (%)	74 (63.8)

^aSSD: schizophrenia spectrum disorders.

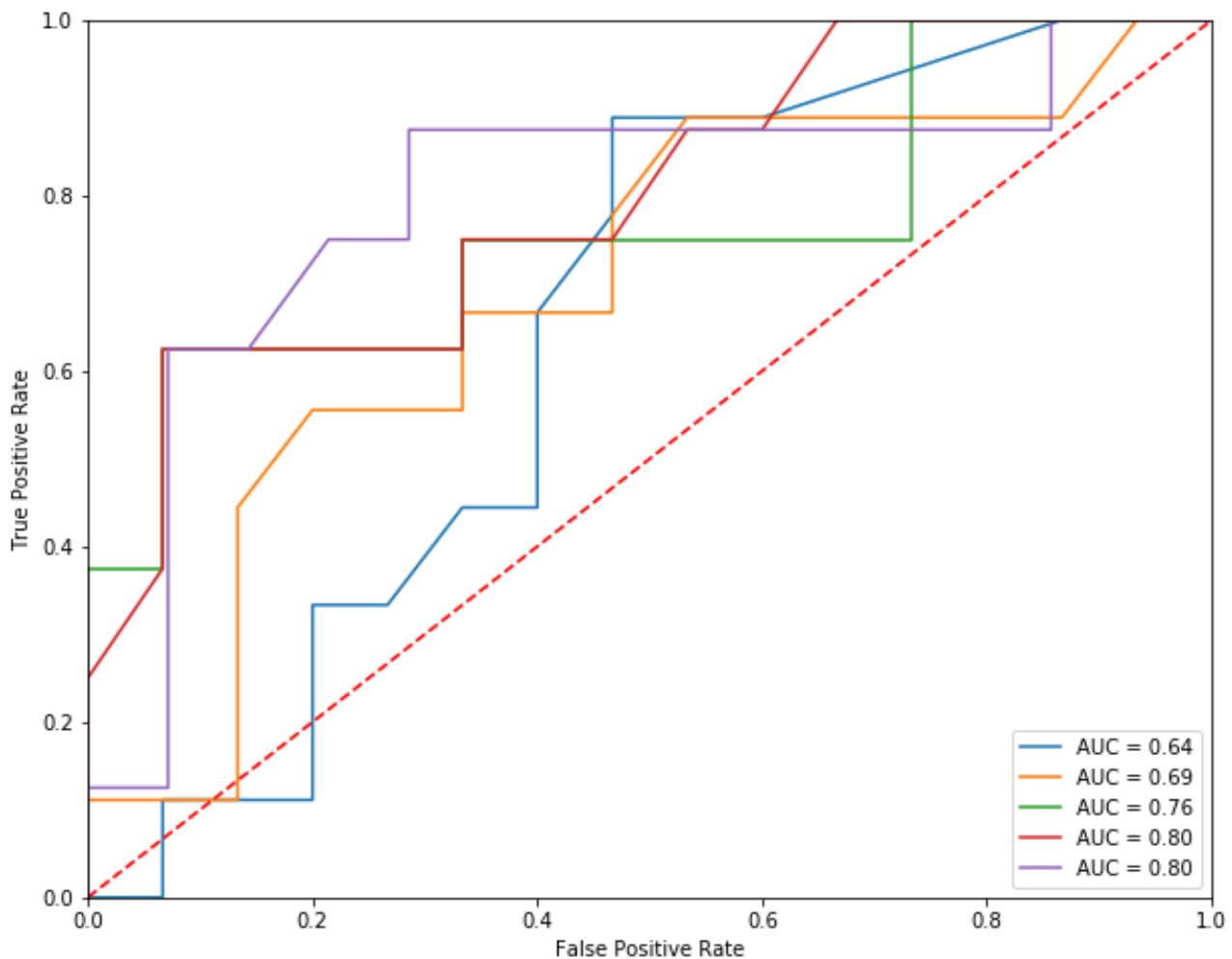
Table 3. Diagnostic classifier results.

Classifier type	Mean F1	Precision (HV ^a)	Precision (SSD ^b)	Recall (HV)	Recall (SSD)	Mean Accuracy	Mean (SD) AUC ^c
Support vector machine	0.49	0.73	0.51	0.73	0.5	0.65	0.66 (0.09)
Random forest	0.54	0.75	0.72	0.86	0.48	0.73	0.74 (0.06)
Gradient boost	0.47	0.71	0.53	0.77	0.44	0.65	0.68 (0.09)

^aHV: healthy volunteers.

^bSSD: schizophrenia spectrum disorders.

^cAUC: area under the receiver operating characteristic curve.

Figure 1. Receiver operating characteristic curves of the random forest diagnostic classifier for each of the 5 folds. AUC: area under the curve.**Table 4.** Quantity of search data provided per group for the diagnostic classifier.

Metric	Healthy volunteers	Participants with SSD ^a
Total average queries (SD)	332.93 (298.1)	192.76 (214.19)
Weekly average queries (SD)	80.37 (71.92)	48.19 (52.91)

^aSSD: schizophrenia spectrum disorders.

For the relapse classifier (Table 5), the SVM and GB models had the same AUC, and therefore both were considered for feature analysis. Further analysis of the feature importance of the SVM and GB relapse model revealed differing features. Herein, we report the SVM model as the identified features included search terms/themes that were deemed to be clinically interpretable and demonstrated some consistency with previous findings [33]; see Multimedia Appendix 1 for a comparison of the important features highlighted by both models. Figure 2 shows the receiver operating characteristics of the SVM relapse classifier for each of the 5 folds. The average F1 score for the SVM model was 0.36 and the average accuracy was 0.63. Table 6 shows the quantity of search data provided per group for the relapse classifier.

For each of the selected models, we calculated the top 20 features using the permutation feature selection method. The

features sorted in decreasing order of feature importance for diagnostic and relapse classifiers are shown in Table 7 and Table 8, respectively. For the two classifiers, both linguistic and behavioral features accounted for the top 20 features, indicating that both categories of features were important drivers of the classification result. Top features pertaining to the diagnostic classifier included a reduced search length between 12 am and 12 pm, lower overall number/frequency of search queries, as well as differences in the use of search terms/words from the “inhibition,” “positive affect,” and “anxiety” categories. Top features pertaining to the relapse classifier included differences in the use of search terms/words from the “sexual,” “health,” “hear,” “anger,” “sadness,” and “perception” LIWC categories, as well as reductions in search length and search frequency prior to a relapse hospitalization.

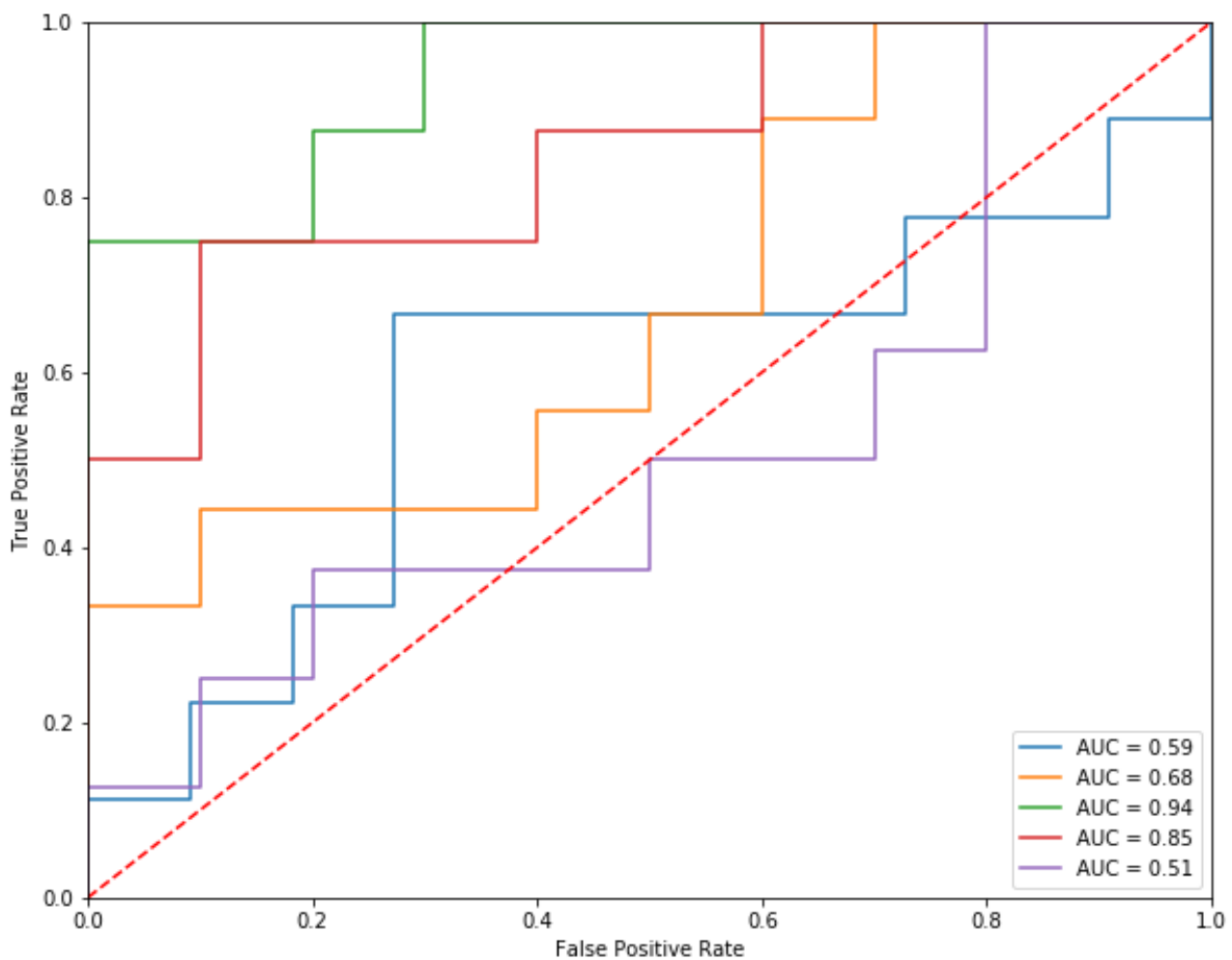
Table 5. Relapse classifier results.

Classifier type	Mean F1	Precision (HV ^a)	Precision (SSD ^b)	Recall (HV)	Recall (SSD)	Mean Accuracy	Mean (SD) AUC ^c
Support vector machine	0.36	0.61	0.77	0.92	0.26	0.63	0.71 (0.16)
Random forest	0.53	0.61	0.61	0.69	0.48	0.61	0.69 (0.09)
Gradient boost	0.57	0.66	0.63	0.75	0.53	0.65	0.71 (0.10)

^aHV: healthy volunteers.

^bSSD: schizophrenia spectrum disorders.

^cAUC: area under the receiver operating characteristic curve.

Figure 2. Receiver operating characteristic curves of the support vector machine relapse classifier for each of the 5 folds. AUC: area under the curve.**Table 6.** Quantity of search data provided per group for the relapse classifier.

Metric	Periods of relative health	Periods of relative illness
Total average queries (SD)	96.80 (98.77)	168.29 (250.18)
Weekly average queries (SD)	24.2 (11.17)	42.07 (39.9)

Table 7. Feature importance of diagnostic classifiers sorted by decreasing order of importance.

Diagnostic classifier features	Average feature importance (random forest)
Reduced search lengths between 8-9 am in participants with SSD ^a compared to HV ^b	0.0315
Reduced search lengths between 6-7 am in participants with SSD compared to HV	0.0255
Length of queries from 23-20 days prior to first hospitalization is lower in participants with SSD compared to HV	0.0178
Reduced usage of “relative” LIWC ^c features in participants with SSD compared to HV	0.0112
Variance in frequency of search lengths is lower in participants with SSD	0.0111
Reduced search lengths between 11 am to 12 pm in participants with SSD compared to HV	0.0091
Reduced usage of “inhibition” LIWC features in participants with SSD compared to HV	0.0078
Reduced search lengths between 4 and 5 am in participants with SSD compared to HV	0.0073
Reduced usage of “quantifier” LIWC features in participants with SSD compared to HV	0.0072
Reduced search lengths between 1 and 2 am in participants with SSD compared to HV	0.0071
Reduced usage of “positive affect” LIWC features in participants with SSD compared to HV	0.0071
Reduced search lengths between 12 am and 1 am in participants with SSD compared to HV	0.0070
Reduced usage of “anxiety” LIWC features in participants with SSD compared to HV	0.0064
Lower overall number of queries in participants with SSD compared to HV	0.0062
Reduced usage of “preposition” LIWC features in participants with SSD compared to HV	0.0061
Reduced usage of “inclusive” LIWC features in participants with SSD compared to HV	0.0059
Frequency of search 19-16 days prior to first hospitalization is lower in participants with SSD compared to HV	0.0059
Reduced usage of “insight” LIWC features in participants with SSD compared to HV	0.0057
Number of queries between 2 and 3 am is lower in participants with SSD compared to HV	0.0056
Number of queries between 11 pm and 12 am is lower in participants with SSD compared to HV	0.0051

^aSSD: schizophrenia spectrum disorders.

^bHV: healthy volunteers.

^cLIWC: linguistic inquiry and word count.

Table 8. Feature importance of relapse classifiers sorted by decreasing order of importance.

Relapse classifier features	Average feature importance (support vector machine)
Reduced length of queries during relapse periods	0.0688
Increased usage of “sexual” LIWC ^a features during relapse periods	0.0523
Reduced length of queries 3-0 days prior to relapse hospitalization	0.0506
Reduced frequency of search activity during relapse periods	0.0263
Reduced usage of “health” LIWC features during relapse periods	0.0245
Increased usage of “hear” LIWC features during relapse periods	0.0224
Increased usage of “bio” LIWC features during relapse periods	0.0223
Increased searches in the 4 days before relapse hospitalization	0.0209
Reduced length of queries in the 7-4 days prior to relapse hospitalization	0.0196
Reduced frequency of searches 23-20 days prior to relapse hospitalization	0.0194
Increased usage of “percept” LIWC features during relapse periods	0.0186
Increased length of queries in the 31-28 days prior to relapse hospitalization	0.0162
Increased usage of “inclusive” LIWC features during relapse periods	0.0143
Denser searches during relapse periods	0.0140
Increased usage of “anger” LIWC features during relapse periods	0.0131
Reduced frequency of searches 19-16 days prior to relapse hospitalizations	0.0125
Reduced length of queries 11-8 days prior to relapse hospitalization	0.0105
Reduced usage of “sadness” LIWC features during relapse periods	0.0105
Increased usage of “indefinite pronoun” LIWC features during relapse periods	0.0104
Reduced frequency of searches 15-12 days prior to relapse hospitalization	0.0097

^aLIWC: linguistic inquiry and word count.

Discussion

Principal Findings

We aimed to explore the feasibility of using collateral online search activity to support the diagnostic process and relapse detection in individuals with SSD. Our results indicate that important differences exist in the timing, frequency, and content of search activity in individuals with SSD compared to healthy volunteers. Furthermore, linguistic and behavioral shifts were identified in the month preceding a relapse hospitalization in individuals with SSD. This study demonstrates the promise of online search activity to potentially serve as collateral information informing diagnostic procedures as well as relapse identification strategies. Much like physicians routinely use medical imaging and blood tests to obtain objective and reliable clinically meaningful patient data, our results support the prospect of incorporating real-time machine learning-based extraction and analysis of online activity into psychiatric assessment.

Features Relevant to the Diagnostic Classifier

Combining linguistic and behavioral features, the RF classifier distinguished individuals with SSD from healthy volunteers with an AUC of 0.74, suggesting that the integration of Google data with clinical information at the time of first hospitalization could potentially serve to improve the accuracy and reliability of clinical diagnoses [52]. Compared to healthy participants,

those with SSD made fewer searches and their searches consisted of fewer words. Reduced search activity may represent declining interests and engagement with the environment [53-55]; as positive and negative symptoms of schizophrenia escalate, individuals with SSD may become less invested in their environment and increasingly internally preoccupied. Alternatively, reduced search activity could be related to cognitive deficits that are commonly associated with schizophrenia [56]. Given that cognitive changes may be subtle early in the course of illness [57], having an objective way by which to identify cognitive markers of SSD could contribute valuable information to the diagnostic process and inform treatment recommendations. Future research will need to explore precisely when changes first manifest online as well as their clinical significance. Online search data typically exist from the origin of an individual’s Google account, and the present results suggest that search data could prove to be particularly useful in charting the trajectory of an individual’s illness, as well as in contributing useful information about the timing of symptomatic changes.

Compared to healthy participants, those with SSD were significantly less likely to search for content related to “positive affect” (eg, “happy,” “good”), and less likely to search for content related to “anxiety” (eg, “nervous,” “tense”). These findings are consistent with the experience of low mood, apathy, and reduced emotional expression often associated with SSD [58,59]. These symptoms often predate the positive symptoms

such as hallucinations and delusions, and therefore an objective method to identify them could help to overcome limitations of patient self-report to inform early intervention. Participants with SSD were also less likely to search using words from the relative (motion, space, time), inhibition (block, constrain), and inclusive (with, include) categories, and were less likely to use quantifiers (few, many, much) and prepositions (on, to, from). Determining the clinical significance of these differences requires additional research; however, they appear to be related to the complexity of the search query. Individuals with SSD often experience concrete thinking [60] in addition to the cognitive limitations noted above, and may therefore use less complex language when searching for information online.

Features Relevant to the Relapse Classifier

Relapse periods could be distinguished from healthy periods with an AUC of 0.71. During a relapse period, participants with SSD were more likely to use words from the hear (heard, listen, sound), bio (eat, blood, pain), perception (see, touch, listen), and anger categories. They were less likely to use words related to health. These changes could be consistent with increasing delusions, hallucinations, and irritability during a psychotic relapse [61-63]. Previous work has identified changes in language use on social media that occur alongside escalating psychotic symptoms [33]. Thus, future research should aim to identify the point in illness progression at which linguistic shifts emerge online so as to make the best clinical use of this information.

Compared with periods of relative health, search length became shorter and the frequency of search activity decreased closer to the date of the relapse hospitalization. This could be indicative of a further decline in cognition function [56], or perhaps due to the presence of distracting internal stimuli. Fewer searches may also represent disengagement from one's environment and reduced desire to ask questions and seek answers. This would be consistent with the avolition and negative symptoms commonly experienced by individuals with first-episode psychosis [59]. Additional research will be required to determine the precise clinical correlates.

Limitations

The first limitation is that our approach was limited by our characterization of monthly periods of relative health and relative illness. The illness trajectory for individuals with SSD does not neatly fall into distinct segments of "health" and "illness," and symptoms instead fluctuate over time. In addition, discharge from hospital does not necessarily mean full resolution of symptoms; therefore, we might have underestimated the potential differences between periods of illness and health. Furthermore, the inpatient hospitalization dates were obtained via medical records, and it is possible that some hospitalizations were missing from the record and therefore not included in our analyses. Related is the fact that the specific symptoms that define an exacerbation for each individual with SSD are often unique, and the impact of symptom heterogeneity on searches should also be explored in future work. To address these limitations and to improve the ability to find associations between online activity and psychotic symptoms, future studies need to monitor participants prospectively and utilize symptom

rating scales to more accurately assess symptom changes and severity as well as to determine the specificity and sensitivity of our findings in comparison to other diagnostic groups. Additionally, future research will need to consider the potential influence of various life events, including search patterns associated with work and school.

Second, some individuals with SSD are diagnosed well before or long after the first psychiatric hospitalization, and therefore the generalizability of our diagnostic classifier is currently unknown. Ongoing efforts focused on understanding search behavior throughout the entire course of illness development, progression, and care should explore potential differences in those who are diagnosed at various time points.

Third, some participants were more active online than others, providing varying degrees of extractable data. An important question for future research will be how much search data is necessary to make reliable clinical predictions.

Fourth, the archives used for our analyses were collected retrospectively. Although retrospective collection eliminates the possibility of altering behavior as a result of being monitored, to achieve the goal of making real-time predictions, identifying clinically meaningful patterns in search data prospectively will be necessary.

Fifth, the eligibility criterion for age was between 15 and 35 years to reflect the inclusion criteria of the Early Treatment Program; however, adolescents may engage with search engines in a distinct manner compared to young adults, and age will need to be considered in future initiatives.

Sixth, we used nonlinear kernels in our classification models to accommodate nonlinear feature dependencies in the models. Although this is recommended for improved classification performance, it can also limit the interpretability of the features based on linear permutation methods. The feature permutation does not test for nonlinear permutations in features.

Seventh, for the purpose of this feasibility study, we considered both classification accuracy as well as feature interpretability in selecting our models. Further research with additional data from more participants is required to test the scalability of the selected classifiers and features as well as their generalizability to other online search engines beyond Google.

Finally, Google takeout only extracts search data collected while an individual is signed in to their account. Some participants may have searched for information while signed out, and these data would not have been captured in their archives.

Conclusion and Prospects

Although search data alone are not sufficient to make a diagnosis or to predict a relapse, the integration of these data with information collected through traditional clinical means could be useful. Previous work has demonstrated that many people search for information online long before seeking help in person [9-11], and this study highlights the existence of a diagnostic signal in daily search patterns. Online services could one day facilitate the transition from information-seeking to help-seeking, hasten the diagnostic process, and help to reduce the burden of untreated psychosis. This approach could also be

beneficial for relapse identification, enabling earlier intervention. Prior initiatives have explored the utility of smartphone sensor data (ie, geolocation, physical activity, phone usage, and speech), wearables, and social media activity to predict symptom fluctuations [44,64-66]. Our results demonstrate that user-generated search activity represents another potentially critical source of digital data contributing to the diagnostic process and relapse identification. Future work combining digital data from multiple sources will likely result in the most effective clinical tools. However, how to effectively and ethically

incorporate personalized patterns of activity into clinical workflow are critical questions of inquiry. Interdisciplinary teams of researchers, clinicians, and patients must continue to work together on exploring challenges in ethics, privacy, consent, clinical responsibility, and data ownership. As our analyses become increasingly sophisticated and our ability to predict health information improves, stakeholders must develop standards to protect the confidentiality and the rights of this sensitive population, and ensure that the enabled technologies are used in the service of positive outcomes for the patients.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Top 20 features for the support vector machine (SVM) and gradient boost (GB) relapse classifiers in order of importance. [[DOCX File , 13 KB - mental_v7i9e19348_app1.docx](#)]

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Abbreviations

AUC: area under the receiver operating characteristic curve.

GB: gradient boost

IRB: Institutional Review Board

LIWC: linguistic inquiry and word count

RF: random forest

SSD: schizophrenia spectrum disorders

SVM: support vector machine

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Original Paper

The Use of Mumsnet by Parents of Young People With Mental Health Needs: Qualitative Investigation

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Abstract

Background: There are high rates of mental health needs in children in the United Kingdom, and parents are increasingly seeking help for their children's needs. However, there is not enough access to child and adolescent mental health services and parents are seeking alternative forms of support and information, often from web-based sources. Mumsnet is the largest web-based parenting forum in the United Kingdom, which includes user-created discussions regarding child mental health.

Objective: This qualitative investigation aimed to explore the emergent themes within the narratives of posts regarding child mental health on Mumsnet and to extrapolate these themes to understand the purpose of Mumsnet for parents of children and young people with mental health needs.

Methods: A total of 50 threads from Mumsnet *Talk Child Mental Health* were extracted. Following the application of inclusion and exclusion criteria, 41 threads were analyzed thematically using the framework approach, a form of qualitative thematic analysis.

Results: In total, 28 themes were extracted and organized into 3 domains. These domains were *emotional support*, *emotional expression*, and *advice and information*. The results suggested that parents of children with mental health needs predominantly use Mumsnet to offer and receive emotional support and to suggest general advice, techniques, and resources that could be applied outside of help from professional services.

Conclusions: This paper discusses the future of health information seeking. Future research is required to establish initiatives in which web-based peer-to-peer support and information can supplement professional services to provide optimum support for parents of children with mental health needs.

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KEYWORDS

mental health; parenting; internet; evidence-based medicine

Introduction

Background

Recent years have seen a slight but notable increase in the prevalence of mental health disorders in children over time in the United Kingdom, 9.7% of those aged 5-15 years with a diagnosable condition in 1999, to 11.2% in 2017 [1]. More recently, in 2018, a separate survey noted that 12.8% of those aged 5-19 years in the United Kingdom met the clinical criteria for a mental health disorder [2]. The demand for Child and Adolescent Mental Health Services (CAMHS) has also risen

significantly [3] as awareness of mental health and help-seeking behaviors for childhood mental health conditions are increasing [4,5].

Fortunately, there are effective treatments for childhood mental health disorders [6]. However, in the United Kingdom, approximately 1 in 4 young people referred to mental health services were refused treatment in 2018 to 2019 [7], and 1 in 5 young people with a disorder reported a waiting time of over 6 months to receive specialist assistance [1]. Survey data have suggested that during this wait for CAMHS, two-thirds of parents report not being referred to or directed toward

(signposted to) appropriate forms of support [8]. Parents and young people are therefore turning to alternative sources of information and support, such as the internet [9,10]. In 2018, 89% of adults in Great Britain used the internet at least weekly [11], and user-driven online discussion fora (web-based discussion in which the content is solely created by the public using the site) for health-related concerns have become increasingly popular [12]. This investigation aims to understand the use of an existing popular user-driven web-based discussion forum (Mumsnet) by parents of children with mental health needs.

To date, no research has been conducted on the role of web-based fora for parents of children with mental health needs. Nonetheless, the purpose of user-driven web-based communities in relation to other health needs has been qualitatively examined by establishing emerging themes within the web-based narratives. Scharett and colleagues [13] qualitatively investigated the purpose of web-based peer support groups for caregivers of people with Alzheimer disease. This investigation suggested that the web-based group provides a platform for caregivers to discuss their confusion over symptoms of the disease and highlights the necessity for emotional support among caregivers. This analysis quantitatively explored the emergent themes and found that 59.6% (149/250) of posts contained emotional content in which the blog was used as an opportunity for emotional expression, for example, “She will sob and cry... which is heart-breaking to us...” Furthermore, 40.16% (98/244) of the responses on the blog provided informational support to caregivers, with 21.31% (52/244) of posts advising other caregivers to seek professional support. Web-based communities for caregivers of people with Alzheimer disease therefore not only provide a platform for information seeking but also create a space for emotional regulation.

Similar lessons can be learned from research regarding the use of web-based platforms for other health needs by young people and parents. Kirk and Milnes [14] examined 151 discussion threads on a cystic fibrosis charity website and discovered 5 emergent themes. These themes included managing treatments, managing emotions, managing relationships, managing identity, and managing support. The web-based community provided a liminal ground between the geographically distant users and their similar experiences, which was particularly important when considering young people with cystic fibrosis cannot make physical contact because of the risks of cross-infection [14]. Therefore, web-based platforms can benefit users by allowing those who may not be able to meet in person the opportunity to share experiences and advice with others.

Widemalm and Hjärthag [15] qualitatively investigated the use of web-based fora by children of parents with mental health needs. The investigation revealed 4 emergent themes. The first of these themes was caregiver burden in which the young people expressed the pressures they faced caring for their parents. The second theme was knowledge seeking within which users sought information from other users on the site. Third, support from the forum was a common theme in which users felt confident in discussing their issues in the virtual platform. This was apparent for stigmatizing illnesses that users did not feel comfortable discussing outside of a web-based capacity. In

addition, users appreciated the ability to discuss their issues anonymously and interact with people who were experiencing similar issues. Finally, frustration and powerlessness over health care were often expressed by young people. The web-based community, established to discuss mental health, provided users with the opportunity to seek social support in a safe environment and gather information about their parents' mental health needs.

The combination of a lack of access to services and the increasing popularity of web-based platforms leaves one questioning the future landscape of mental health support and information for parents of children with mental health needs. Could this popular and accessible method of web-based information and support be proliferated to help parents in need, especially those who desperately require support and information while on CAMHS waiting lists? As no research to date has been conducted on the role of web-based fora for parents of children with mental health needs, exploring the emergent themes within web-based fora for parents could aid our understanding of the reasons why parents of children with mental health needs use these sites. Furthermore, such research could provide evidence as to whether web-based platforms may be used as an adjunct and/or alternative to traditional services.

Aims and Objectives

In summary, there are high rates of mental health problems in young people in the United Kingdom and an increase in help-seeking behaviors for these disorders. Despite effective treatments for these disorders, there is not enough access to CAMHS. Parents are increasingly turning to web-based methods of communication and information seeking, and many studies have highlighted not only the benefits of posting but also the emergent themes within web-based narratives about health care. However, there is a lack of research investigating the reasons why parents of children with mental health needs are turning to web-based sources of information or support seeking. This study aimed to explore the role of an internet forum for parents of young people with mental health needs (Mumsnet). Mumsnet is the largest parenting forum in the United Kingdom [16], which is used by 14% of the UK population and has received over 3.9 billion views in the last 10 years [17]. The research used qualitative thematic analysis, which is not dictated by a hypothesis [18]. The specific objectives were as follows: (1) to explore the emergent themes within the narratives of posts on the web-based forum and (2) to extrapolate these themes to understand the purpose of the web-based forum for parents of children and young people with mental health needs.

Methods

Study Design and Data Analysis

The study used qualitative methods outlined in Braun and Clarke [19] to investigate the reasons why parents of children with mental health needs posted on Mumsnet. The analysis was based on the methodology of studies investigating Twitter, blogs, and web-based fora [20,21].

Mumsnet

This investigation analyzed posts on the Mumsnet discussion forum *Talk*. Mumsnet *Talk* offers an open platform for

discussions organized around over 200 established topics, known as threads, and receives over one million visits per month [22]. The Mumsnet *Talk* discussion forum can be viewed by any internet user, but only Mumsnet account holders can participate in the discussion. This study analyzed content posted under the *Talk* discussion page titled *Child Mental Health*. As of June 6, 2019, there were more than 900 active discussions under the *Child Mental Health* section.

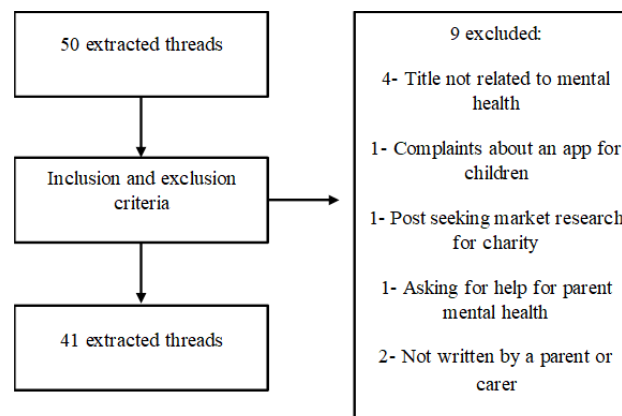
Ethics

The study received University College London (UCL) ethical approval (ref: 15209/001) and Research and Development approval from the UCL Joint Research and Development Office (19PP05). In line with the recommendations of the Association of Internet Researchers Ethics Working Committee [23], all data were extracted without the inclusion of usernames, and direct quotes were altered slightly (without changing meaning) to maintain the privacy of those posting on the forum during the initial data extraction stage of the analysis.

Data Collection

The most recent threads of the *Talk: Child Mental Health* heading were extracted to capture up-to-date narratives posted

Figure 1. Flow chart of eligible threads and reasons for exclusion.



Data Extraction

Parsehub was used to extract data from Mumsnet threads. Parsehub is a freely available web-based scraping tool designed to extract internet data. Any original posts or comments including information that could potentially identify the user, such as age, name, or location, were omitted manually by the researchers before the data were analyzed. Following this, the raw data were transferred into word documents for analysis.

Qualitative Analysis of Posts

All data were analyzed using the framework approach [19], a form of qualitative thematic analysis. All threads were read several times by the principal researcher. Key themes were then highlighted within the text, and notes were made within the margins of the raw data where applicable. The notes were used to create themes within the threads that, in line with qualitative research principles, were grounded in the data and established from users' own words [25]. These initial themes from all threads were reviewed to ensure that the themes were distinct and sensible, in line with recommendations from a study by

on the site. In line with qualitative research guidelines [24], data extraction was complete once the analysis reached data saturation, suggesting all possible themes within the chosen narratives were discovered. The initial data set consisted of 50 threads that contained over 750 posts. The threads dated from February 4, 2019, to June 6, 2019.

Inclusion and Exclusion Criteria

Only posts or comments within a thread in which the original post was directly related to child mental health were considered, and posts discussing child physical health or school attainment were excluded from the analysis. Posts had to be written by a person who identified as a parent or carer of a child with a mental health need, rather than professionals, as far as investigators could establish from reading the posts. The investigators excluded threads in which the original message was posted by agents other than parents or carers such as businesses seeking marketing research or professional mental health workers. Figure 1 shows a flowchart of eligible threads and reasons for exclusion.

Maguire and Delahunt [26]. Themes were then synthesized into a single document for subsequent analysis. The themes and subthemes were synthesized into a code framework. The framework was revisited and revised where necessary, and in line with the principles of qualitative research [27], a manageable index of 20 themes was created from the synthesized original codes. The framework was then applied to the original data [27]. This allowed the researcher to establish whether all themes within the framework were relevant. This enabled the consistency of the themes to be established, and any neglected codes were added. Links were identified within the themes that were then synthesized to establish 3 domains. Thematic charts highlighting examples of each domain and themes within the domains were created. The reliability of the codes was tested by another member of the research team (EM) using the formula described by Miles and Huberman [28]. The second researcher was required to apply the codes established from the final framework to a random selection of 8 threads (20% of the final data set). The threads were chosen using a random number generator, and the second researcher blind coded the threads into the categories they deemed appropriate.

There is debate within the field regarding the efficacy of interrater reliability in qualitative research [29]; thus, there is no established threshold within the literature determining an acceptable level of agreement between coders [30]. The researchers agreed that any interrater reliability percentage of 70% or above was acceptable for this methodology, based on the Cohen substantial 0.61 to 0.80 kappa statistic [31]. There was 70% agreement between coders for the nature of codes within the data set. The remainder were resolved by discussion with RS and SB.

Results

Themes Identified

Following the application of the inclusion and exclusion criteria, 9 threads were excluded, and 41 threads were deemed eligible

Table 1. The number of threads discussing each mental health need.

Mental health need	Number of threads
Anxiety	10
Multiple	6
Undiagnosed	6
Depression	5
Self-harm	3
Not stated	3
Autistic spectrum condition	2
Attention-deficit hyperactivity disorder	2
Intrusive thoughts	1
Transgender	1
Other	1
Obsessive compulsive disorder	1

Domain 1: Emotional Support

Content grouped within this domain demonstrated Mumsnet users expressing a need for support or offering support.

In Need of Support

Of 41 selected threads, 10 (24%) expressed a lack of or need for support:

I don't have any support with this. [Thread 5, page 3]

I have been looking for a support thread. [Thread 5, page 7]

Web-Based Community

Of 41 analyzed threads, 10 (24%) included elements of the web-based community on Mumsnet. This included expressions of camaraderie between users:

You are amongst friends here. [Thread 5, page 34]

This also included posts in which users updated and kept in touch with each other via the forum by asking questions:

for analysis. The flowchart of the eligible threads is displayed in [Figure 1](#). The characteristics of each included thread according to featured mental health needs are displayed in [Table 1](#).

A total of 28 themes were highlighted within the selected threads on Mumsnet *Talk*. These themes were organized into 3 domains: *emotional support*, *emotional expression*, and *advice and information*. The 28 themes are explored below, supported with extracts of Mumsnet *Talk* posts. [Multimedia Appendix 1](#) visually displays the themes and subthemes within the posts.

I was just wondering how you are getting on? [Thread 3, page 6]

Furthermore, posts within this category included instances comparing the use of the web-based community with discussing issues in person:

I'm not really talking to real people about this. [Thread 5, page 34]

Offering Emotional Support

The largest category within the emotional support domain was offering emotional support, which featured in 21 of the 41 posts (51%). Posts within this category included comments in which Mumsnet users offered emotional support to other users. This was evident in the form of empathy and sympathy:

So sorry you're feeling it too [Thread 5, page 4]

This was also evident as Mumsnet users discovered that they were not alone in their struggles:

You are not alone. [Thread 38, page 3]

Furthermore, emotional support was offered through well wishes and encouragement:

Know that things CAN get better. [Thread 28, page 2]

In addition, praise for the parents by other Mumsnet users provided emotional support:

Your son is fortunate to have you on side and it's great that you're seeking advice. [Thread 34, page 2]

Sounds Like Me or My Child

Of 41 threads, 13 (32%) featured emotional support when users highlighted the similarities between their own and another user's child. Parents shared comments that allowed Mumsnet users to normalize their experiences through learning that other mothers are experiencing similar issues:

He sounds very similar to my son. [Thread 1, page 13]

Domain 2: Emotional Expression

The second domain centered around parents using Mumsnet as a platform to express their emotions.

Desire to Write About Experiences

Of 41 threads, 5 (12%) featured expressions of a desire to write about experiences:

I'm just going to use this as a place to vent and write everything down. [Thread 10, page 4]

Struggling to Cope

The most frequent theme within the emotional expression domain was struggling to cope, which featured in 16 of the 41 threads (39%). Within this theme, Mumsnet users professed their difficulties in managing their child's mental health problems:

I'm struggling to help him. [Thread 36, page 1]

Guilt

This theme encompassed comments in which users blamed themselves for their children's issues or expressed feelings of guilt about their child's condition. This theme was apparent in 9 of the 41 selected threads (22%):

I do blame myself – have I broken her? [Thread 34, page 6]

Frustrated With the Situation

Parents often used the discussion thread as a platform to express their frustrations with the situation they were facing. This theme was apparent in 5 of the 41 threads (12%). This included posts discussing comparisons with physical health issues, expressing a desire for their child to be 'normal' and wishing for solutions to their children's complex problems:

Cannot face it anymore, can't face talking to him, just want him to be normal. [Thread 5, page 19]

Desperation

Of 41 threads, 7 (17%) featured users' expressions of desperation as their situation escalated or worsened:

I'm posting out of desperation. [Thread 36, page 1]

Parent Mental Health

Posts within this theme mentioned the users' own mental health issues. This theme was found in 7 out of 41 threads (17%):

I have been to the GP very recently because I was too stressed with it all. [Thread 5, page 5]

This theme also included posts in which users encouraged other users to seek help for their own mental health:

It's also important to look after your own mental health. [Thread 34, page 6]

Fear

The second most common theme within the emotional expression domain was fear and worry, which occurred in 13 of the 41 threads (32%):

I'm absolutely terrified for my son. [Thread 11, page 1]

Confusion

Mumsnet users also used the forum to discuss their confusion regarding certain issues. This theme was apparent in 5 of the 41 threads (12%):

What's OCD, what's ASD and what is typical teenageryness. It's impossible to untangle it all. [Thread 5, page 27]

Domain 3: Advice and Information

Mumsnet users often used the discussion forum to not only receive but also offer advice and information on certain problems.

Sharing and Offering Advice and Information

Personal Experiences

Complaints

Of 41 threads, 15 (36%) included complaints about services. These complaints were grouped into 3 broad categories.

Issues With Access

Mumsnet users used the site to complain about accessing mental health services:

My DS has been referred to CAMHS, but as we all know, it can be a long wait. [Thread 16, page 1]

It seems ridiculously hard [to find a specialist]. [Thread 4, page 1]

Issues With Help Received

Mumsnet users also complained about the help they had received from mental health services:

The clinician was so disorganised, patronising and incompetent, he ended up making our son's problems worse. [Thread 20, page 3]

Issues With the System Generally

Mumsnet users also complained more generally about the mental health system:

The underfunding has caused a huge mess of the service and this is where the anger should be directed.
[Thread 20, page 10]

Praise

The forum was also used as an opportunity to praise services. This theme occurred in 7 of the 41 threads (17%):

All professionals/practitioners are supportive, nice people. [Thread 5, page 41]

In My Experience as a Child

Mumsnet users would often share stories from their own childhoods to allow other users to understand their children's situations. This theme was found in 9 of the 41 threads (22%):

I suffered from horrible nausea and anxiety at the same age as your child. [Thread 28, page 4]

In My Experience With My Child

Of the 41 threads, 14 (34%) featured instances of users offering advice to others by sharing what worked with their own child who was experiencing similar problems:

It helped us all to take the Psychiatrist's advice to speak about the OCD as something other than our son and not lump them together. [Thread 5, page 49]

Advice

Suggesting Resources and Techniques

The most frequently found theme within the advice and information domain was suggesting resources and techniques, which occurred in 21 of the 41 selected threads (51%). This theme incorporates instances in which parents suggested techniques, resources, or general advice on how to help their children, outside of help from professional services:

Look at gentle parenting sites to help him. [Thread 11, page 3]

Often, parents would signpost other parents to appropriate resources:

Hi there are some useful resources here [shares website]. [Thread 29, page 1]

Suggesting Services

The second most common theme within the advice sharing domain was suggesting services, which occurred in 18 of the 41 threads (44%):

Ask your gp for a referral to your local camhs service.
[Thread 40, page 1]

Sharing Advice on How the System Works

Of 41 threads, 11 (27%) featured instances of users providing practical advice to other Mumsnet users on how to get appropriate support within various mental health services:

This is what I've found helps: Read up before your meetings (e.g. nice guidelines) and don't fill gaps with more words. [Thread 5, page 53]

Sharing Information and Knowledge

As well as offering advice, users often share knowledge about childhood or certain disorders to enable other users to better understand their situation. This theme was found in 15 of the 41 threads (37%):

The NHS suggest that all children be given a vitamin d supplement. [Thread 22, page 5]

Sharing Opinion on Case

Of 41 threads, 11 (27%) included occasions in which Mumsnet users shared their opinion on the original post. This theme incorporates instances in which users endeavor to aid the primary poster in establishing a diagnosis or reasons for the behavior in the presented case:

Do you think there's any chance she could be on the autistic spectrum? [Thread 15, page 3]

Asking for Advice and Information

Advice Seeking

The most common help-seeking theme was seeking advice, which occurred in 19 of the 41 threads (46%). This was achieved by asking direct questions or asking for advice from other Mumsnet users:

Anybody got any thoughts on how I help and support him?[Thread 30, page 1]

Do Not Know What to Do

Of 41 threads, 13 (32%) included instances of Mumsnet being used as a platform for users to express that they did not know what to do:

I don't know how to help him. [Thread 31, page 1]

Looking for Services and Resources

Of 41 threads, 9 (22%) depicted parents asking for specific services and resources:

Can anyone suggest how to find a consultant who specialises in ADHD in children and who will see patients privately. [Thread 4, page 1]

Looking for Extra Services, Resources, or Techniques

Of 41 threads, 6 (15%) contained instances of parents asking for extra services or resources while waiting to receive specialist help:

We are waiting for CAMHS appointment now as life for our family has gotten so intense because of this. In the mean-time I am looking for a parenting course.
[Thread 15, page 11]

This theme also incorporated instances in which users had completed certain interventions with a service and were looking for extra support:

He's recently just finished a course of therapy for his anxiety in CAMHS, so we're not too sure who to turn to. [Thread 3, page 1]

Looking for Similar Experiences

Of 41 threads, 9 (22%) showed Mumsnet users expressing a desire to hear stories from other parents who were experiencing similar situations:

Any thoughts on what I should do from those who might have been through this? [Thread 5, page 56]

Should I Be Worried?

Of 41 analyzed threads, 3 (7%) displayed how Mumsnet was used as a platform for parents to seek reassurance or guidance from other users by asking whether they should be concerned about their child's behaviors:

Should I be worried about her? [Thread 12, page 1]

Questions About Services or Resources

As well as providing a platform to seek resources, the Mumsnet discussion forum also allowed users to ask questions about specific services or resources. This theme occurred in 7 of the 41 (17%) selected threads:

Has anyone's child been offered CBT (or DBT) through CAMHS/NHS? If so what was it for? How did they get it? [Thread 41, page 1]

Discussion

Principal Findings

This qualitative investigation aimed to explore the role of a web-based forum for parents of young people with mental health needs (Mumsnet). To our knowledge, this is the first investigation of web-based fora by parents of children with mental health needs. The main domains derived from the narratives were *emotional support*, *emotional expression*, and *advice and information*. Overall, the results suggest that parents of children with mental health needs predominantly use Mumsnet to offer and consequently receive emotional support and to suggest general advice, techniques, and resources that could be applied outside of help from professional services. This suggests a potential role in supporting parents who may not be able to access traditional CAMHS services, those on waiting lists for services, and/or those already accessing services.

The most common form of assistance featured on Mumsnet was offering and receiving emotional support, which featured in 21 of the 41 threads (51%). This is consistent with the research by Widemalm and Hjärthag [15], which examined the use of online fora for young people caring for parents with serious mental health needs. Widemalm and Hjärthag [15] suggested that social isolation caused by caring for someone with a mental health disorder is eased by discussing the situation on web-based platforms. Furthermore, in survey research relating to the use of a web-based mental health site by young people experiencing their own mental health issues, it has been suggested that befriending others with similar realities assures people they are not alone [32]. This research has extended the literature on the formation of social support on web-based fora by young people by highlighting the utility of web-based platforms for facilitating

the exchange of social support for parents of children with mental health needs.

Of 41 threads, 10 (24%) embodied the nature of a web-based community, including instances of updating other users and expressing statements of camaraderie. This extends previous research on Mumsnet, highlighting the community nature of the forum through a questionnaire survey and discourse analysis of discussions related to belonging on the site [22]. Mumsnet can be used as a platform for the development of social support, which may be difficult to ascertain in real life because of the burdens associated with caring for a child with mental health needs [33] and a lack of support from professional services. Therefore, as findings have suggested that parents of children with mental health needs seek social support, services should endeavor to signpost parents toward local support groups before, during, and after interventions. Alternatively, it is possible that parents could be signposted to these discussion fora as they have been suggested to provide valuable support.

Although this research has suggested that social support can be meaningfully sought and received on web-based platforms, one must be cautious as, in line with previous research [13], a key theme within the narratives was information sharing and receiving. Discussions on Mumsnet provide parents with general advice and information that could either supplement information provided by professional services or help while families are waiting to receive input from those services. One must be mindful of the quality of information posted on web-based platforms, particularly the extent to which this is evidence based. This research question is being examined in a separate investigation on the same dataset.

Parents expressed concerns regarding not only their inability to help their children but also their confusion over where to look for help. As a lack of knowledge regarding child mental health conditions is a significant barrier to seeking professional help [34], Mumsnet may act as a platform to enable parents to gain advice and information to disseminate barriers to seeking professional help. This suggests that services could create informational resources that are catered to the needs of users of internet support groups to be shared on the sites to increase mental health literacy and confidence in help seeking.

Many posts included discussions about services. A proportion included parents asking direct questions about specific resources and services (7/41, 17%), some included information on how to access specialist care (11/41, 27%), some included providing service recommendations (18/41, 44%), and others asked for service recommendations (9/41, 22%). This suggests that Mumsnet serves as a means to gather information about services, rather than being a replacement for CAMHS and other services. This finding supplements previous research, suggesting parents want information about how CAMHS works before their first appointment [35]. Posts were more likely to request and offer information and advice regarding resources and techniques outside of professional services (21/41, 51%) than recommending services (18/41, 44%). This is contrary to previous research investigating diabetes fora suggesting the most common form of advice offered on web-based platforms is signposting to professional services [36].

Of 41 threads, 15 (36%) in the discussion forum contained a complaint about mental health services, compared with 17% containing praise. This contradicts a previous cross-sectional study examining parent and child satisfaction with CAMHS using a questionnaire [37], suggesting that more than three-quarters of parents and adolescents were either mostly or very satisfied with their experiences with CAMHS. However, McNicholas et al [37] sent the 8-item Client Satisfaction Questionnaire to open cases only and therefore did not include the views of those who had left the service due to dissatisfaction, those who were on waiting lists, or those not able to access services, something which this study was able to consider. A total of 63 complaints were found within the threads that were grouped into 3 broad categories: issues with access, issues with help received, and issues with the system generally. Most complaints within the threads were too general to make any inferences about specific difficulties with existing services, for example, “mental health services are a shambles” (Thread 19). Nevertheless, it must be noted that services were also praised within the threads, for example, “I can vouch for the fact that every member of CAMHS staff I have dealt with has been lovely, professional, helpful” (Thread 20). Future research should endeavor to explore the potential motivators for using web-based fora to criticize as opposed to praise services.

Parents offered personal experiences from looking after their child in 14 of the 41 threads (34%) and offered personal experiences from their own childhoods in 9 of the 41 threads (22%). This supports the suggestion that personal expertise shared on web-based platforms is expressed through stories from people who have experienced certain situations that are more accessible to others [38]. Offering support and sharing experiences, advice, and recommendations were major themes within the narratives on Mumsnet. This supports research by Anderson and colleagues [20], suggesting that altruism is apparent in web-based caregiver communities.

Of 41 threads, 7 (17%) included examples of parents using Mumsnet when their child’s condition had escalated, which adds a new domain to previous research suggesting people seek web-based support at a critical period in their experiences of mental health issues [39]. It may also be apparent that parents seek web-based help during a critical period in their own ability to cope with their child’s needs. Another 7 of the 41 threads (17%) in this study mentioned the mental health problems faced by parents. This extends previous research, which suggested that children of parents with mental health needs discuss their own mental health needs on web-based platforms [15,40]. This analysis displayed instances not only of parents expressing their own mental health struggles but also instances of other users encouraging Mumsnet users to seek help for their own well-being. This suggests that Mumsnet could act as an additional platform that parents can access during a critical time in their experiences. As a web-based source, Mumsnet is constantly accessible, and support within the site is not restricted to opening hours.

On sites such as Facebook, users are conscious of revealing concerns around stigmatizing illnesses because of the identifiable nature of the site [41,42]. In contrast, Mumsnet *Talk: Child Mental Health* featured thousands of posts regarding

potentially stigmatizing concerns. Previous research suggests that parents fear judgment from health care professionals [43], and this was supported within this research through statements such as, “I’m worried that the doctor will laugh at me” (Thread 38) and “I don’t want to go to the GP if it’s basically my fault” (Thread 39). Anonymity on web-based platforms encourages self-disclosures [44]. Mumsnet may therefore provide an anonymous space that could act as an alternative to face-to-face services within which parents of children with mental health needs can comfortably express their concerns.

Limitations

This study is not without its flaws. There is a lack of demographic data available about Mumsnet users because of both the anonymized nature of the site and ethical restrictions that required any identifiable information such as age or occupation to be removed. Thus, inferences cannot be made about whether sample characteristics may have influenced the results. Nonetheless, Mumsnet census data report that the majority of its users are middle-class, university-educated women, and 74% of users have a household income of over the national average [45]. Therefore, suggestions from this research may not be generalizable to the wider population. In addition, as the extracted data could not include the pseudonyms used by parents, it is not possible to know whether all instances of some themes were posted by separate users, as opposed to one, vocal Mumsnet user. Finally, this research cannot be generalized to create inferences about the needs of all parents of children with mental health needs. The results may be specific not only to those with internet access but also those who already actively use Mumsnet in the United Kingdom. It should also be acknowledged that the use of web-based data restricts researchers’ ability to influence conversations, which, although providing an insight into the spontaneous interactions between parents, does not allow the researchers the ability to inquire about comments and extrapolate certain themes.

Directions for Future Research

As discussed, interventions and resources could be created to cater to the needs of the members of Mumsnet, given the site’s vast popularity and influence among British mothers [22]. Furthermore, parents of children with mental health needs could be signposted toward the site to receive support in the interim period between seeking and accessing help. This research lays the foundations for future research to consider the mechanisms involved in peer-to-peer connections and the benefits of these in supporting parents and promoting appropriate mental health advice. However, caution has been urged regarding the formation of strong web-based relationships as a dependency for these relationships can exacerbate social withdrawal [46,47]. In addition, as Mumsnet support is not supplemented by professional support, one must consider the consequences of a serious event happening within a supportive group that Mumsnet users are not equipped to deal with, for example, the suicide of a young person discussed in the group. Further research into the disadvantages of such support fora is warranted. For this reason, Mumsnet cannot be a substitute for professional help, and yet thousands of mothers are using the site to receive information and support. Further research should investigate

the motivation underlying the use of web-based communities and discussion fora and how they can complement existing professional services.

Conclusions

In conclusion, the study suggests that parents of children with mental health needs use Mumsnet discussions to offer and consequently receive emotional support and to suggest general

advice, techniques, and resources that could be applied outside of help from professional services. In this study, the need for information and advice was particularly apparent for parents who had yet to begin their journey with CAMHS. Overall, this suggests an important role of web-based support for parents looking after young people with mental health needs that warrants further exploration.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Domains, themes and subthemes.

[PDF File (Adobe PDF File), 412 KB - [mental_v7i9e18271_app1.pdf](#)]

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Abbreviations

CAMHS: Child and Adolescent Mental Health Services

NIHR: National Institute for Health Research

UCL: University College London

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Original Paper

Virtual Reality Meditation Among Youth Experiencing Homelessness: Pilot Randomized Controlled Trial of Feasibility

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Abstract

Background: Homelessness among youth is devastating, with high rates of substance use disorders and mental health comorbidity. Mindfulness-based interventions that include meditation and mindfulness skills training reduce stress and symptoms of anxiety or depression. However, engaging high-risk youth in interventions is challenging. Virtual reality is a more flexible platform for delivering meditation and may be appealing to youth.

Objective: The study objectives were to evaluate the feasibility of delivering virtual reality meditation and of collecting outcome measures, including anxiety and physiologic stress.

Methods: A sample of 30 youth experiencing homelessness was enrolled in the study. Youth were randomized to receive 10 minutes of one of three interventions: (1) virtual reality meditation, (2) audio meditation (through a web-based platform), or (3) virtual reality imagery of historical pictures and text. Subjects who consented to the study attended two research visits. The first visit collected survey measures of demographics, mental health, and substance use, and oriented subjects to the intervention platforms. The second visit (1-3 days later) delivered the intervention and collected pre and post outcome measures of anxiety and physiologic stress (salivary cortisol). Changes in anxiety and cortisol at the second visit were compared across groups using a linear regression model in which the primary analysis compared virtual reality meditation to audio meditation and secondary analyses compared virtual reality meditation to virtual reality imagery.

Results: Anxiety scores decreased in all groups, with a larger reduction among the virtual reality meditation group (difference=10.8) compared to the web-based meditation or virtual reality images groups (difference=5.8 and 5.0, respectively). After controlling for baseline values, there were no significant group differences in changes in anxiety scores or cortisol levels. In comparing virtual reality meditation and audio meditation, the effect size for anxiety was moderate (Cohen $d=0.58$) while the effect size for cortisol was small (Cohen $d=0.08$).

Conclusions: Preliminary results suggest that virtual reality meditation has a moderate benefit for anxiety but not physiologic stress. Future research is needed to confirm these results in a larger sample and to investigate whether the effects are sustained or increase with repeated use of virtual reality mediation. Virtual reality meditation appears feasible to deliver among homeless youth and merits further study.

Trial Registration: ClinicalTrials.gov NCT04004520; <https://clinicaltrials.gov/ct2/show/NCT04004520>

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KEYWORDS

virtual reality; meditation; homelessness; stress

Introduction

Youth homelessness is common in the United States, with an estimated 3.5 million young adults experiencing homelessness in a given year [1]. Youth who experience homelessness have a high prevalence of mental health conditions [2]. Many homeless youth have experienced physical or sexual abuse prior to or after becoming homeless [3,4] and are at high risk for suicide [4-8]. The toxic effects of the everyday stress of homelessness are devastating. Reducing anxiety among homeless youth could have numerous health benefits given that anxiety and mood disorders are the leading causes of disability worldwide [9,10].

A growing body of evidence supports the benefits of meditation for reducing stress and improving mental and physical health, both immediately following meditation practice and over longer periods of follow up [11,12]. Mindfulness-based interventions (MBI) were developed to help individuals manage stress or illnesses, and are typically delivered in a group format that integrates meditation with mindfulness skills training [13,14]. Randomized controlled trials of MBI have demonstrated positive effects on reducing depression and anxiety symptoms [15,16]. Virtual reality (VR) meditation has recently become more widely available through commercialized apps that can be downloaded to smartphones or VR headsets and can provide users with an immersive guided meditation experience. The addition of VR meditation to MBI in adults with generalized anxiety disorder had higher retention than those who received MBI only [17]. VR meditation could promote greater engagement with MBI or other therapies, giving patients an opportunity to practice mindfulness skills in a setting removed from everyday distractions. However, we are unaware of any prior studies that have tested the feasibility of VR meditation for youth experiencing homelessness.

We assessed the feasibility of delivering one session of VR meditation and collecting momentary stress-related outcomes, including self-reported anxiety and physiologic measures of stress (salivary cortisol), among homeless youth. We focused the present study on momentary outcomes to assess the immediate changes following exposure to VR meditation, consistent with the design of other prior studies of meditation [12]. A convenience sample of 30 youth was recruited from a homeless youth drop-in center and enrolled in this randomized study of two meditation conditions (VR meditation and audio meditation as the meditation control) and VR-guided images as an attention control. The objectives of the study were to describe feasibility and changes in self-reported anxiety and salivary cortisol before and after intervention sessions along with interest in future use of VR by homeless youth. Assessing the feasibility of research procedures in marginalized populations, particularly among homeless youth, is critical given the potential for their greater mistrust and reluctance to accept interventions [18]. Our analysis compared pre and post differences in outcomes for the VR meditation group to the audio meditation group, and a secondary analysis was performed to compare the VR meditation group to the VR imagery group. We also describe qualitative findings regarding the experience

of the youth with using the VR headset among those who received VR meditation or VR imagery.

Methods

Study Sample

A convenience sample of youth was recruited from a homeless youth drop-in center in a midwestern city in the United States. The drop-in center provides youth with access to food, laundry, and shower facilities, and recreational activities such as television, checking out books, and playing board games or video games. Drop-in center staff provide case management and link youth to community resources, including two full-time therapists who provide crisis counseling. Youth who attended the drop-in center were approached by research staff. Youth were eligible if they were between the ages of 18 and 24 years and met the current federal McKinney-Vento Act definition of homelessness in which they lacked a fixed, regular, and adequate nighttime residence [19]. Youth who were eligible and interested in the study consented to participate. The Institutional Review Board at The Ohio State University approved the study.

Data Collection Procedures

Data collection occurred over 2 visits. At visit 1, subjects completed the baseline survey and were randomized. Participants who were randomized to one of the VR interventions were also provided a demonstration of the VR platform. Visit 2 occurred 1-3 days later and included the collection of a brief survey and 4 saliva samples before and after the intervention. The first saliva sample was collected immediately after the preintervention survey, sample 2 was collected 5 minutes later, sample 3 was collected immediately after the intervention, and sample 4 was collected 15 minutes later. Participants were compensated in person at the end of each data collection visit with cash in the amount of US \$10 for visit 1 and US \$40 for visit 2. As with all study measures, participants were free to decline any measure (including saliva collection).

Intervention Conditions

Participants were randomly assigned at the first visit to one of three possible intervention groups: (1) VR meditation, (2) audio meditation as the meditation control, or (3) VR imagery as the attentional control [20]. The research study provided participants with one-time access to the Oculus Go headset in a private setting during the research appointment. For VR meditation, participants completed a guided meditation exercise with their choice of natural scenery ("Guided Meditation VR") on the Oculus Go headset [21]. Guided Meditation VR was selected because it is a widely used platform, readily available for download, and has high-quality design features grounded in the core principles of meditation shown to improve outcomes related to stress [15,22]. Guided Meditation VR provides an immersive experience of guided meditation in which users complete an exercise in mindfulness meditation in natural scenes (eg, beach, mountains, forest) with a 360-degree field of view that allows participants to feel present in the scene as they complete the exercise. The audio meditation was accessed through a website and participants used headphones to listen to 10 minutes of a

guided mindfulness meditation exercise [23]. The audio meditation was similar to the VR meditation with a focus on increasing relaxation and calmness through guided awareness of breath, body scans, and a nonjudgmental attitude toward distractions. However, the exact phrasing and voice instructions on meditation varied between the audio and VR meditations. Participants assigned to VR imagery used the Oculus Go headset to view historic images and text (Looking Glass VR) [20].

Instructions for how to navigate the platforms were given at the first visit. At the second visit, participants completed their randomly assigned intervention. There was some variation in the number of minutes that each intervention condition lasted. The meditation conditions lasted a set number of minutes, both approximately 10 minutes, whereas the VR imagery condition was self-directed. However, the timing given to access all modules was selected a priori so that all subjects had the same amount of time to complete or explore the modules (10-15 minutes).

Measures

Feasibility Measures

Several additional measures were assessed to evaluate aspects of VR feasibility in the population and were collected from those who participated in either of the VR conditions (VR meditation or VR imagery) at the second visit, but not audio meditation. First, the feasibility of VR use was assessed by return participation rates and with open-ended questions assessing previous experience with VR, whether youth would be interested in using VR in the future, and how individuals felt their stress level changed following VR use (see [Multimedia Appendix 1](#)). In addition, three scaled items that are frequently used in VR research [24] were adopted to measure the sense of VR “presence” or “immersion” during use, including (1) sense of “being there,” (2) how close to reality the VR experience was felt to be, and (3) whether VR felt more like images that they saw or an experience they had. These items are scored on a scale from 1 to 7, with higher scores indicating a more immersive experience. These items were included to evaluate whether there were differences in the two VR groups in terms of how “real” the experience was for participants, aside from the differences in content.

Self-Reported Anxiety

Anxiety was assessed pre and post intervention at visit 2 with the 6-item short form of the State-Trait Anxiety Inventory-6 (STAI-6) [25], a validated and widely used instrument to measure momentary anxiety [25,26]. Each item on the STAI-6 asks subjects to rate how they feel (eg, “calm,” “relaxed,” “worried”) in that moment on a 4-point Likert scale ranging from “not at all” to “very much.” Following scoring instructions, positive feelings were reverse-scored, all items were summed, and the total was multiplied by 20 and divided by 6 to obtain the total score. The STAI-6 score ranges from 20 to 80 with higher scores indicating higher levels of anxiety.

Physiologic Stress

Physiologic stress was measured using salivary cortisol collected pre and post intervention at visit 2 via unstimulated passive

saliva drool and stored at -20°C . Assays were conducted using Salimetrics Cortisol Enzyme Immunoassay Kits. The interassay coefficient of variation was 2.9% and the intraassay coefficient of variation was 8.9%. Similar to the STAI-6, salivary cortisol captures momentary stress given the physiologic response of cortisol to stress exposures and was used as a biomarker comparison to self-reported anxiety.

Baseline Measures

At visit 1, baseline measures were collected, including demographic characteristics (age, sex, and race), and self-reported lifetime diagnoses of mental health and substance use disorders, including depressive disorder, anxiety disorder, attention deficit and hyperactivity disorder, posttraumatic stress disorder, bipolar disorder, schizophrenia, personality disorder, alcohol use disorder, or drug use disorder. In addition, participants were asked to self-report any previous month use of alcohol, marijuana, illicit drugs, or tobacco (including cigarettes or vaping).

Analysis

Descriptive statistics were used to describe self-reported demographic and clinical characteristics across groups, as well as average pre and post intervention values for anxiety and cortisol measures (log-transformed due to the skewed distribution). Feasibility of VR use was assessed based on summaries of participation rates and how positively youth reported the VR experience to be (both qualitative and scaled presence measures). Cohen d was calculated to estimate the effect size on anxiety and cortisol outcomes for VR meditation relative to other groups. Linear regression analyses were used to evaluate significant differences between intervention groups in pre and post intervention changes in anxiety scores, and separately for log-transformed salivary cortisol levels (comparing sample 2 vs 3, and sample 2 vs 4). Analyses compared differences in pre and post changes for the VR meditation group relative to the audio meditation group, and the VR meditation group relative to the VR imagery group. Because of varying preintervention anxiety scores and cortisol levels across groups, linear regression analyses included the preintervention value (anxiety score or cortisol level) as a covariate. Significant differences between groups were evaluated at $P < .05$ and all analyses were performed in SAS version 9.4.

Results

Among the 35 youth who were screened for eligibility, 30 consented to participate and were randomized to study conditions ([Multimedia Appendix 2](#) and [Table 1](#)). Over the two study visits, only 1 participant, who was assigned to the VR meditation group, was lost to follow up and did not return for study visit 2. Among the youth who completed either VR condition ($n=18$), only 1 participant who had a seizure disorder chose not to participate in their assigned condition (VR meditation) owing to concerns that VR could trigger a seizure.

In open-ended questions, almost half of the youth had used VR in the past ($n=8$) and all reported interest in future use. The reported sense of “presence” was high in both groups, with a mean VR presence score of 5.3 (SD 2.2) for “how close it felt

to reality,” 6.4 (SD 1.5) for whether the virtual environment felt more like “images that you have seen or a place that you have visited,” and 6.8 (SD 0.5) for “being there.” All youth in the VR meditation group reported that their stress had “dropped”

or that they felt “calm.” However, only 2 participants in the VR images group reported feeling “relaxed” or “calm,” whereas most participants reported a positive experience such as being “entertained.”

Table 1. Sample characteristics for all participants and by intervention type.

Characteristics	Total sample (N=29)	VR ^a meditation (n=8)	Audio meditation (n=11)	VR imagery (n=10)	P value ^b
Age (years), mean	21.6	21.9	21.7	21.2	.71
Male, n (%)	15 (52)	5 (63)	6 (55)	3 (30)	.72
Race, n (%)					.68
White	6 (21)	2 (25)	3 (27)	1 (10)	
Black	16 (55)	3 (38)	6 (55)	7 (70)	
Mixed	7 (24)	3 (38)	2 (18)	2 (20)	
Mental health diagnosis^c, n (%)					
Any mental health disorder	22 (76)	6 (75)	7 (64)	9 (90)	.48
Depressive disorder	17 (59)	6 (75)	6 (55)	5 (50)	.64
Anxiety disorder	15 (52)	4 (50)	5 (46)	6 (60)	.89
ADHD ^d	15 (52)	5 (63)	5 (46)	5 (50)	.81
Posttraumatic stress disorder	13 (45)	4 (50)	4 (36)	5 (50)	.80
Bipolar disorder	15 (52)	5 (63)	5 (46)	5 (50)	.81
Schizophrenia	3 (10)	1 (13)	2 (18)	0 (0)	.47
Personality disorder	6 (21)	2 (25)	2 (18)	2 (20)	>.99
Substance use disorder diagnosis^e, n (%)					
Illicit drug use disorder	4 (14)	1 (13)	2 (18)	1 (10)	>.99
Alcohol use disorder	3 (10)	0 (0)	3 (27)	0 (0)	.09
Any past-month alcohol use	14 (48)	6 (75)	5 (46)	3 (30)	.19
Any past-month marijuana use	17 (59)	6 (75)	7 (64)	4 (40)	.36
Any past-month illicit drug use (not including marijuana)	3 (10)	0 (0)	2 (18)	1 (10)	.76
Any past-month tobacco use	25 (86)	7 (88)	9 (82)	9 (90)	>.99

^aVR: virtual reality.

^bP values for assessing group differences: small sample sizes limited the power to detect differences; one-way analysis of variance was conducted for age×randomization and the Fisher exact test was performed for all other comparisons by randomization.

^cMental health diagnoses are self-reported lifetime diagnosis of a mental health condition.

^dADHD: attention deficit/hyperactivity disorder.

^eSubstance use disorder diagnoses are lifetime; substance use frequency is based on a past-month timeframe.

Among the youth who completed their assigned intervention (n=29; VR or non-VR), mean anxiety scores declined in all groups, with the greatest difference observed in the VR meditation group (Table 2). However, the pre and postintervention difference in log-transformed salivary cortisol

values had little variation across groups. The effect sizes for the log-transformed cortisol difference for the VR meditation group relative to the audio meditation group were small with Cohen *d* of 0.08 (sample 2 vs 3) and 0.43 (sample 2 vs 4).

Table 2. Mean (SD) scores for anxiety and log-transformed cortisol levels pre and post intervention by intervention group.

Variable	VR ^a meditation (n=8)	Audio meditation (n=11)	VR imagery (n=10)
Anxiety score pretest ^b	43.8 (14.9)	38.8 (17.5)	29.7 (8.4)
Anxiety score posttest ^c	32.9 (9.8)	33.0 (12.7)	24.7 (5.9)
Anxiety score difference	10.8 (8.3)	5.8 (8.9)	5.0 (8.8)
Log cortisol sample 1 pretest ^d	-1.52 (0.56)	-1.31 (0.56)	-1.40 (0.46)
Log cortisol sample 2 pretest ^d	-1.35 (0.64)	-1.15 (0.61)	-1.43 (0.50)
Log cortisol sample 3 posttest ^e	-1.48 (0.86)	-1.25 (0.59)	-1.31 (0.50)
Log cortisol sample 4 posttest ^e	-1.36 (0.82)	-1.36 (0.72)	-1.47 (0.34)
Log cortisol sample 2 vs 3 difference score	0.127 (0.36)	0.095 (0.42)	-0.121 (0.36)
Log cortisol sample 2 vs 4 difference	0.004 (0.39)	0.205 (0.54)	0.045 (0.41)

^aVR: virtual reality.

^bCollected before the intervention.

^cCollected after the intervention at visit 2.

^dSalivary samples collected before the intervention at visit 2.

^eSalivary samples collected after the intervention at visit 2.

Based on linear regression analyses, there were no significant differences between the VR meditation group and other groups in pre and post differences for any anxiety or cortisol outcomes (Table 3). Relative to other groups, the VR meditation had a modest effect size relative to audio meditation and VR imagery

on anxiety scores, but comparisons between groups in salivary cortisol depending on the timing of the saliva sample were less consistent (Table 4). Audio meditation relative to VR imagery had a very small effect size for anxiety and a modest effect size for salivary cortisol.

Table 3. Linear regression analyses examining anxiety and log-transformed salivary cortisol differences pre and post intervention.

Comparison	Model 1 ^a			Model 2 ^b			Model 3 ^b		
	β	SE	<i>P</i> value ^c	β	SE	<i>P</i> value	β	SE	<i>P</i> value
VR ^d meditation (n=8) vs audio meditation (n=11, reference group)	3.13	2.82	.28	.04	0.19	.84	-.19	0.23	.43
VR meditation (n=8) vs VR imagery (n=10, reference group)	-1.80	3.34	.59	.04	0.04	.30	-.06	0.07	.38

^aModel 1: difference in pre and post State-Trait Anxiety Inventory-6 anxiety scores reflect measures collected before vs after the interventions at visit 2, controlling for preintervention anxiety levels.

^bModels 2/3: difference in pre and post log cortisol values reflect measures collected before (sample 2) vs after (sample 3/sample 4) the interventions at visit 2, controlling for preintervention logged cortisol levels from sample 2.

^c*P* values are based on the Wald test, comparing VR meditation to the referent group (audio meditation or VR imagery).

^dVR: virtual reality.

Table 4. Effect sizes (Cohen *d*) in comparisons between intervention groups.

Comparison	Anxiety pretest vs posttest	Log cortisol sample 2 vs sample 3	Log cortisol sample 2 vs sample 4
VR ^a meditation vs audio meditation	0.58	0.08	0.43
VR meditation vs VR imagery	0.68	0.69	0.10
Audio meditation vs VR imagery	0.09	0.54	0.33

^aVR: virtual reality.

Discussion

Among youth experiencing homelessness, we evaluated two different meditation platforms (VR meditation and audio meditation) and a VR platform with imagery. Overall, the

interventions appeared to be feasible to deliver, and the youth rated their experiences positively. Importantly, the study had a high degree of retention in a high-risk and difficult-to-engage population, with all but one youth completing their assigned VR condition and all youth completing comparison group

interventions. We observed a moderate positive effect on anxiety for VR meditation relative to audio meditation; although the difference in anxiety changes was not significant in our small sample, the results suggest that a moderate effect size may be possible in a larger trial. These results thus demonstrate the potential of using VR meditation in a study of the homeless youth population. In addition to the potential benefits for reduced anxiety, the youth also reported interest in using VR in the future. Collection of physiologic measures of stress also appeared feasible, with all youth providing samples to assess salivary cortisol. Together, these results suggest that the VR meditation and comparison interventions are feasible to complete and the measures to capture momentary changes in stress-related outcomes are also feasible to collect in a high-risk population.

Although self-reported anxiety decreased in all groups, salivary cortisol levels did not decline, and there were no statistically significant differences in anxiety or cortisol levels between the VR meditation group and the referent audio meditation and VR imagery groups. The small sample of youth limited our ability to detect significant differences, and it is possible that youth may need longer, repeated sessions or mindfulness skills training [27] for a significant beneficial change to be observed. In

addition, the demographic characteristics of the intervention groups were not balanced by sex and race/ethnicity.

Nevertheless, the present study is the first to demonstrate the feasibility of recruiting youth experiencing homelessness to participate in a study evaluating different VR platforms and modes of meditation (VR vs audio). The study had a high retention rate, and the youth were enthusiastic about using VR platforms in the future if made available to them. However, there was one participant who declined participation in VR meditation due to a self-reported medical condition that precluded their participation (epilepsy), and studies that use this technology in the future may need to consider excluding participants with this or other conditions that limit VR participation. Although the high retention rate could reflect the increased monetary incentive amount at visit 2 compared to visit 1, this is a strategy often used to reduce attrition in difficult-to-engage populations of homeless youth [28,29]. Moreover, the increased incentive amount was used to compensate for the greater burden of data collection and was the same for all groups. There was a trend toward a greater reduction in anxiety among the VR meditation group relative to the audio group. These results suggest that further study is warranted in a larger sample and over a longer follow-up period.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Open-ended questions about virtual reality (VR) experience.

[[DOCX File, 13 KB - mental_v7i9e18244_app1.docx](#)]

Multimedia Appendix 2

Consolidated Standards of Reporting Trials (CONSORT) flow diagram of the study.

[[PDF File \(Adobe PDF File\), 97 KB - mental_v7i9e18244_app2.pdf](#)]

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Abbreviations

MBI: mindfulness-based intervention

STAI-6: State-Trait Anxiety Inventory-6

VR: virtual reality

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Viewpoint

Pediatric Telebehavioral Health: A Transformational Shift in Care Delivery in the Era of COVID-19

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Abstract

The use of telebehavioral health has been expanding in the past decade to improve access to psychiatric care and address critical shortages in the psychiatric workforce. The coronavirus (COVID-19) pandemic forced a sudden shift from traditional in-person visits to alternative modalities. There are key factors associated with successful transitional and large-scale implementation of telehealth with existing resources. We describe the experience of a large health care system using telehealth technology, and we identify strategies and discuss considerations for long-term sustainability after the pandemic.

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KEYWORDS

telepsychiatry; telebehavioral health; child and adolescent psychiatry; COVID-19

Introduction

As of May 5, 2020, there were approximately 1,012,000 confirmed cases and more than 60,000 deaths in the United States associated with the coronavirus disease (COVID-19) pandemic [1]. COVID-19 profoundly changed behavioral health care delivery. In a period of only weeks, most states issued social distancing guidelines and stay-at-home orders to reduce the spread of the disease. The practice of in-person psychiatric and therapy visits was effectively halted, raising concerns that treatment would be unavailable or clinically compromised. Given the crisis of youth suicide rates, which increased by 69% from 2008 to 2018, and given that hospitalization for all pediatric mental health conditions has increased by nearly 50% during the past decade, the public health implications of lack of care or inadequate treatment could be substantial [2,3]. In this clinical perspective, we discuss how the COVID-19 crisis has exposed opportunities to improve access and care via

telehealth technology for youth living with behavioral health conditions. We describe our hospital system's experience of rapid transition to telebehavioral health services to reduce interruptions in behavioral health care. Finally, we offer suggestions to ensure that telebehavioral health continues to be a priority after the COVID-19 pandemic has passed.

How a Pandemic Revealed the Value of Telebehavioral Health

An accumulating body of evidence indicates that telebehavioral health is an effective service delivery model for children and adolescents. There are well-established data on the feasibility and acceptability of delivering telebehavioral health services across a variety of clinical settings, and the evidence base for the reliability and clinical outcomes of these services is evolving [4]. Although telebehavioral health is acknowledged as an important tool to reach the broadest population of youth and

families, its adoption is not widespread. Barriers to adoption include significant variability in regulations among individual states and regulatory boards; prohibitive federal regulations such as the Ryan Haight act, which restrict prescribing; and lack of reimbursement for certain clinical services (eg, group therapy), provider-to-provider consultation models, and prevention activities; poor distribution of broadband connectivity and availability, which creates a digital divide between urban, rural, and underserved communities; and social determinants, including poverty, literacy, and socioeconomic disadvantage, which affect affordability of telebehavioral health for the vulnerable population that needs but cannot access these services.

As health care organizations, we must be cognizant of the inherent uncertainties in the health care environment, such as sudden regulatory and payor policy changes, shortages of drugs/vaccines due to market disruption, and evolving trends of technology adoption, to be prepared for such contingencies. However, the urgency created by this pandemic forced us to rapidly transition to telehealth to maintain continuity of care while reducing risk of contagion to both our patients and our workforce. The process of technology evaluation, budget allocation, implementation planning, and operational infrastructure generally lasts several months or years. Our experience demonstrated that the introduction of an effective telehealth program can be greatly accelerated using existing resources. There are a few key factors in the success of this rapid transition:

- Relatively inexpensive, cloud-based video technology solutions are available that do not require additional infrastructure, hardware, or separate end user devices.
- The pediatric population of “digital natives” is highly immersed in digital technology and adept at integrating interactive audioconferencing and videoconferencing tools for socializing with peers, accessing education, and using social media [5]. Using similar modalities to access their health care providers can be a natural extension of the social interaction of younger patients and can even enhance their sense of control and psychological safety.
- On the provider end, significant adjustments are needed to ensure the telebehavioral health experience is natural and authentic while still enabling the collection of sufficient information for clinical decision making. While it is optimal to provide appropriate training to enhance the “websites

manner” of our providers, telehealth can be considered as a new venue and a new modality for delivering care, therefore obviating the need for extensive clinical retooling [6].

- Telehealth has the potential to address access issues arising due to geographic distance and critical shortages of pediatric behavioral health specialists [7]. However, simply offering these services is not sufficient; we need to consider social determinants such as barriers to internet connectivity, trust or perception issues based on prior interactions with social services, language barriers, and system capacity to offer virtual interpreter services. These issues should be identified and addressed during implementation of telehealth services to provide equitable access.

What We Have Learned To Date From Our Experience

As one of the largest pediatric behavioral health departments offering a full continuum of services and serving a large geographic area of the state and parts of neighboring states, it was crucial that we be decisive and nimble in transitioning to telebehavioral health in the context of COVID-19. Our department did have some prior telebehavioral health experience; however, it was limited to approximately 300 annual visits and restricted to medication management services. Within the short span of 3 weeks after completion of implementation, we conducted over 12,500 televisits across a range of services, including psychiatry, psychology, therapy, and autism services. These televisits represent approximately 70% of usual outpatient visits; they included approximately 9500 video visits and 3500 phone and other technology visits, with a trend towards increasing video visits over time. To avoid exposure risk, we decided to transition all ambulatory care from in-person to telehealth. We prioritized children with acute and ongoing needs for continued services and new assessments during this time, while stable cases were initially deferred. For instance, psychiatry services provided medication refills and scheduled later appointments. Outpatient therapy services were initiated for the more acute patients on the waiting list and sustained for established patients. Diagnostic, psychological, and developmental assessment services were initiated for children with greater acuity or risk. Decisions regarding patient priority were based on clinician judgement and family input about the patient’s acuity and comfort with the decision.

Table 1. The telebehavioral health transition during the first 4 weeks of implementation.

Week	Unique providers ^a , n	Total telebehavioral health visits, n	Telephone visits, n (%)	Video visits, n (%)
March 22, 2020	314	1735	389 (22.4)	1346 (77.6)
March 29, 2020	407	3102	1180 (38.0)	1922 (62.0)
April 5, 2020	456	3608	981 (27.2)	2627 (72.8)
April 12, 2020	478	4052	828 (20.4)	3224 (79.6)

^aUnique providers include psychiatrists, psychologists, and masters-level clinicians across the service line.

We adopted a version of the Zoom video platform (Zoom Video Communications) that was compliant with the Health Insurance Portability and Accountability Act (HIPAA) and integrated it

into our electronic health record system. All providers were encouraged to use this secure internal solution rather than other, less secure options that were temporarily allowed by the

Department of Health and Human Services during the pandemic [8]. Furthermore, we used a coordinated communication strategy to disseminate internally developed training materials and policy updates and provided ongoing live technical support from a virtual command center staffed by internal telehealth content experts within the department.

As expected, caregiver and provider experiences varied depending on previous experience with technology, clinical complexity, and the degree to which clinical interventions needed to be adapted for telebehavioral health encounters. Difficulty reliably connecting to the technology, largely due to rapid implementation, sometimes necessitated the use of alternative modes such as telephone calls to provide service successfully. We also explored multiple technology solutions as backups to the current preferred technology. Due to the minimal planning time, all clinical and operations leaders dedicated resources and applied continuous process improvement based on daily reports. The closure of schools added another layer of challenges for school-based prevention and therapy services requiring coordination with school personnel. While we were able to create workflows to accommodate team-based evaluations, certain components, such as psychological testing, physical exams, or reliable vital signs, could not be accommodated. We also noted a preference for telephone instead of video visits in a subset of families with lower socioeconomic status and in families with significant financial concerns and additional stressors related to COVID-19. Engaging families with few basic resources to effectively participate in care remains challenging. However, the rapid full-scale transition served as a venue to provide behavioral health services on a similar scale without major interruptions in the continuity of clinical care. We recognize the need for careful evaluation of the impact and outcomes of telebehavioral health using the measures outlined by the American Telemedicine Association [9].

Challenges and Opportunities

The current experience provides significant insights into the feasibility of rapidly scaling and using telebehavioral health services to address the long-standing challenge of access to care and effective use of a scarce specialty workforce. Further innovation is required to operationalize all elements of service

delivery that traditionally necessitate in-person interactions to develop a patient-centered hybrid model of in-person and telebehavioral health visits. Conducting a telebehavioral health visit has implications across all stages of clinical operation, ranging from checking in, the consent process, and payment of services to follow-up and remote management of emergencies; all of this necessitates a paradigm shift in which telebehavioral health is regarded as a distinct venue for providing care. In that context, it is also clear that in addition to content expertise, distinct competencies are required for TBH leaders and champions to effectively coordinate transdisciplinary care. The feasibility of ambulatory care experiences must be translated into a variety of activities, such as acute crisis services, group therapy, expanded psychological assessments, and parent-mediated treatments for children with autism.

Furthermore, evolving technologies such as mobile health (apps), artificial intelligence, and immersive virtual reality, which are all currently being developed in isolation, could become an extension of telebehavioral health in conceptualizing “virtual health” as the next step to promote this innovation.

Conclusions

The COVID-19 pandemic has revealed the inherent value of pediatric telebehavioral health to reach a broad population of young people and families and to meet the clinical needs of people who cannot access in-person behavioral health care due to geography, stigma, or social determinants. Our most recent projections indicate that we will perform over 50,000 telebehavioral health visits within a 6-week period, indicating acceptance of this modality on a large scale. Further analysis of differential adoption as well as the barriers and factors related to social determinants of health is underway. This successful rapid implementation and acceptance on a large scale indicates that telebehavioral health is finding a permanent place as a feasible and efficient way to provide care and partially address the critical shortage of behavioral health care workers. We urge policy makers, health care administrators, clinicians, and other key stakeholders to consider the long-term benefits of investment in this important tool not only as a solution during times of crisis but as a routine component of health care service delivery.

Conflicts of Interest

JAB is a member of the Scientific Advisory Board of Clarigent Health. The other authors have no conflicts of interest to declare.

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Abbreviations

COVID-19: coronavirus disease

HIPAA: Health Insurance Portability and Accountability Act

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Corrigenda and Addenda

Correction: Effectiveness of an 8-Week Web-Based Mindfulness Virtual Community Intervention for University Students on Symptoms of Stress, Anxiety, and Depression: Randomized Controlled Trial

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In “Effectiveness of an 8-Week Web-Based Mindfulness Virtual Community Intervention for University Students on Symptoms of Stress, Anxiety, and Depression: Randomized Controlled Trial” (*JMIR Ment Health* 2020;7(7):e18595) the authors noted two errors.

Member names of the group author “MVC Team” were not added to the PubMed listing of this article at the time of publishing. All member names have now been added as collaborators on the PubMed listing, as follows:

Sahir Abbas, Yvonne Bohr, Manuela Ferrari, Wai Lun Alan Fung, Louise Hartley, Amin Mawani, Kwame McKenzie, Jan E Odai.

As well, MVC Team was incorrectly noted as having contributed equally. This note has been removed from MVC Team. Only Christo El Morr, Paul Ritvo, and Farah Ahmad contributed equally.

The correction will appear in the online version of the paper on the JMIR Publications website on September 30, 2020, 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

Prevalence of Perceived Stress, Anxiety, Depression, and Obsessive-Compulsive Symptoms in Health Care Workers and Other Workers in Alberta During the COVID-19 Pandemic: Cross-Sectional Survey

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Abstract

Background: During pandemics, effective containment and mitigation measures may also negatively influence psychological stability. As knowledge about COVID-19 rapidly evolves, global implementation of containment and mitigation measures has varied greatly, with impacts to mental wellness. Assessing the impact of COVID-19 on the mental health needs of health care workers and other workers may help mitigate mental health impacts and secure sustained delivery of health care and other essential goods and services.

Objective: This study assessed the self-reported prevalence of stress, anxiety, depression, and obsessive-compulsive symptoms in health care workers and other workers seeking support through Text4Hope, an evidence-based SMS text messaging service supporting the mental health of residents of Alberta, Canada, during the COVID-19 pandemic.

Methods: An online cross-sectional survey gathered demographic (age, gender, ethnicity, education, relationship, housing and employment status, employment type, and isolation status) and clinical characteristics using validated tools (self-reported stress, anxiety, depression, and contamination/hand hygiene obsessive-compulsive symptoms). Descriptive statistics and chi-square analysis were used to compare the clinical characteristics of health care workers and other workers. Post hoc analysis was conducted on variables with >3 response categories using adjusted residuals. Logistic regression determined associations between worker type and likelihood of self-reported symptoms of moderate or high stress, generalized anxiety disorder, and major depressive disorder, while controlling for other variables.

Results: Overall, 8267 surveys were submitted by 44,992 Text4Hope subscribers (19.39%). Of these, 5990 respondents were employed (72.5%), 958 (11.6%) were unemployed, 454 (5.5%) were students, 559 (6.8%) were retired, 234 (2.8%) selected “other,” and 72 (0.9%) did not indicate their employment status. Most employed survey respondents were female (n=4621, 86.2%). In the general sample, the 6-week prevalence rates for moderate or high stress, anxiety, and depression symptoms were 85.6%, 47.0%, and 44.0%, respectively. Self-reported symptoms of moderate or high stress, anxiety, and depression were all statistically significantly higher in other workers than in health care workers ($P<.001$). Other workers reported higher obsessive-compulsive symptoms (worry about contamination and compulsive handwashing behavior) after the onset of the pandemic ($P<.001$), while health care worker symptoms were statistically significantly higher before and during the COVID-19

pandemic ($P < .001$). This finding should be interpreted with caution, as it is unclear the extent to which the adaptive behavior of health care workers or the other workers might be misclassified by validated tools during a pandemic.

Conclusions: Assessing symptoms of prevalent stress, anxiety, depression, and obsessive-compulsive behavior in health care workers and other workers may enhance our understanding of COVID-19 mental health needs. Research is needed to understand more fully the relationship between worker type, outbreak phase, and mental health changes over time, as well as the utility of validated tools in health care workers and other workers during pandemics. Our findings underscore the importance of anticipating and mitigating the mental health effects of pandemics using integrated implementation strategies. Finally, we demonstrate the ease of safely and rapidly assessing mental health needs using an SMS text messaging platform during a pandemic.

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KEYWORDS

health care worker; COVID-19; pandemic; mental health; depression; anxiety; stress; obsessive compulsive

Introduction

Significant public health efforts have been implemented to contain the spread of SARS-CoV-2 [1] and mitigate its far-reaching impacts [2], including the negative psychological effects of the COVID-19 pandemic. After its first recognition in December 2019, COVID-19 spread rapidly, leading to it being declared a Public Health Emergency of International Concern, and later, a global pandemic, by the World Health Organization (WHO) [3]. Confirmed COVID-19 cases reached 1 million on April 1, 2020, doubling again only 9 days later [4]. Despite widespread efforts to “flatten the curve,” predictions on the ultimate resolution of the pandemic remain elusive due to variance in geographic disease burden, physical distancing requirements, and outbreak phase, among other factors [5], both within and beyond Canadian borders.

As knowledge of the COVID-19 pandemic increases and multilevel emergency response plans are activated [3], the implementation of containment and mitigation measures to stop the spread of COVID-19 continues to vary greatly by outbreak phase and between jurisdictions [5]. Unfortunately, pandemic containment and mitigation measures [6-8], while effective in limiting COVID-19 disease transmission, also likely contribute to negative psychological sequelae of affected individuals. The dynamic and rapidly changing circumstances related to the pandemic are creating uncertainty, stress, and anxiety, among other known adverse psychosocial correlates of the pandemic [9-14].

The negative impact of COVID-19 on global mental health is clear and increasing [9,13-26]. From a societal perspective, the emergent mental health burdens in health care workers [11-13,16,18,24-31] and other workers is of significant concern to the sustainment of health care services, as well as the maintenance of critical goods, services, and supply chains in other economic sectors.

While there is a dearth of research comparing health care workers' mental health symptoms to that of other workers, especially during outbreaks, emerging research into health care worker mental health during the COVID-19 pandemic has documented high rates of depression [11,18,24,27-29], anxiety [11-13,18,24,26-29], stress [27-29], and other mental health conditions, including fear, insomnia [24], grief [25],

posttraumatic stress disorder somatization [25], obsessive-compulsive symptoms [11,13,28], and vicarious traumatization [20]. Similar effects for health care workers were found in reviews and studies assessing the effects of past outbreaks [32-41].

Multiple studies of mental health symptoms in the general public during the current pandemic and past outbreaks also show evidence of depression [9,11,14,15,23,24,33,34,37,42,43], anxiety [11,15,23,24,33,42-44], stress [15,23,43], and other mental health conditions [15], including posttraumatic stress disorder [37,42,44-46], distress [14,33,37], fear [33,44,46], guilt, anger, and vicarious traumatization [20], conditions that can exacerbate panic or hysteria reactions [47]. Despite similar trends in both health care workers and the general population, the extent to which the mental health symptoms of health care workers and other workers differ is unclear. Notably, similar effects are also reported by individuals after exposure to other natural disasters and negative social conflict events including emergencies, terrorist attacks, earthquakes, and other calamities [9,10,17,32-37,42,48,49].

Negative effects on mental well-being also occur more frequently in those with pre-existing mental health concerns [23,26,39,41], which has important implications during the COVID-19 pandemic [47,50]. In Canada, approximately 75.0% of those who accessed health services for a mental illness sought help for mood and anxiety problems. In Alberta in particular, a relatively high proportion of Albertans are known to experience mood and anxiety disorders (eg, 12.9% for females and 6.4% for males) [51].

Studies that describe, assess, and compare the mental health symptoms of health care workers and other workers during the COVID-19 pandemic can offer service planners, policy makers, and leaders important insights about how best to mitigate mental health risks and preserve worker health and well-being. Ultimately, such research can help protect the sustained delivery of health care services, goods, and services in other key economic sectors, as well as maintain supply chains.

Unfortunately, adequate resources to limit negative psychological effects are almost invariably lacking during pandemics and other crises [18,39,40,52,53], evidenced by the mental health and well-being lessons emerging early in the COVID-19 pandemic. Attention to mental health and well-being

is commonly superseded by urgent physical and public health needs during an emergency (ie, immediately caring for people with the disease, as well as monitoring, testing, and preventing further disease burden). However, systematic integration of mental health and well-being supports into the overall pandemic response may effectively mitigate and/or prevent health care and other worker, patient, and public harms, avoid burnout, and further help preserve the long-term stability and effectiveness of health care systems [31,45,50,54,55]. Although mental health harms are often noted or alluded to in pandemic guidance, there is a real need and opportunity to define practical measures guiding health care professionals in the psychological care of patients with COVID-19 and go beyond mere calls to action [50,56]. The sustainable delivery of goods and services in health care and other sectors is contingent on worker health and well-being. It is essential to understand if and how worker mental health varies during pandemics so that adequate supports are put in place.

Given the known risks associated with declining mental health correlates from past emergency situations and emerging COVID-19 studies, it is critical to understand the needs of health care workers and other essential workers and offer them appropriate, digital, and timely access to mental health supports. Within this context, we launched Text4Hope, a cognitive-behavioral therapy (CBT)-based SMS text messaging service that delivers once-daily supportive messages to support individuals' mental health during the COVID-19 pandemic. The program offers support-seeking subscribers help identifying and modifying pandemic-related negative thoughts, feelings, and behaviors through texted advice and encouragement regarding the development of coping and resiliency skills [57]. The program was modeled after the Text4Mood program, a pre-existing, effective, evidence-based, and low-cost SMS text messaging intervention, developed as a therapeutic adjunct to support and optimize the mental health and treatment outcomes of people with mental health and addictions concerns residing in Alberta, Canada [58-62].

This study is an effort to better understand the mental health symptoms of health care workers and other workers during the COVID-19 pandemic, and to contribute evidence for mental health service planning. The specific aim of the study was to explore self-reported perceived stress, anxiety, depression, and obsessive-compulsive symptoms in health care workers and other workers who sought mental health support by subscribing to Text4Hope during the early phase of the COVID-19 pandemic.

Methods

A cross-sectional survey was used to explore the self-reported prevalence of perceived stress, anxiety, depression, and obsessive-compulsive symptoms in health care workers and other workers who subscribed to Text4Hope.

Recruitment

Text4Hope was offered to Alberta residents in the early stages of the COVID-19 pandemic through government and provincial health care delivery service news releases, email notifications,

and website [57] postings related to COVID-19. Albertans seeking mental health support were invited to join the 3-month program by texting "COVID19HOPE" to a short code number. Subscription triggered a welcome text message containing a 5-10 minute online survey link requesting demographic characteristics (gender, age, ethnicity, education, relationship status, employment, type of employment [health care or other], housing status, and isolation status) and clinical characteristics (self-reported perceived symptoms of stress, anxiety, depression, and contamination- and cleanliness-associated obsessive-compulsive behaviors).

Clinical characteristics were assessed using validated screening scales for self-reported symptoms, including the Perceived Stress Scale (PSS; PSS score ≥ 14 indicates moderate or high stress) [63], the Generalized Anxiety Disorder 7-item (GAD-7) Scale (GAD-7 score ≥ 10 indicates likely generalized anxiety disorder [GAD]) [64], the Patient Health Questionnaire-9 (PHQ-9; a score ≥ 10 indicates likely major depressive disorder [MDD]) [65], and two items on the Brief Obsessive-Compulsive Scale (BOCS; pertaining to worry about dirt, germs, and viruses and handwashing behavior) [66]. Validated scales were chosen to better understand support seekers' self-reported symptoms, potential symptom severity, and to screen for symptomatology. These scales were not intended as diagnostic tools.

Participant consent was indicated via submission of subscribers' survey responses. The continuation of participation in the Text4Hope program was not dependent on the completion of the survey by participants; this was clearly stated to subscribers in the SMS text messaging program information provided at subscription. Ethical approval for the research was obtained through the University of Alberta Health Research Ethics Board (Pro00086163).

Based on a provincial population estimate of approximately 4.3 million people, the necessary sample size to generate prevalence estimates was 4157, assuming a 99% confidence level and 2% error. Previous research employing similar methodology in Alberta generated a 20% response rate [61]. Therefore, we planned to extract and analyze data after obtaining a minimum recruited sample of 20,785 Text4Hope subscribers.

Analysis

Data analysis was undertaken using SPSS Statistics for Windows (Version 26; IBM Corp) [67]. Demographic characteristics of employed respondents were summarized by absolute numbers and percentages, by employment category (health care workers and other workers). Chi-square analysis with two-tailed significance ($P < .05$) was performed to assess the statistical differences between health care workers and other workers by their clinical characteristics. Variables with more than three responses in the chi-square test were subjected to post hoc analysis using adjusted residuals, with z scores and P values reported.

To assess the impact of "worker type" on self-reported symptoms of moderate or high stress, likely GAD, and likely MDD while controlling for demographic characteristics and isolation status, we entered all demographic predictors along with "worker type" into a logistic regression model. Correlation

analysis was performed before the logistic regression analysis to rule out very strong correlations among predictor variables. Odds ratios from the binary logistic regression analysis were examined to determine the association between “worker type” and the likelihood of respondents self-reporting symptoms of moderate or high stress, likely GAD, and likely MDD, controlling for the other variables in the model. There were no imputations for missing data and the results presented reflect completed responses from the survey.

Results

Overview

During the first 6 weeks after launching the program (March 23 to May 4, 2020), a total of 44,992 subscribers joined Text4Hope; this data was extracted for analysis and is presented here. Of the 44,992 subscribers, 8267 responded to the online survey invitation, yielding a 19.4% response rate. Overall, 5990 (72.5%) respondents reported current employment, 958 (11.6%) reported current unemployment, 454 (5.5%) were students, 559 (6.8%) were retired, and 72 (0.9%) did not indicate their employment status. Of those who indicated they were employed, 1414 (23.6%) indicated health care industry employment and 3951 (66.0%) indicated employment in other industries. The

remaining 625 (10.4%) of employed respondents did not indicate an industry affiliation.

The 6-week prevalence rates in the sample (n=8267) for moderate or high stress, likely GAD, and likely MDD were 85.6%, 47.0%, and 44.0%, respectively. Descriptive demographic characteristics of survey respondents, by worker type, are displayed in [Table 1](#). There was no imputation for missing data and the data analyzed and displayed were from the data set remaining after cases with missing data were excluded.

Of employed support-seeking respondents, over 90.0% were aged ≥ 26 years (n=4939). Of this group, more than half were aged ≥ 41 years (n=2888) ([Table 1](#)). Most respondent workers identified as female (n=4621, 86.2%), were Caucasian (n=4441, 83.1%), were married, cohabiting, or partnered (n=3974, 74.2%), reported completion of postsecondary education (n=4814, 89.9%), and owned their own home (n=3836, 72.2%). There were statistically significant differences between health care workers and other workers on all demographic variables and isolation status. Health care workers had higher proportions of self-reported postsecondary education and home ownership, and higher rates of married, cohabiting, or partnered relationship status than other workers.

Table 1. Demographic characteristics of employed survey respondents.

Demographics and characteristics	Health care workers (N=1414)	Other workers (N=3951)	P value	Chi-square test result	Degrees of freedom	Total, n (%)
Sex			<.001	53.10	2	N/A ^a
Male	105 (7.4)	588 (14.9)	N/A	N/A	N/A	693 (12.9)
Female	1298 (91.1)	3323 (84.2)	N/A	N/A	N/A	4621 (86.2)
Gender diverse	9 (0.6)	37 (0.9)	N/A	N/A	N/A	46 (0.9)
Age (years)			.003	13.80	3	N/A
≤25	60 (3.4)	272 (7.0)	N/A	N/A	N/A	332 (6.3)
26-40	540 (38.8)	1511 (38.9)	N/A	N/A	N/A	2051 (38.9)
41-60	714 (51.4)	1915 (45.3)	N/A	N/A	N/A	2629 (49.9)
>60	76 (5.5)	183 (4.7)	N/A	N/A	N/A	259 (4.9)
Ethnicity			.01	11.05	3	N/A
Caucasian	1175 (83.3)	3266 (83.2)	N/A	N/A	N/A	4441 (83.1)
Indigenous	37 (2.6)	140 (3.6)	N/A	N/A	N/A	177 (3.3)
Asian	94 (6.7)	188 (4.8)	N/A	N/A	N/A	282 (5.3)
Other	107 (7.4)	333 (8.5)	N/A	N/A	N/A	438 (8.2)
Education			<.001	90.71	3	N/A
Less than high school diploma	6 (0.4)	81 (2.1)	N/A	N/A	N/A	87 (1.6)
High school diploma	38 (2.7)	382 (9.7)	N/A	N/A	N/A	240 (7.8)
Postsecondary	1358 (96.3)	3456 (87.6)	N/A	N/A	N/A	4814 (89.9)
Other education	8 (0.6)	28 (0.7)	N/A	N/A	N/A	36 (0.7)
Relationship status			<.001	21.73	4	N/A
Married, cohabiting, or partnered	1098 (77.2)	2876 (72.9)	N/A	N/A	N/A	3974 (74.2)
Separated or divorced	116 (8.2)	296 (7.5)	N/A	N/A	N/A	412 (7.7)
Widowed	9 (0.6)	29 (0.7)	N/A	N/A	N/A	38 (0.7)
Single	183 (13.0)	715 (18.1)	N/A	N/A	N/A	898 (16.8)
Other	7 (0.5)	30 (0.8)	N/A	N/A	N/A	37 (0.7)
Housing status			<.001	28.74	3	N/A
Own home	1083 (77.2)	2752 (70.4)	N/A	N/A	N/A	3836 (72.2)
Living with family	51 (3.6)	242 (6.2)	N/A	N/A	N/A	294 (5.5)
Renting	259 (18.4)	892 (22.8)	N/A	N/A	N/A	1115 (21.7)
Other	10 (0.7)	21 (0.5)	N/A	N/A	N/A	31 (0.6)
Self-isolated or self-quarantined	303 (21.7)	681 (17.5)	<.001	12.20	1	984 (18.6)

^aN/A: not applicable.

Univariate Analysis

In [Table 2](#), we assessed the association between worker type and perceived stress, likely GAD, and likely MDD. [Table 2](#)

suggests that other workers reported higher moderate or high stress, higher likely GAD, and higher likely MDD compared to health care workers, with small effect sizes for each condition.

Table 2. Chi-square test of association between worker type, perceived stress, likely generalized anxiety disorder, and likely major depressive disorder.

Psychological symptom	Health care worker, n (%)	Other worker, n (%)	P value	Effect size (ϕ)
Perceived stress (moderate or high stress ^a)	1079 (81.7)	3149 (85.6)	<.001	0.05
Likely generalized anxiety disorder ^b	461 (38.1)	1600 (47.7)	<.001	0.09
Likely major depressive disorder ^c	401 (32.1)	1490 (43.6)	<.001	0.10

^aModerate or high stress was defined as a Perceived Stress Scale score ≥ 14 .

^bLikely generalized anxiety disorder was defined as a Generalized Anxiety Disorder Scale score ≥ 10 .

^cLikely major depressive disorder was defined as a Patient Health Questionnaire score ≥ 10 .

Logistic Regression

To assess the impact of “worker type” on moderate or high stress, likely GAD, and likely MDD while controlling for demographic characteristics and isolation status, we entered all seven characteristics in Table 1 and “worker type” into a logistic regression model.

For moderate or high stress, the full model containing all eight predictors was significant (X^2 [df=20, N=4874]=235.25, $P<.001$), suggesting the model was able to distinguish between respondents who reported moderate or high stress and those who did not. The model explained between 4.7% (Cox and Snell R^2) and 8.2% (Nagelkerke R^2) of the variance and correctly classified 84.7% of all cases. Controlling for all demographic characteristics and isolation status, health care worker type made a unique statistical contribution (Wald=8.44, $P<.01$) to the likelihood that a respondent presented with moderate or high stress. Other workers were 1.3 times more likely to report moderate or high stress during the COVID-19 pandemic compared to health care workers when all demographic variables and isolation status were controlled for (OR 1.30, 95% CI 1.10-1.55).

For likely GAD, the full model containing all eight predictor variables was significant (X^2 [df=20, N=4454]=364.75, $P<.001$), meaning the model was able to distinguish between respondents who had likely GAD and those who likely did not have GAD. The model explained between 7.9% (Cox and Snell R^2) and 10.5% (Nagelkerke R^2) of the variance and correctly classified 62.5% of all cases. Controlling for all demographic characteristics and isolation status, health care worker type made a unique statistical contribution (Wald=21.62, $P<.001$) to the likelihood of respondents meeting the cutoff threshold for likely GAD. Other workers were 1.4 times more likely to meet the cutoff threshold for likely GAD during the COVID-19 pandemic compared to health care workers when all demographic variables and isolation status were controlled for (OR 1.40, 95% CI 1.22-1.62).

For likely MDD, the full model containing all eight predictors was significant (X^2 [df=20, N=4 535]=341.33, $P<.001$), implying

the model was able to distinguish between respondents who had likely MDD and those who likely did not have MDD. The model explained between 7.3% (Cox and Snell R^2) and 9.8% (Nagelkerke R^2) of the variance and correctly classified 63.9% of all cases. Controlling for all demographic characteristics and isolation status, health care worker type made a unique statistical contribution (Wald=27.79, $P<.001$) to the likelihood that respondents presented with likely MDD. Other workers were 1.5 times more likely to meet the cutoff threshold for likely MDD during the COVID-19 pandemic compared to health care workers when all demographic variables and isolation status were controlled for (OR 1.47, 95% CI 1.30-1.71).

As shown in Table 3, there were statistically significant associations between worker type and the tendency to worry about dirt, germs, and viruses and the tendency to wash hands repeatedly or in a special way due to fears of contamination. Post hoc analysis using adjusted residuals demonstrated that health care workers were significantly less likely to worry about dirt, germs, and viruses since the start of the COVID-19 pandemic compared to other workers (53.9% versus 62.5%, respectively; $z=5.3$, $P<.001$). Conversely, the proportion of health care workers who were worried about dirt, germs, and viruses before the COVID-19 pandemic was significantly higher than other workers (28.2% versus 22.1%, respectively; $z=4.3$, $P<.001$). Though the proportion of health care workers reporting compulsive hand washing due to fears of contamination after the COVID-19 pandemic began was lower than the proportion of other workers reporting the same (46.1% versus 57.6%, respectively; $z=7.0$, $P<.001$), a significantly higher proportion of health care workers engaged in compulsive hand washing before the pandemic due to fears of contamination (35.3% versus 29.3%, respectively; $z=3.9$, $P<.001$). In sum, the self-reported prevalence of obsessive-compulsive symptoms (ie, pre-existing worry and compulsive handwashing behavior) was higher in health care workers than in other workers, while the self-reported prevalence of worry about hand contamination and compulsive hand washing after the COVID-19 pandemic began was higher in other workers compared to health care workers.

Table 3. Chi-square test of association between worker type and manifestation of obsessive-compulsive symptoms.

Clinical variable	Health care workers, n (%)	Other workers, n (%)	P value	Effect size (ϕ)
Worried about dirt, germs, and viruses			<.001	0.08
Only since the COVID-19 pandemic	663 (53.9)	2137 (62.5)	N/A ^a	N/A
Before and during the COVID-19 pandemic	347 (28.2)	756 (22.1)	N/A	N/A
Never	220 (17.9)	525 (15.4)	N/A	N/A
Wash hands repeatedly or in a special way due to fears of contamination with dirt, germs, and viruses			<.001	0.11
Only since the COVID-19 pandemic	566 (46.1)	1969 (57.6)	N/A	N/A
Before and during the COVID-19 pandemic	433 (35.3)	1002 (29.3)	N/A	N/A
Never	229 (18.6)	447 (13.1)	N/A	N/A

^aN/A: not applicable.

Discussion

Overview

This is the first large-sample, cross-sectional Canadian study to examine the self-reported prevalence of stress, anxiety, depression, and obsessive-compulsive symptoms by worker type during the COVID-19 pandemic. We used an online survey to gather self-reported symptoms of stress, anxiety, depression, and obsessive-compulsive behaviors in support-seeking individuals subscribing to the Text4Hope daily SMS text messaging support program. Text4Hope sent once-daily supportive text messages to provide Alberta residents with advice and encouragement to develop coping skills and optimize resiliency during the COVID-19 pandemic.

Principal Results

Our study sample comprised support-seeking individuals who subscribed to Text4Hope and had self-reported elevated symptomatology. The proportion of employed respondent subscribers ($n=3721$, 72.2%) was comparable to the 2017 Alberta employment rate (66.7%), the full-time employment rate for females (73.3%), and the proportion of female Albertans employed in the health care/social assistance sector, particularly in the ≥ 45 years age cohort (79.5%) [68]. Respondent demographics were comparable to only some Alberta resident worker characteristics (ethnicity, housing status) and Alberta health care worker characteristics (age, ethnicity, gender, education, and housing status) [69,70].

Health care worker demographic characteristics were comparable to surveyed health care worker characteristics in other international jurisdictions during the COVID-19 pandemic [11,12,18,24].

We found that the overall self-reported 6-week prevalence of moderate or high stress, likely GAD, and likely MDD symptoms were higher than baseline [51] during the early COVID-19 outbreak phase and were statistically significantly higher in other workers than in health care workers.

The prevalence of pre-COVID-19 worry and compulsive handwashing behavior was higher in health care workers than in other workers, while worry and compulsive handwashing

behavior after the COVID-19 pandemic began was significantly higher in other workers than in health care workers.

Limitations

Our study has several important limitations. The prevalence of self-reported stress, anxiety, depression, and obsessive-compulsive symptoms was assessed in health care workers and other workers who voluntarily sought support by subscribing to Text4Hope. Despite demographic similarities, voluntary subscribers seeking support may differ significantly from the nonsubscribing employed or general employed population of Alberta, thereby influencing self-reported symptom prevalence rates. In addition, an overall elevated symptomatology, while higher than that of the general population, would be expected given that survey respondents were a sample of mental health support-seeking subscribers. Not all respondents answered every survey question, resulting in missing data for multiple variables and reduced sample sizes, thereby potentially reducing the generalizability of the findings.

Given both the dearth of comparative evidence on mental health burden in workers and the limitations of our study design, we were unable to explore subtle dynamics related to subtypes of health care workers and other workers (eg, frontline versus nonfrontline, high-risk occupations in the “other” category). Similarly, we were unable to further refine our understanding of other pandemic dynamics that likely occurred during the study period, such as fluctuating employment status, disease exposure risk, and worker access to and use of personal protective equipment. This study is limited by its inability to address these factors, which nonetheless ought to be considered in comparisons with other, related literature.

There are several limitations related to the use of screening tools. Logistics, sample size, cost, resources, and time factors precluded the use of diagnostic interviews; our use of screening scales estimated self-reported symptom burden and was not intended to yield mental health diagnoses. However, a screening tool is appropriate in the context of capturing data quickly at a general population level and was thus the tool indicated for use in the current study.

In addition, it should be noted that it is unclear the extent to which the BOCS screening tool is valid for, and can differentiate the range of adaptive-to-obsessive-compulsive behaviors during

a pandemic. For example, consistent and repeated handwashing has been emphasized as an important means of avoiding COVID-19 transmission.

Finally, we assessed self-reported symptoms during an early pandemic phase. It is possible that the timing of these measurements (and/or other contextual features that we did not study) were maligned with studies measuring the same outcomes during different pandemic phases and could bias the interpretation of our findings.

Comparison With Prior Work

Several studies of health care worker mental health during the COVID-19 pandemic revealed higher stress [11-13,18,26,29], anxiety [18,24,29], depressive [11,12,18,24], and obsessive-compulsive [11] symptoms; these results align well with our 6-week prevalence findings. These studies also found that heightened stress, anxiety, and depressive symptoms were consistently more pronounced in females, and in those with increased exposure to afflicted individuals (eg, frontline health care workers, close proximity to higher intensity outbreak conditions). Although our 6-week prevalence findings matched this overall increase in health care worker mental health burden during an outbreak, higher levels of stress, anxiety, and depressive symptoms were also reported by other workers in our study.

Based on existing evidence, there may be several plausible explanations for our findings, although their interpretation should be approached with caution, given the lack of published studies directly comparing mental health symptoms by worker type, particularly during COVID-19.

There are many possible factors contributing to mental health concerns among the general public during times of societal unrest, as documented during previous infectious disease outbreaks [32,38-42], emergencies, disasters [15-17,19,44,62], and the current pandemic [18,38,71]. Within the Alberta context, several of these factors (eg, high unemployment [69], job uncertainty, strict confinement, and mitigation measures, as well as pre-existing, unaddressed mental health concerns arising in part from economic downturn and natural disasters [51,62,72]) or other contextual factors may be contributing to the increased mental health symptoms in other workers. These factors may be more prevalent in other workers who actively sought support by subscribing to Text4Hope, contributing to a higher symptom burden in this worker group. Current trends in Alberta align with this hypothesis: a recent Mental Health Index survey of 3000 Canadians [73] showed Alberta residents experienced the highest national month-over-month decline in Mental Health Index scores. Decreases were observed in all Index subscores (including risk measures for anxiety, depression, work productivity, optimism, and isolation, in decreasing order of magnitude), with greater declines among the unemployed, females, and younger individuals. Albertans had the second highest reported Mental Stress Change Score across Canada [73]. Nonetheless, our observation of elevated symptomatology overall might be anticipated given that respondents were a sample of mental health support-seeking Text4Hope subscribers.

Alternatively, it is also possible that the health care workers seeking support in our study sample were protected from mental health harms due to the influence of other documented but unassessed modifiers such as the following: ready access to relevant knowledge, training, protocols, timely information, personal protective equipment, and a support network of peers experiencing similar stress, as well as coordinated efforts, clear communication, and other occupational and/or social supports [12,13,41,53,55,74]. Past research shows the presence of these and other precautionary measures may help health care workers feel a heightened sense of certainty or control over their situation. Perhaps support-seeking health care worker respondents' pre-existing knowledge and training served to reinforce their roles and practice, provided comfort and enhanced resiliency, and helped mitigate the negative effects of the pandemic as well as subsequent confinement and mitigation strategies [12,13,35,38,39,41,45,55].

Such a resilience hypothesis in health care workers would contrast with recent COVID-19-related studies by Lai and colleagues [18] and Huang and colleagues [24], which demonstrated an increased risk of negative mental health sequelae in females [11-14,18,27,29], nurses [11,12,14,18,27,29], frontline staff, and those with closer proximity to higher intensity outbreak working conditions [11,12,14,18,23,25,26,55]. Similar findings from past outbreaks also implicated concerns about health of self and family, disease spread, adequate supplies/resources, an influx of suspected cases, occupational changes, pre-existing chronic disease, isolation, and feelings about isolation and vulnerability as key negative contributing factors [18,38,41,75]. Zhang and colleagues' recent survey comparing medical and nonmedical health care worker mental health symptoms in China post-COVID-19 showed higher prevalence and total scores for insomnia, anxiety (GAD-2), depression (PHQ-2), somatization, and obsessive-compulsive (Symptom Checklist 90-Revised) symptoms in health care workers [11]. Similar findings for anxiety occurred in a mixed sample survey undertaken during the COVID-19 pandemic [13]. Additionally, a quasi-comparator study of mental health concerns in frontline workers and administrative health care workers found frontline workers were 1.4 times more likely to feel fear and 2 times more likely to suffer anxiety and depression than their administrative (ie, nonfrontline, low-risk exposure) counterparts (despite lower relative exposure, both worker groups were health care sector employed, making clear comparisons difficult) [11,13,28]. Lastly, the most relevant large post-COVID-19 pandemic web-based survey by Huang and Zhao [24] failed to find any statistically significant differences between health care and other workers' prevalence of anxiety or depressive symptoms, and only a higher prevalence of sleep disruptions in health care workers.

Clearly, large longitudinal studies that specifically compare the symptoms, risk exposure [18], and other contextual correlates (eg, pre-existing knowledge of disease and disease transmission, outbreak phase, and geographic proximity to high risk situations) of health care workers and other workers are needed. Ongoing evidence syntheses would also help to clarify and explain these apparent discrepancies in the future.

Our self-reported 6-week prevalence rates for likely GAD (47.0%) and likely MDD (44.0%) were slightly higher and lower than symptom estimates reported by Lai et al [18] (44.6% GAD, 50.4% MDD), even considering the authors' use of a slightly lower GAD-7 cutoff score (7). Our prevalence estimates for likely MDD (44.0%) were also higher than the estimates of moderate or severe depression symptoms reported by Kang et al (28.6%) [27] and Huang and Zhao (20.1%) [24] in the postpandemic period. Although these findings may reflect true mental health burden differences, it is possible that the timing of symptom measurement during a pandemic influences symptom severity, particularly if the implementation of confinement and mitigation measures varies as widely as during the COVID-19 pandemic [5]. This study captured 6-week prevalence in an early pandemic phase, whereas Lai et al measured the same burden during the pandemic. Kang and colleagues and Huang and Zhao both measured health care worker symptoms in the postpandemic phase. It is also possible that jurisdictions most rapidly affected by the pandemic have less knowledge, less time to prepare and assess/address risk, and possess fewer supplies and resources, and thus may report higher mental health concerns [12,13]. Furthermore, despite the elevated psychopathology we observed, we note that respondents were a sample of mental health support-seeking Text4Hope subscribers and our findings should be considered in light of this context.

In our study, the prevalence of worry about dirt, germs, and viruses and compulsive handwashing behavior since the COVID-19 pandemic began was significantly higher in other workers than in health care workers. This finding is aligned with a population-based study by Wang et al [15] early in the COVID-19 pandemic, in which members of the general public reported newly adopting handwashing after touching contaminated objects (66.6%), washing their hands with soap (56.5%), and always washing their hands after coughing, sneezing, or rubbing their nose (41.0%). These authors found that handwashing behavior was linked to lower mental health symptom scores, suggesting they had a protective effect during the early stages of the pandemic [15]. This finding aligns with our observation of lower reported worry in other workers before and during the COVID-19 pandemic, and their subsequent adoption of compulsive handwashing behavior since the onset of the COVID-19 pandemic.

With respect to health care workers' obsessive-compulsive symptoms, it is unclear the extent to which professional training; heightened attention to dirt, germs, and viruses; handwashing behavior, and disease transmission could appear maladaptive when assessed with the BOCS tool during a pandemic. Using a different validated scale, Zhang and colleagues [11] recently observed higher measures of obsessive-compulsive symptoms after the peak of the COVID-19 pandemic in frontline health care workers, which aligns with our finding of higher health care worker worry and handwashing due to fears of contamination before and during the pandemic. The BOCS tool was validated for use in adult psychiatric outpatients, not specifically for pandemics, nor for profession-specific groups, and therefore we advise caution in the interpretation of these findings. Certainly, the negative impacts of pervasive

multimodal media and recurring widespread handwashing advice during COVID-19 are well documented [76] and particularly problematic for those with pre-existing obsessive-compulsive behaviors [77]. Further study is needed to understand how worry of contamination and compulsive handwashing behavior relate to worker type and timing of symptom assessment during outbreak phases. Future research is also needed to understand the extent to which worry and handwashing due to fears of contamination are adaptive during a pandemic, when assessed with validated scales.

Conclusions

Demographic and clinical correlate data pertaining to mental health needs were successfully collected through Text4Hope and provided insight on the state of mental health concerns in health care workers and other workers.

Overall, our study findings mirrored much of the emerging literature documenting increased stress, anxiety, and depression symptoms arising during the current COVID-19 pandemic, and during previous infectious disease outbreaks. However, as compared to the literature and given our stated limitations, discrepant findings may be a function of measurement timing during a particular outbreak phase (early, interim, post), attributable to pre-existing context, and/or may be related to our study population, which was comprised of support-seeking individuals. A health care worker resilience hypothesis (eg, that health care workers are protected by knowledge, resources, supplies, messaging, and heightened certainty and control over workload [12,18]) is not well supported by our findings, nor the bulk of the existing and emergent COVID-19 pandemic literature pertaining to mental health concerns in this group. Furthermore, we note that the array of documented mental health risk factors, combined with higher proportions of females working in health care, community, caregiving, and domestic roles, seems to indicate an increased mental health vulnerability for females during COVID-19.

We observed support-seeking health care workers report significantly higher worry about contamination and compulsive handwashing symptoms prior to the onset of the COVID-19 pandemic and a higher proportion of other workers reporting these symptoms only since the onset of the pandemic. However, both of these findings should be interpreted with caution given it is unclear the extent to which validated scales accurately differentiate adaptive and maladaptive symptoms associated with worry about contamination and handwashing behavior in health care workers, or accurately differentiate symptoms during pandemic periods.

These findings add to our understanding of mental health needs during the COVID-19 pandemic; however, further research is required to understand and confirm in more detail the potential effects of a given outbreak phase on the measurement of mental health burden, the role of context, and the extent to which validated tools have utility in health care workers and in different worker groups during pandemics. The findings also underline the importance of anticipating and mitigating mental health needs as an integrated part of planning and confinement/mitigation strategy implementation [50,55,78-82] and highlight the ease with which current mental health needs

can be safely assessed using a self-subscribing SMS text messaging platform. This study took place in a nation where the health care system is publicly funded, reasonably accessible to most residents, and operationally sound; however, it is

possible that the mental health effects we observed could be further amplified, particularly for females, in nations where these circumstances are not the norm.

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Authors' Contributions

VIOA conceived and designed the study, including the Text4Hope program, and completed data analysis. KJM drafted the initial manuscript with VIOA. AG, WV, and SS participated in data collection. All authors contributed to study design, and reviewed and approved the final draft of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

AHS: Alberta Health Services
BOCS: Brief Obsessive-Compulsive Scale
CBT: cognitive behavioral therapy
GAD: generalized anxiety disorder
GAD-7: Generalized Anxiety Disorder Scale, 7-item scale
MDD: major depressive disorder
PHQ-9: Patient Health Questionnaire, 9-item scale
PSS: Perceived Stress Scale
Text4Hope: Alberta Health Services Text for Hope program
WHO: World Health Organization

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