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Original Paper

Developing Social Media-Based Suicide Prevention Messages in Partnership With Young People: Exploratory Study

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Abstract

Background: Social media is increasingly being used by young people for health-related issues, including communicating about suicide. Due to the concerns about causing distress or inducing suicidal thoughts or behaviors, to date young people neither have been engaged in the development of social media-based suicide prevention interventions nor have interventions focused on educating young people about safe ways to communicate about suicide online. Given the potential that social media holds to deliver messages to vast numbers of people across space and time and the fact that young people often prefer to seek help from their friends and peers, safely educating and engaging young people to develop suicide prevention messages that can be delivered via social media is an obvious next step.

Objectives: The objectives of this study were to (1) provide education to a small number of secondary school students about safe ways to communicate about suicide via social media; (2) engage the same young people in the development of a suite of social media-based suicide prevention multimedia messages; (3) assess the impact of this on participants; and (4) assess the acceptability and safety of the messages developed.

Methods: This study involved two phases. In phase 1, 20 participants recruited from two schools took part in an 8- to 10-week program during which they were provided with psychoeducation about mental health and suicide, including how to talk safely about suicide online, and they were then supported to design and develop their own media messages. These participants completed an evaluation questionnaire at the conclusion of the program. In phase 2, a larger group of participants (n=69), recruited via an opt-in process, viewed the media messages and completed a short questionnaire about each one.

Results: Participants in phase 1 enjoyed the program and reported that they learned new skills, such as how to talk safely about suicide online, and felt more able to provide emotional support to others (16/20, 80%). No participants reported that the program made them feel suicidal. Participants in phase 2 generally rated the media messages as safe and acceptable, although some messages were rated more highly than others.

Conclusions: This study suggests that young people can be safely engaged in developing suicide prevention messages, which can be disseminated via social media. Engaging young people in this process may improve the traction that such campaigns will have with other young people. The study also suggests that educating young people regarding how to talk safely about suicide

online has multiple benefits and is not associated with distress. Overall, these findings pave the way for new approaches to prevent suicide among young people.

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KEYWORDS

suicide; suicidal ideation; social media; youth; adolescents; mass media

Introduction

Suicide and Young People

Suicide is the leading cause of death among young people worldwide, including Australia [1,2]. It accounts for one-third of all deaths in Australians younger than 25 years and, despite decades of government attention and some improvement in youth suicide rates between 1997 and 2012, rates have increased again in the recent years [1]. In addition, many more young people make a suicide attempt and even more live with suicidal feelings [3,4].

The Relationship Between Suicide and the Media

Certain types of media reporting on suicide have been linked to an increase in suicide deaths [5]. This is thought to be the result of contagion, whereby the suicide of one individual may lead another person (particularly someone who identifies with the deceased) to take their own life; young people are thought to be particularly susceptible to this process [6]. For this reason, the role of the media in suicide prevention has long been recognized. Indeed, the World Health Organization [2] states that working with media on the responsible reporting of suicide is an evidence-based suicide prevention strategy that should form part of national suicide prevention approaches. In response to this and to research that suggests an association between media reporting of suicide and suicidal behavior, several countries, including Australia, have developed media guidelines that advocate for responsible and sensitive reporting and portrayal of suicide [5,7-10]. However, the increasing popularity of social media platforms such as Facebook, Instagram, YouTube, and Snapchat, in particular among young people, has presented a new set of opportunities and challenges for suicide prevention. For example, challenges include the potential for further contagion and the spreading of information about suicide methods [11]. A further challenge arises from the fact that because young people are now the creators of their own content, strategies that engage media professionals to safely and responsibly report on suicide may have limited impact on other communication channels such as social media [12].

Despite these challenges, there are also potential benefits that arise from the reach, acceptability, and cost-effectiveness of interventions delivered via social media platforms [13,14]. To date, however, there has been limited evaluation of social media-based interventions, largely because of methodological challenges associated with the fast-moving, amorphous, and anonymous nature of these platforms [13-17]. As a result, new approaches to prevent youth suicide and to evaluate youth suicide prevention efforts are required [18]. One such approach could involve educating and supporting users directly about safe and unsafe ways to communicate about suicide via social

media; to the best of our knowledge, this approach has not been tested.

In addition to strategies that influence the news and entertainment media, the delivery of population-wide suicide prevention media campaigns has also gained attention as a possible effective strategy. Limited evidence exists for the effectiveness of these campaigns to change behavior; however, they have been shown to improve outcomes such as knowledge and awareness of suicide, attitudes toward suicide and help-seeking, and may have the potential to reduce suicide rates [19-25]. To date, however, limited evidence exists regarding the impact of such campaigns, specifically on young people, and few campaigns, if any, focus purely on social media or actively involve young people in their design and implementation.

Participatory design processes are critical to ensure that the views and preferences of end users are accounted for, which in turn is likely to enhance uptake and engagement [26]. These processes may be especially important in the development of suicide prevention materials, given that young people are more likely to seek help from their friends than professionals [27,28]. Researchers have so far successfully engaged young people in the development of computerized cognitive behavioral therapy programs for depression and psychosis [29,30]. To date, however, no studies have reported on the development of media messaging on suicide prevention using participatory design processes.

Study Aims

To address this gap, this exploratory study aimed at the following:

1. To engage small groups of young people (up to 10 per group) in the development of a suite of suicide prevention media messages that can be delivered to other young people via social media platforms;
2. To assess the impact of participating in the program on participants' knowledge of mental health issues and suicide, their ability to talk safely about suicide both online and offline, and any potential iatrogenic effects; and
3. To evaluate the acceptability, efficacy, and safety of the media messages developed.

Methods

Study Design

The methodology comprised two phases. Phase 1 examined the perceived impact of participating in the program on participants. This was assessed by a specifically designed questionnaire administered at the end of the program. Phase 2 examined the perceived acceptability of the media messages by a wider group

of students. To evaluate this, brief Web-based questionnaires were administered immediately after viewing the messages.

Setting

The study was conducted by researchers from Orygen, The National Centre of Excellence in Youth Mental Health, in partnership with String Theory Creative, a creative and digital communications agency. String Theory Creative provided education to participants on using digital media (including how to edit short films) and also provided assistance in producing the media messages (eg, balancing sound and editing footage where necessary). Other partners were the University of Melbourne and the Hunter Institute of Mental Health, who developed the Mindframe resources for media professionals reporting on suicide [9].

Phase 1: Development of Media Messages

Participants

Participants were students from two secondary schools in Melbourne, Australia. One school was a coeducational vocational college and the other was a high-performing all-boys school. Recruitment into the study was different for each school. For School 1, participants were students from two senior business marketing classes, and the program was integrated into the curriculum. Students in these classes who did not want to participate were given alternative work to complete in a different location. For School 2, the study was advertised on the school news feed (accessed by both parents and students) and was also promoted by the school counselor to some students. Students at School 2 self-selected into the study.

Measures

A Web-based survey was developed consisting of items specifically developed for this study (Multimedia Appendix 1).

Participants were asked for their age and gender, as well as 6 questions about their personal experience with suicidal thoughts, self-harm, mental health problems, helping a friend with mental health problems or suicidal thoughts, and bereavement by suicide. A total of 18 questions were used to assess participants' views on the project, including whether they had learned new skills with regard to communicating about suicide; whether they found it enjoyable, worthwhile, or upsetting; and whether they would recommend it to a friend.

Procedure

The program comprised eight sessions delivered over an 8- to 10-week period. Each session lasted approximately 2 hours and was delivered by a research assistant (EB), with support from senior researchers (JR and SH) and a staff member from String Theory Creative (SP). The sessions were delivered in school premises during school hours and at least one school staff member was either present or nearby during the sessions. No homework was set; however, students were encouraged to work on their media messages in their own time if they did not have sufficient time during the sessions. Table 1 presents the structure of sessions.

Intervention

The intervention took the form of the development of a suite of media messages made by young people for other young people. No limits were imposed on either the format or content of the media messages. In developing their media messages, participants were encouraged, however, to use their existing resources. For example, they were asked to record video footage using their mobile phones or tablets and edit it using software already installed on their school computers. One researcher (SP) with extensive experience in recording and editing videos was available to provide assistance if required.

Table 1. Structure of sessions.

Session	Description
1	Meet participants and introduce project; Discuss goals for the program and set boundaries; and Show some examples of social media being used for suicide prevention.
2	Provide psychoeducation about mental health and suicide, including information about: <ul style="list-style-type: none"> the prevalence of mental health problems, including depression and anxiety, and suicide and suicidal behavior; signs and symptoms of mental health problems; and warning signs and risk factors for suicide.
3	Provide psychoeducation about safe ways of communicating about suicide based on resources such as the Mindframe media guidelines [9]; and Provide psychoeducation about how to help a friend who might be thinking about suicide based on resources from mental health organizations such as SANE, headspace, and beyondblue.
4	Brainstorm with students about ideas for their media messages and decide on concepts; and Provide education about designing and creating multimedia content.
5-7	Development of media messages.
8	Presentation day for media messages; and Participants complete questionnaires.

Two researchers (JR and EB) oversaw the content of the media messages, giving feedback and advice where necessary to ensure their safety and appropriateness. For the most part, participants created their media messages during the sessions; however, some also worked on them in their own time.

A closed Facebook group was set up for each group of study participants so that participants could communicate about the project outside the school-based sessions, and the research team could share relevant information, such as links to useful websites, with the students. The Facebook groups were moderated daily by a research assistant (EB) and deleted on completion of the program.

Phase 2: Evaluation of Media Messages

Participants

Participants were students from the same two secondary schools described above. In both schools, the study was advertised to all year 11 and 12 students (aged 16-18 years). Students who provided informed consent were eligible to participate in the evaluation.

Measures

A survey was specifically designed for this purpose ([Multimedia Appendix 2](#)). It contained 1 item about participants' age and 3 items about the experience of suicidal thoughts (lifetime, within the last 4 months, right now). It also contained 9 questions for each of the media messages being evaluated, which did not change between evaluations. Questions 1 and 2 required participants to indicate how helpful they thought the message would be for someone who is experiencing thoughts of suicide or wants to help somebody else experiencing suicidal thoughts. Questions 3 and 4 required participants to indicate how likely they were, after viewing the intervention, to seek help for suicidal thoughts or help somebody else experiencing suicidal thoughts. Questions 5 and 6 required participants to rate their mood before and after viewing the media message using a 7-point modified faces pain rating scale. Questions 7 and 8 required participants to specify their thoughts about the content and format of the media message. Finally, Question 9 asked whether participants would share the message with others.

Procedure

Participants viewed the media messages and subsequently completed the Web-based survey at school in the presence of a research assistant (EB). EB received an automated email if any participant indicated that they had experienced recent or current suicidal thoughts. These participants were responded to as per the safety protocol (see below).

Data Analysis

Qualtrics survey software was used to collect all data. Simple frequencies and percentages were calculated for each set of response options.

Ethics and Safety

The evaluation received approval from the Melbourne University Human Research and Ethics Committee (ID 1442942). All students provided written consent to take part in the study. In the case of students aged less than 18 years, consent was also obtained from a parent or guardian.

A comprehensive safety protocol was developed to ensure that any participant determined to be at risk at any stage of the process would be recognized and responded to appropriately. This included responses to (1) survey items pertaining to suicidality; (2) any student who became distressed during one of the school-based sessions; and (3) any student who indicated distress on the Facebook group. In all cases, the protocol required that if a student was identified as being potentially at risk, the RA would conduct a risk assessment and, if required, refer the student to the school well-being team for follow-up.

Results

Phase 1: Development of Media Messages

Participants

A total of 26 students took part in the project, of whom 20 completed the questionnaires. The 6 participants who did not complete questionnaires had left either the school or class during the study period.

Among these students, 80% (16/20) were male, and the mean age was 17.1 years (standard deviation 1.69). At baseline, 45% (9/20) of the students had experienced a mental health problem in their lifetime, 55% (11/20) had experienced suicidal thoughts or feelings, 20% (4/20) had engaged in self-harm, 80% (16/20) had supported a friend experiencing mental health problems, and 70% (14/20) had supported a friend experiencing suicidal thoughts. In addition, 30% (6/20) of the students said that somebody close to them had died by suicide.

Messages Developed

A total of 8 media messages were produced. Of these, 7 were short videos (ranging from 30 s to 3 min in duration) and one was a series of 4 images designed to be used on a platform such as Instagram or Snapchat. A description and screenshot for each media message is shown in [Multimedia Appendix 3](#). All the media messages contained contact information for helplines or services.

Project Evaluation

Participants' responses to the project evaluation questions are displayed in [Tables 2](#) and [3](#). [Tables 2](#) and [3](#) contain participants' responses to the items about knowledge or skills gained and about project safety and acceptability, respectively.

In general, participants reported that they had gained new skills and abilities. In particular, most participants (16/20, 80%) felt more able to talk about suicide both generally and online, and the same number felt better able to provide emotional support to others.

Table 2. Skills or knowledge gained through Safe Conversations.

Variable	Agree or strongly agree, n (%)	Neutral, n (%)	Disagree or strongly disagree, n (%)
Participating in this project has helped me to develop new skills.	18 (90)	1 (5)	1 (5)
As a result of this project, I have a better understanding of how to talk about suicide safely online.	16 (80)	3 (15)	1 (5)
As a result of this project, I have a better understanding of how to talk about suicide generally.	16 (80)	4 (20)	0
The project has helped to improve my self-confidence.	9 (45)	7 (35)	4 (20)
The project has helped me to develop my leadership and mentoring skills.	10 (50)	9 (45)	1 (5)
The project has helped me to further develop my interpersonal skills.	12 (60)	7 (35)	1 (5)
The project has helped me to further develop my communication skills.	14 (70)	5 (25)	1 (5)
As a result of participating, I feel more able to provide emotional support to others.	16 (80)	4 (20)	0
As a result of participating, I feel more able to educate others about cyber safety.	14 (70)	6 (30)	0

Table 3. Acceptability and safety of Safe Conversations project.

Variable	Agree or strongly agree, n (%)	Neutral, n (%)	Disagree or strongly disagree, n (%)
The Safe Conversations project was enjoyable.	16 (80)	4 (20)	0
The Safe Conversations project was helpful.	17 (85)	3 (15)	0
The Safe Conversations project made me feel upset.	1 (5)	4 (20)	15 (75)
The Safe Conversations project made me feel suicidal.	0	3 (15)	17 (85)
The Safe Conversations project was boring.	2 (10)	3 (15)	15 (75)
The Safe Conversations project took up too much of my time.	0	6 (30)	14 (70)
I found participating in the Safe Conversations project stressful.	0	4 (20)	16 (80)
I feel motivated after participating in the Safe Conversations project.	10 (50)	5 (25)	2 (10)
The Safe Conversations project was worthwhile.	15 (75)	4 (20)	1 (5)

Table 4. Participants' responses to the evaluation questions.

Questionnaire item	Beach video, n (%)	Vox pop, n (%)	Signs video, n (%)	Post-it-note video, n (%)	Suicide can't be reversed, n (%)	Letter video, n (%)	Mask video, n (%)	Series of 4 images, n (%)
Helpful or extremely helpful for suicidal person	16 (80)	7 (39)	8 (42)	30 (71)	33 (79)	24 (57)	8 (19)	7 (70)
Helpful or extremely helpful for someone wanting to help a suicidal person	13 (65)	8 (45)	7 (37)	35 (83)	36 (86)	24 (57)	12 (29)	6 (60)
Less likely to seek help	1 (5)	0	4 (21)	0	2 (5)	0	16 (38)	0
More likely to seek help	6 (6)	2 (11)	4 (21)	15 (36)	19 (45)	15 (36)	3 (7)	5 (50)
More likely to help a friend	10 (50)	6 (33)	6 (32)	23 (55)	25 (60)	29 (69)	7 (17)	4 (40)
Mood decreased after viewing	1 (5)	1 (6)	1 (5)	8 (19)	19 (45)	29 (69)	11 (26)	0
Likes or really likes the format	11 (55)	5 (28)	9 (47)	21 (50)	32 (76)	23 (55)	12 (29)	9 (90)
Likes or really likes the content	12 (60)	12 (67)	8 (42)	29 (69)	30 (71)	30 (71)	12 (29)	7 (70)
Would share with others	8 (40)	10 (56)	6 (32)	22 (52)	28 (67)	20 (48)	9 (21)	5 (50)
Total N	20	18	19	42	42	42	42	10

Most participants (16/20, 80%) enjoyed participating in Safe Conversations; 17 (85%) thought it was helpful, and 15 (75%) thought it was worthwhile. No participants thought that the program was stressful or time consuming, and no participants reported that the program made them feel suicidal (although one participant said that the program made them feel upset). In addition, no participants became visibly distressed during any of the sessions. Likewise, there were no occasions where participants communicated that they were distressed or suicidal using the Facebook groups. Finally, 19 (95%) participants said that they would recommend the project to a friend.

Phase 2: Evaluation of Media Messages

Participants

A total of 69 participants took part in the evaluation, including 18 from School 1 and 51 from School 2. Of these, 10 participants were students from School 2, who participated in phase 1 of the project and had recently completed the phase 1 questionnaire; as such, they did not provide any additional demographic or suicide risk information.

The mean age of the remaining participants ($n=59$) was 16.4 years. Of these, 25 (42%) reported that they had experienced suicidal thoughts or feelings at some point in their lives, 5 (9%) reported that they had experienced these feelings in the past 4 weeks, and 1 (2%) reported that they were currently experiencing these feelings.

Evaluation Data

Responses of the participants to each of the media messages described above are shown in Table 4. The total number of participants who evaluated each media message differed because participants at School 1 were only required to evaluate at least two media messages because of time constraints. As such, not all participants evaluated all media messages. Moreover, participants in phase 1 at School 2 evaluated the media messages developed by School 1.

The media messages varied in terms of how helpful they were perceived to be for a person experiencing suicidal thoughts. The “beach” video was rated as the most helpful (rated as “helpful” or “very helpful” by 80% of participants [16/20]), followed by the “suicide can’t be reversed” video (33/42, 79%), the “post-it-note” video (30/42, 71%), and the series of 4 images (7/10, 70%). The majority were rated as being more helpful for someone who wants to help a suicidal person than for a suicidal person themselves, although there were three exceptions (beach video, signs video, and image series). The “suicide can’t be reversed” video was rated as most helpful for someone who wants to help somebody else having thoughts of suicide (36/42, 86%).

The format that participants liked the most was the series of 4 images (90% of participants [9/10] either “liked it” or “really liked it”); this was the only media message that took the format of a static image rather than a video. The majority of participants generally liked the content of the media messages, with the exception of the “mask” and the “signs” videos that were liked by only 29% (12/42) and 42% (8/19) of participants,

respectively. Approximately 50% of the participants were likely to share the media messages with others.

Most of the media messages were *not* associated with a decrease in help-seeking intentions, although 38% of participants (16/42) reported a decrease in their likelihood of seeking help after seeing the “mask” video. Although the majority of participants indicated that their help-seeking intentions remained the same, all media messages were associated with increased likelihood of seeking help in at least some participants (ranging from 7% to 50%). Additionally, all media messages, with the exception of the image series, were more highly associated with increased likelihood of helping others than they were with increased likelihood of helping oneself.

Most of the media messages were not associated with a decrease in mood, including among those participants who had experienced recent suicidal ideation. However, almost 70% of the sample (29/42) reported that their mood decreased after viewing the “letter” video, including 2 of the 5 participants who had experienced recent suicidal ideation. Despite this, 71% (30/42) reported that they liked the content and 57% (24/42) thought it would be helpful for a suicidal person.

Discussion

Principal Findings

This exploratory study examined the feasibility, safety, and impact of engaging young people in the development of suicide prevention media messages that can be delivered to other young people via social media. In total, 8 media messages were produced, including 7 short films and one series of static images. Overall, students found the program to be useful and worthwhile. The majority of students reported that they felt better able to communicate safely about suicide, including online. In addition, they reported to feel better able to provide emotional support to others and educate others about staying safe online. Notably, no students felt suicidal as a result of taking part in the program, and the majority reported the program to be enjoyable, helpful, and worthwhile.

In general, the media messages developed were found to be both safe and acceptable, although some more so than others. For example, the format that participants liked the most was the series of 4 images; this was the only message that adopted a static format. This message was also rated by the most participants as increasing their likelihood of seeking help and was the only one that was not associated with any decrease in participants’ mood. Another media message of note was the “letter” video, which was most strongly associated with a decrease in mood. Despite this, most participants reported that they liked the content, over 50% of the participants thought it would be helpful for a suicidal person, and it was not associated with decreased likelihood of seeking help. Also of note were the participants’ ratings of the “mask” video, as it was the only message designed to be humorous. This was arguably the least acceptable message, with less than one-third of participants reporting that they liked the format or content and less than 20% thinking that it would be helpful for a suicidal person. Moreover, 38% of participants reported a decreased likelihood of seeking

help after viewing it; this was by far the highest percentage in this category. Finally, participants rated all but one of the media messages as more likely to improve their intentions to *help others* than their intentions to *seek help for themselves*. This suggests that media messages may have the potential to influence viewers to talk to people who they are worried about. Overall, these data provide some indication about the type of medium and content that appears to be most appealing to young people and the potential impact they may have on the likelihood of young people helping themselves and others. It also indicates that just because a media message may lead to a decrease in mood in some viewers does not mean that it is perceived to be unhelpful. It is hoped that these findings may help in the development of future suicide prevention campaigns.

Limitations

First, this was a small study conducted in two secondary schools in Melbourne, Australia. One school was an all-boys school and the other was a vocational secondary college. As such, the results obtained in this study may not necessarily be generalizable to other school settings. It is also worth noting that a significant proportion of the sample reported previously experiencing either a mental health problem, suicidal feelings and/or supporting a friend with suicidal feelings, which may also impact upon the generalizability of the study findings.

Second, this was a simple posttest study that assessed participants' perceptions using a simple survey administered at one time point. This was intentional based on the exploratory nature of the project, but it does impact on the robustness of the findings.

Third, we did not have the scope to examine the reach and impact of the media messages developed beyond what is described above. As such, the findings with regard to the potential impact of the media messages outside the school context must be interpreted with caution. On a related note, we were not able to examine how the messages were perceived by mental health professionals or suicide prevention experts. There is a risk that, although they were rated favorably by young people, professionals may not consider them as safe or acceptable; this should be the focus of future studies of this nature.

Comparison With Prior Work

Notwithstanding the limitations, this novel study has implications regarding the ways in which social media can be used in suicide prevention and how young people can be engaged in this process. It also builds on previous work in numerous ways.

The ways in which suicide is discussed in the media have long been considered to have an impact on suicide-related behaviors, in particular, among vulnerable individuals [31,32]. As noted above, historically, a key and accepted approach to address this has been through the development and active dissemination of guidelines for media professionals using traditional media outlets [9,10,33]. It has been suggested that similar guidelines should be developed for Web-based platforms [12]. Although some such guidelines exist, such as those developed by the International Association for Suicide Prevention to assist

bloggers reporting on suicide [34] and advice developed for social media content under the Mindframe National Media Initiative in Australia [35], their impact on the ways in which suicide is discussed online has not been tested and may be limited. For example, without targeting young people directly, these guidelines are unlikely to impact the way young people discuss suicide with their peers using social media platforms, where consumers, not professionals, create their own content. As such, it is acknowledged that a different approach is required [36]. The approach taken in this study of educating young people regarding safe ways to communicate about suicide and then supporting them to develop their own media messages appears to be promising. This was not only the case in terms of participants' perceived ability to communicate more safely about suicide but also their perceived ability to support others expressing emotional distress, both online and offline.

Concerns have been expressed on the safety of communicating about suicide via social media platforms [14-16] and about the safety of delivering suicide prevention education to young people in a classroom setting [37]. The fact that no immediate adverse effects were reported by the students who participated in this study, however, suggests that both of these strategies can be implemented safely, as long as care is taken to ensure that participants are monitored for signs of distress and responded to appropriately if required. This supports our recent research indicating that educating high school students about suicide prevention is both safe and acceptable [38] and that social media holds potential for the delivery of suicide prevention messages [13,39].

It is well documented that young people prefer to talk to their friends and peers than health professionals about emotional problems [27,40]. In addition, one aspect of social media valued by young people is its ability to connect them with others who have had similar experiences in a nonjudgmental and more egalitarian way [13,41]. Thus, it stands to reason that social media messages that have been developed by young people may well be more acceptable to other young people than those developed by adults. This study provides evidence that young people can successfully be engaged in this process.

The type of media messages developed here could readily be delivered via platforms such as YouTube, Snapchat, and Instagram either as stand-alone messages or as part of a large-scale suicide prevention campaign. Despite recent interest in the development of suicide prevention media campaigns [19], limited evidence exists regarding their efficacy, in particular among young people. This study did not have the capacity to conduct a broad evaluation of the reach and acceptability of the media messages developed. As no iatrogenic effects were reported, it is possible to engage young people in the development of a suicide prevention campaign; the impact of which could then be evaluated on a larger scale.

Finally, the Facebook group proved to be a useful and safe way to communicate with young people throughout this project. This suggests that as professionals, we can be more confident in using social media platforms to communicate with young people on sensitive issues such as suicide. To the best of our knowledge, no previous studies have used social media platforms in this

manner. Historically, professionals have been shown to use social media differently from young people when it comes to suicide prevention [39] and concerns exist with regard to ethical issues, including client confidentiality and duty of care [42]. Although it is right to remain cautious, particularly when considering using social media platforms in clinical care, it is becoming more apparent that these types of platforms can provide a useful and acceptable medium through which professionals can communicate with young people.

Conclusions

Social media is increasingly being used by young people for health-related issues, including communicating about suicide

[43,44]. It presents a range of benefits, including its reach, accessibility, and acceptability, and as such, it provides an ideal platform through which suicide prevention media campaigns can be delivered. This study suggests that young people can be safely engaged in the process of developing such a campaign, which as a result may have more traction with this population. Furthermore, educating young people about how to talk safely about suicide online has multiple benefits. Overall, these findings pave the way for new approaches to suicide prevention in young people.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Impact of student involvement questionnaire.

[PDF File (Adobe PDF File), 32KB - [mental_v4i4e40_app1.pdf](#)]

Multimedia Appendix 2

Media message evaluation questionnaire.

[PDF File (Adobe PDF File), 34KB - [mental_v4i4e40_app2.pdf](#)]

Multimedia Appendix 3

Messages developed.

[JPEG File, 148KB - [mental_v4i4e40_app3.jpeg](#)]

References

1. ABS. 2016. 3303.0 - Causes of death, Australia, 2015 URL: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3303.0> [accessed 2017-09-13] [WebCite Cache ID 6tRcF5fy0]
2. WHO. 2014. Preventing suicide: a global imperative URL: http://www.who.int/mental_health/suicide-prevention/world_report_2014/en/ [accessed 2017-09-13] [WebCite Cache ID 6tRcSt6qM]
3. Nock MK, Borges G, Bromet EJ, Cha CB, Kessler RC, Lee S. Suicide and suicidal behavior. Epidemiol Rev 2008;30:133-154 [FREE Full text] [doi: [10.1093/epirev/mxn002](https://doi.org/10.1093/epirev/mxn002)] [Medline: [18653727](https://pubmed.ncbi.nlm.nih.gov/18653727/)]
4. health.gov. The Mental Health of Children and Adolescents : Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing URL: <https://www.health.gov.au/internet/main/publishing.nsf/Content/9DA8CA21306FE6EDCA257E2700016945/%24File/child2.pdf> [accessed 2017-09-20] [WebCite Cache ID 6tbykutRD]
5. Pirkis J, Blood R. SPRC. 2010. Suicide and the news and information media: a critical review URL: <http://www.sprc.org/resources-programs/suicide-and-news-and-information-media-critical-review> [accessed 2017-09-14] [WebCite Cache ID 6tSmfXWlJ]
6. Gould M, Jamieson P, Romer D. Media contagion and suicide among the young. Am Behav Sci 2003 May 01;46(9):1269-1284. [doi: [10.1177/0002764202250670](https://doi.org/10.1177/0002764202250670)] [Medline: [22973420](https://pubmed.ncbi.nlm.nih.gov/22973420/)]
7. Pirkis J, Blood RW. Suicide and the media. Part I: reportage in nonfictional media. Crisis 2001;22(4):146-154. [doi: [10.1027//0227-5910.22.4.146](https://doi.org/10.1027//0227-5910.22.4.146)] [Medline: [11848658](https://pubmed.ncbi.nlm.nih.gov/11848658/)]
8. Pirkis J, Blood RW, Beautrais A, Burgess P, Skehans J. Media guidelines on the reporting of suicide. Crisis 2006;27(2):82-87. [doi: [10.1027/0227-5910.27.2.82](https://doi.org/10.1027/0227-5910.27.2.82)] [Medline: [16913330](https://pubmed.ncbi.nlm.nih.gov/16913330/)]

9. Hunter Institute of Mental Health. Mindframe-media. 2014. Reporting suicide and mental illness: a Mindframe resource for media professionals URL: <http://www.mindframe-media.info/home/resource-downloads/?a=10217> [accessed 2017-09-14] [WebCite Cache ID 6tSnGTj4g]
10. Pirkis J, Blood R, Dare A, Holland K. Mindframe-media. 2008. The media monitoring project: changes in media reporting of suicide and mental illness in Australia: 2000/01–2006/07 URL: http://www.mindframe-media.info/_data/assets/pdf_file/0018/5166/Pirkis,Blood,Dare-and-Holland,-2008-MediaMonitoringProject.pdf [accessed 2017-09-14] [WebCite Cache ID 6tSnOhxjP]
11. Luxton DD, June JD, Fairall JM. Social media and suicide: a public health perspective. *Am J Public Health* 2012 May;102(Suppl 2):S195-S200. [doi: [10.2105/AJPH.2011.300608](https://doi.org/10.2105/AJPH.2011.300608)] [Medline: [22401525](https://pubmed.ncbi.nlm.nih.gov/22401525/)]
12. Maloney J, Pfuhmann B, Arensman E, Coffey C, Gusmão R, Poštuvan V, et al. How to adjust media recommendations on reporting suicidal behavior to new media developments. *Arch Suicide Res* 2014;18(2):156-169. [doi: [10.1080/13811118.2013.824833](https://doi.org/10.1080/13811118.2013.824833)] [Medline: [24627947](https://pubmed.ncbi.nlm.nih.gov/24627947/)]
13. Robinson J, Cox G, Bailey E, Hetrick S, Rodrigues M, Fisher S, et al. Social media and suicide prevention: a systematic review. *Early Interv Psychiatry* 2015 Feb 19;10(2):103-121. [doi: [10.1111/eip.12229](https://doi.org/10.1111/eip.12229)] [Medline: [25702826](https://pubmed.ncbi.nlm.nih.gov/25702826/)]
14. Daine K, Hawton K, Singaravelu V, Stewart A, Simkin S, Montgomery P. The power of the web: a systematic review of studies of the influence of the internet on self-harm and suicide in young people. *PLoS One* 2013;8(10):e77555 [FREE Full text] [doi: [10.1371/journal.pone.0077555](https://doi.org/10.1371/journal.pone.0077555)] [Medline: [24204868](https://pubmed.ncbi.nlm.nih.gov/24204868/)]
15. Mehlum L. The internet, suicide, and suicide prevention. *Crisis* 2000;21(4):186-188. [doi: [10.1027//0227-5910.21.4.186](https://doi.org/10.1027//0227-5910.21.4.186)] [Medline: [11419530](https://pubmed.ncbi.nlm.nih.gov/11419530/)]
16. Biddle L, Donovan J, Hawton K, Kapur N, Gunnell D. Suicide and the internet. *BMJ* 2008 Apr 12;336(7648):800-802 [FREE Full text] [doi: [10.1136/bmj.39525.442674.AD](https://doi.org/10.1136/bmj.39525.442674.AD)] [Medline: [18403541](https://pubmed.ncbi.nlm.nih.gov/18403541/)]
17. Mishara BL, Weisstub DN. Ethical, legal, and practical issues in the control and regulation of suicide promotion and assistance over the internet. *Suicide Life Threat Behav* 2007 Feb;37(1):58-65. [doi: [10.1521/suli.2007.37.1.58](https://doi.org/10.1521/suli.2007.37.1.58)] [Medline: [17397280](https://pubmed.ncbi.nlm.nih.gov/17397280/)]
18. Robinson J, Bailey E, Browne V, Cox G, Hooper C. Orygen. 2016. Raising the bar for youth suicide prevention URL: <https://www.orygen.org.au/Policy-Advocacy/Policy-Reports/Raising-the-bar-for-youth-suicide-prevention> [accessed 2017-09-14] [WebCite Cache ID 6tSolzyTj]
19. Torok M, Cleave A, Shand F, Christensen H. A Systematic Review of Mass Media Campaigns for Suicide Prevention: Understanding Their Efficacy and the Mechanisms Needed for Successful Behavioral and Literacy Change. *Suicide Life Threat Behav* 2017 Jan 03;- Epub ahead of print. [doi: [10.1111/sltb.12324](https://doi.org/10.1111/sltb.12324)]
20. Pirkis J, Rossetto A, Nicholas A, Ftanou M. Advancing knowledge about suicide prevention media campaigns. *Crisis* 2016 Sep;37(5):319-322. [doi: [10.1027/0227-5910/a000441](https://doi.org/10.1027/0227-5910/a000441)] [Medline: [27868447](https://pubmed.ncbi.nlm.nih.gov/27868447/)]
21. Jenner E, Jenner LW, Matthews-Sterling M, Butts JK, Williams TE. Awareness effects of a youth suicide prevention media campaign in Louisiana. *Suicide Life Threat Behav* 2010 Aug;40(4):394-406. [doi: [10.1521/suli.2010.40.4.394](https://doi.org/10.1521/suli.2010.40.4.394)] [Medline: [20822366](https://pubmed.ncbi.nlm.nih.gov/20822366/)]
22. Klimes-Dougan B, Lee CS. Suicide prevention public service announcements: perceptions of young adults. *Crisis* 2010;31(5):247-254. [doi: [10.1027/0227-5910/a000032](https://doi.org/10.1027/0227-5910/a000032)] [Medline: [21134844](https://pubmed.ncbi.nlm.nih.gov/21134844/)]
23. Klimes-Dougan B, Yuan C, Lee S, Houry AK. Suicide prevention with adolescents. *Crisis* 2009 May;30(3):128-135. [doi: [10.1027/0227-5910.30.3.128](https://doi.org/10.1027/0227-5910.30.3.128)]
24. Ftanou M, Cox G, Nicholas A, Spittal MJ, Machlin A, Robinson J, et al. Suicide prevention public service announcements (PSAs): examples from around the world. *Health Commun* 2017 Apr;32(4):493-501. [doi: [10.1080/10410236.2016.1140269](https://doi.org/10.1080/10410236.2016.1140269)] [Medline: [27308843](https://pubmed.ncbi.nlm.nih.gov/27308843/)]
25. Acosta J, Ramchand R, Becker A. Best practices for suicide prevention messaging and evaluating california's "know the signs" media campaign. *Crisis* 2017:1-13 Epub ahead of print. [doi: [10.1027/0227-5910/a000446](https://doi.org/10.1027/0227-5910/a000446)] [Medline: [28228062](https://pubmed.ncbi.nlm.nih.gov/28228062/)]
26. Hagan P, Collins P, Metcalf A, Nicholas M, Rahilly K, Swainston N. Westernsydney. 2012. Participatory design of evidence-based online youth mental health promotion, intervention and treatment: a Young and Well Cooperative Research Centre innovative methodologies guide URL: https://www.westernsydney.edu.au/_data/assets/pdf_file/0005/476330/Young_and_Well_CRC_IM_PD_Guide.pdf [accessed 2017-09-14] [WebCite Cache ID 6tSouwK3t]
27. Rickwood D, Deane FP, Wilson CJ, Ciarrochi J. Young people's help-seeking for mental health problems. *Adv Mental Health* 2005 Dec;4(3):218-251. [doi: [10.5172/jamh.4.3.218](https://doi.org/10.5172/jamh.4.3.218)]
28. Rickwood DJ, Deane FP, Wilson CJ. When and how do young people seek professional help for mental health problems? *Med J Aust* 2007 Oct 1;187(7 Suppl):S35-S39. [Medline: [17908023](https://pubmed.ncbi.nlm.nih.gov/17908023/)]
29. Sundram F, Hawken SJ, Stasiak K, Lucassen MF, Fleming T, Shepherd M, et al. Tips and traps: lessons from codesigning a clinician e-monitoring tool for computerized cognitive behavioral therapy. *JMIR Ment Health* 2017 Jan 11;4(1):e3 [FREE Full text] [doi: [10.2196/mental.5878](https://doi.org/10.2196/mental.5878)] [Medline: [28077345](https://pubmed.ncbi.nlm.nih.gov/28077345/)]
30. Wadley G, Lederman R, Gleeson J, Alvarez-Jimenez M. Participatory design of an online therapy for youth mental health. 2013 Presented at: Proceedings of the 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration; November 25-29, 2013; Adelaide, Australia p. 517-526. [doi: [10.1145/2541016.2541030](https://doi.org/10.1145/2541016.2541030)]

31. Sisask M, Värnik A. Media roles in suicide prevention: a systematic review. *IJERPH* 2012;9(12):123-138. [doi: [10.3390/ijerph9010123](https://doi.org/10.3390/ijerph9010123)]
32. Leonard EC. Confidential death to prevent suicidal contagion: an accepted, but never implemented, nineteenth-century idea. *Suicide Life Threat Behav* 2001;31(4):460-466. [Medline: [11775721](https://pubmed.ncbi.nlm.nih.gov/11775721/)]
33. Skehan J, Greenhalgh S, Hazell T, Pirkis J. Reach, awareness and uptake of media guidelines for reporting suicide and mental illness: an Australian perspective. *Int J Ment Health Promot* 2012 Jan 30;8(4):29-35. [doi: [10.1080/14623730.2006.9721749](https://doi.org/10.1080/14623730.2006.9721749)] [Medline: [26281194](https://pubmed.ncbi.nlm.nih.gov/26281194/)]
34. Bloggingonsuicide. 2017. Recommendations for blogging on suicide URL: <http://www.bloggingonsuicide.org/> [accessed 2017-02-28] [WebCite Cache ID 6obRie22r]
35. Mindframe-media. 2014. Tips for social media content: communicating suicide and mental illness URL: http://www.mindframe-media.info/data/assets/pdf_file/0014/5171/Tips-for-Social-Media-content.pdf [accessed 2017-09-14] [WebCite Cache ID 6tSqD4fzJ]
36. Pirkis J, Mok K, Robinson J, Nordentoft M. Media influences on suicidal thoughts and behaviours. In: O'Connor RC, Pirkis J, editors. *International Handbook of Suicide Prevention*. Chichester: Wiley-Blackwell; 2016.
37. Shaffer D, Gould M. Suicide prevention in schools. In: Hawton K, Van Heeringen K, editors. *The International Handbook of Suicide and Attempted Suicide*. Chichester, UK: Wiley; 2000.
38. Bailey E, Spittal M, Pirkis J, Gould M, Robinson J. Universal suicide prevention in young people: an evaluation of the safeTALK program in Australian high schools. *Crisis* 2017;1-9 Epub ahead of print. [doi: [10.1027/0227-5910/a000465](https://doi.org/10.1027/0227-5910/a000465)]
39. Robinson J, Rodrigues M, Fisher S, Bailey E, Herrman H. Social media and suicide prevention: findings from a stakeholder survey. *Shanghai Arch Psychiatry* 2015 Feb 25;27(1):27-35 [FREE Full text] [doi: [10.11919/j.issn.1002-0829.214133](https://doi.org/10.11919/j.issn.1002-0829.214133)] [Medline: [25852253](https://pubmed.ncbi.nlm.nih.gov/25852253/)]
40. Wilson CJ, Deane FP, Ciarrochi J, Rickwood D. Measuring help-seeking intentions: properties of the general help seeking questionnaire. *Can J Couns* 2007;39(1):15-28.
41. Greidanus E, Everall RD. Helper therapy in an online suicide prevention community. *Brit J Guid Couns* 2010 May;38(2):191-204. [doi: [10.1080/03069881003600991](https://doi.org/10.1080/03069881003600991)]
42. Lehavot K, Ben-Zeev D, Neville RE. Ethical considerations and social media: a case of suicidal postings on facebook. *J Dual Diagn* 2012 Nov;8(4):341-346. [doi: [10.1080/15504263.2012.718928](https://doi.org/10.1080/15504263.2012.718928)]
43. Borzekowski DL, Rickert VI. Adolescent cybersurfing for health information: a new resource that crosses barriers. *Arch Pediatr Adolesc Med* 2001 Jul;155(7):813-817. [Medline: [11434849](https://pubmed.ncbi.nlm.nih.gov/11434849/)]
44. Dunlop SM, More E, Romer D. Where do youth learn about suicides on the internet, and what influence does this have on suicidal ideation? *J Child Psychol Psychiatry* 2011 Oct;52(10):1073-1080. [doi: [10.1111/j.1469-7610.2011.02416.x](https://doi.org/10.1111/j.1469-7610.2011.02416.x)] [Medline: [21658185](https://pubmed.ncbi.nlm.nih.gov/21658185/)]

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Original Paper

#MyDepressionLooksLike: Examining Public Discourse About Depression on Twitter

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Abstract

Background: Social media provides a context for billions of users to connect, express sentiments, and provide in-the-moment status updates. Because Twitter users tend to tweet emotional updates from daily life, the platform provides unique insights into experiences of mental health problems. Depression is not only one of the most prevalent health conditions but also carries a social stigma. Yet, opening up about one's depression and seeking social support may provide relief from symptoms.

Objective: The aim of this study was to examine the public discourse of the trending hashtag #MyDepressionLooksLike to look more closely at how users talk about their depressive symptoms on Twitter.

Methods: We captured 3225 original content tweets for the hashtag #MyDepressionLooksLike that circulated in May of 2016. Eliminating public service announcements, spam, and tweets with links to pictures or videos resulted in a total of 1978 tweets. Using qualitative content analysis, we coded the tweets to detect themes.

Results: The content analysis revealed seven themes: dysfunctional thoughts, lifestyle challenges, social struggles, hiding behind a mask, apathy and sadness, suicidal thoughts and behaviors, and seeking relief.

Conclusions: The themes revealed important information about the content of the public messages that people share about depression on Twitter. More research is needed to understand the effects of the hashtag on increasing social support for users and reducing social stigma related to depression.

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KEYWORDS

social media; depression; community networks; social stigma

Introduction

Seven out of 10 Americans use social media to share personal information, engage with content, and connect with others [1]. One of the most popular platforms, Twitter, has over 313 million active users who produce 500 million tweets—140-character comments—each day [2,3]. Hashtags (ie, a word or phrase preceded by a # sign) are often used in tweets to signal a specific topic and link tweets together by topic, thereby facilitating the potential for dialogue on a topic. Twitter has become a valuable resource to study topics ranging from diurnal sleep patterns to dietary behavior and changes in mood [4-6]. Twitter users

commonly tweet in-the-moment experiences of daily life, with one of the most common topics consisting of emotional status updates, which may not be feasible to share in real-world, face-to-face settings [7]. Therefore, Twitter offers a unique data source for examining stigmatized topics such as mental health. Whereas researchers have only recently begun studying Twitter data, prior examinations of user- and investigator-initiated hashtags such as #Depression, #Schizophrenia, #DearMentalHealthProfessionals, and #WhyWeTweetMH [8-10] have already illustrated the value of doing so.

Depression is one of the most prevalent mental health issues and is a disorder well known to carry social stigma [11,12].

Individuals with depression are more likely to become socially isolated and less likely to seek help [12,13]. Social rejection-related stressors are significantly linked to the cognitive, emotional, and biological changes that lead to depression [14]. Fearing social interactions may lead to loneliness, which is also a risk factor for depression [15]. In one study, individuals who reported more social and emotional support were 87% less likely to report recurrent depression [16]. Connection through engaging in a Web-based community such as Twitter may foster social support among those experiencing depression, as well as provide a potential resource for relief. Sharing or engaging with others online may buffer the fear of in-person social interaction and provide a platform for normalizing the discussion about this prevalent mental health issue.

Prior research indicates that social media can provide a supportive environment for talking about depression [17]. An analysis of responses to an investigator-initiated Twitter hashtag intended to ask users why they tweet about their mental health found that users primarily post about their mental health to seek connection with other users [8]. In one study, Facebook users who received online reinforcement from friends about a post that indicated depressive symptoms were subsequently more likely to discuss symptoms outwardly on Facebook [18]. Further, having at least one characteristic in common, such as depression, can foster a sense of community between members in a Web-based group [19]. Although social media can provide a supportive environment, it may also have deleterious effects. Social media can become a modality fraught with negative social comparison, jealousy, and comment wars, which can decrease quality of life [20-24]. Studies have found associations between social media use and depression [25,26], social isolation and loneliness [27], poorer sleep quality and lower self-esteem [28]. In one study examining the relationship between social media use and mood and personality disorders, those who spent more time on Facebook were more likely to have clinical symptoms of depression [29].

Many of the previous studies of depression-related social media content have relied heavily on Facebook [18,23,29,30], whereas fewer have studied Twitter content [9,10]. However, findings indicate that there are key differences between the two platforms that lead to uniquely different content. Twitter users frequently use pseudonyms and are more likely to be connected with users they have never met in person, offering users a more anonymous way to communicate. Studying discourse on Twitter may provide a less biased account of individuals' experiences, as it is naturalistic, contains a broad population of people who may not frequently participate in research, and is often anonymous, thus overcoming some limitations of traditional data collection methods.

Given the potential for understanding stigmatizing disorders through Twitter [30], it is imperative to look more closely at the discourse on Twitter about mental health. To start with, studies are needed that qualitatively examine how those with depression talk about their symptoms online. As May is mental health month, several hashtags on mental health such as #MyDepressionLooksLike, #MyAnxietyLooksLike, and #MyMentalIllnessFeelsLike trended in May of 2016. The

hashtag #MyDepressionLooksLike caught the attention of popular news sites, such as the *Huffington Post*, *ABC news*, *US News* and *World Report*, *NY Magazine*, *Teen Vogue*, and *Cosmopolitan*, and attracted users. In the first known study of this hashtag, we analyzed tweets from #MyDepressionLooksLike using a content analysis approach, to answer the following research question: how do people talk about their experiences of depression on Twitter using the hashtag #MyDepressionLooksLike?

Methods

To improve our understanding of discourse on social media about depression and public communication of symptomology, we downloaded tweets using the hashtag #MyDepressionLooksLike from the social networking site Twitter. We used NCapture, an addition to the qualitative analysis NVivo software (QSR International), to collect tweets. NCapture allowed for reliable access to Twitter's public streaming application programming interface (API) [31] and retrieved a 10% random sample from Twitter's public content. Data collection spanned 1 week, from Wednesday, May 25, 2016 to Wednesday, June 1, 2016. Data were not collected over Memorial Day weekend, as the holiday would skew regular computer use. Data were captured at approximately 10:00 AM Eastern Standard Time each weekday. Out of a total of 11,178 tweets that were captured, 9237 were retweets. For this sample, we restricted analysis to the 3225 original content tweets. Each observation included the following: username, number of followers, number following, tweet ID (a number assigned to the tweet by Twitter's API), text of tweet, date and time tweeted, tweet URL, and latitude-longitude data of each Internet Protocol address. Only tweets that directly referenced #MyDepressionLooksLike were included in this analysis. Although tweets often included pictures, only text was included in the final dataset. Tweets without relevance were removed from this dataset [32]. Content was limited to English-language tweets. After eliminating public service announcements, spam, and tweets with links to pictures or videos, our final dataset included 1978 tweets.

As Twitter provides a public platform for users to interface, is widely accessible, and is among the most used social media sites, *tweets should be considered public conversation* [32]. Furthermore, the anonymity allowed by Twitter, in combination with the creation of virtual communities and simulated social interaction, makes Twitter an optimal setting to examine the effects of anonymity on public discourse surrounding mental health, patient needs, and symptomology. Researchers Bruckman [33] and Whitehead [34] establish that this analysis meets the standards to waive informed consent and similar guidelines, based on the public nature of Twitter content. It is important to note that tweets can only be captured if the Twitter user's profile is set to public, thus protecting those who have private profiles from being subject to research studies. This study was approved by the (university name blinded for review) institutional review board.

Analysis

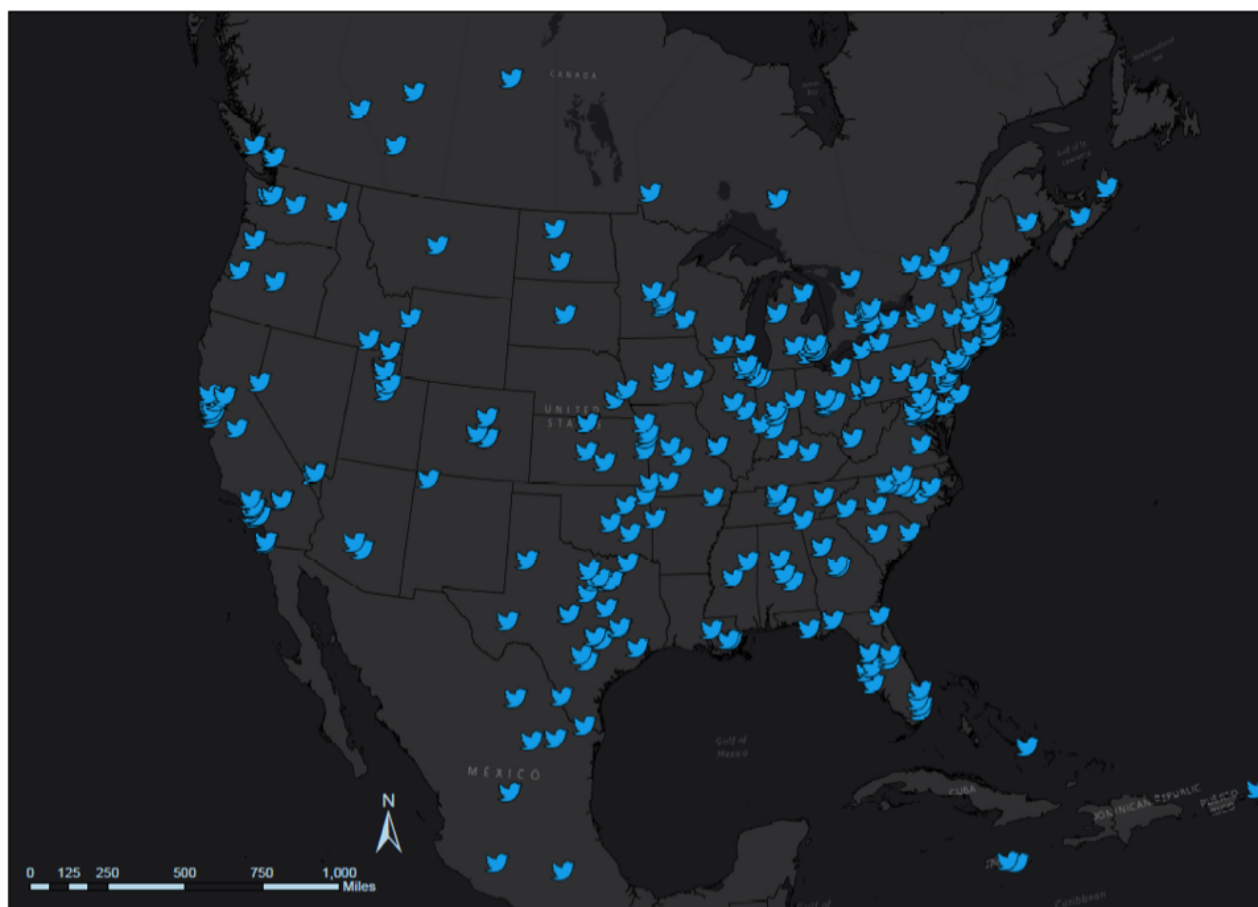
Data were imported into NVivo and analyzed by the first 2 authors using qualitative content analysis methods. Both coders have expertise in clinical depression. Content analysis is a systematic method for making inferences from text to summarize the content of communication [35]. In this study, an inductive open coding approach was used to allow themes to be generated directly from the data [36]. The 2 independent researchers read the first 10% of the tweets to become familiar with the content. Then, each researcher independently categorized each of the first 10% of the tweets into codes and subcodes, as is common in sensitizing concepts of qualitative research [37]. The researchers met to compare codes and to establish consensus on the definition of each code. All 1978 tweets were then read independently by each researcher and sorted into the defined codes, a process designed to establish trustworthiness and credibility and to consider whether new codes emerged in the remaining tweets [35]. The coders then discussed the coding of each tweet until consensus was reached. No new themes emerged when the full dataset was coded. In some cases, tweets fit into more than one theme. In these cases, we either chose the theme most fitting or coded the tweet for more than one theme. The codebook is available from researchers upon request.

Twitter Users

Although we were unable to gather demographic data from the Twitter users, we were aware of what Twitter users look like in general. Twitter users are vastly more overrepresented in populous counties, according to a study that compared Twitter users to the US Census data [38]. The proportion of men and women who use Twitter is roughly equivalent [39]. Twitter users tend to be younger than 50 years and have a college education [40]. Trends also indicate a higher rate in the number of users who earn high incomes and identify as white [39,40].

Although the majority of Twitter users live in urban areas, Web-based communities may be particularly useful in rural communities for those experiencing health symptoms that carry stigma [41]. In this context, rural social media users are more frequently the recipients of support regarding health topics, whereas urban users are providers of social support [41]. In this study, we were able to obtain geotags of users, which included the latitude-longitude location of the user at the time they tweeted. We used this information to assess the geographic location of the sample. We used the geotag instead of the profile location because about 34% of Twitter users enter fake locations in their profile [42]. An image of the geographic location of tweets can be seen in Figure 1. The majority of tweets in the final dataset came from North America; therefore, only those are shown in the figure.

Figure 1. Map of Twitter icons representing tweet locations of users.



Service Layer Credits: Esri, HERE, DeLorme, MapmyIndia, © OpenStreetMap contributors, and the GIS user

Results

Seven themes emerged from the #MyDepressionLooksLike Twitter data: dysfunctional thoughts, lifestyle challenges, social struggles, hiding behind a mask, apathy and sadness, suicidal thoughts and behaviors, and seeking relief. See Table 1 for an overview.

Theme 1: Dysfunctional Thoughts

Tweets in this theme described distorted and dysfunctional cognitions (n=498 tweets) and included negative thoughts about self; perceptions that feelings of depression are invalid; feeling unlovable, hopeless, helpless, and invisible; as well as putting others' needs before their own. Some Twitter users described difficulty with their own thoughts:

*I can't bear to lie awake with my thoughts.
...being unable to enjoy alone time, because the inside of my head is too dark of a place.*

Tweets also revealed negative views about oneself such as:

*...standing in the mirror and repeating "I hate myself" every other week.
...a punch to the gut that makes me curl up in bed because I'm a worthless and disgusting trash excuse for a human.*

Many tweets described these negative views of oneself in the form of anger at themselves, as described by one user:

...incredible anger, self-loathing and unfounded guilt, every morning I wake up.

Twitter users also questioned their own feelings of depression:

...feeling like I shouldn't be depressed bc I have lots of good things in life that I should be happy about.

These negative views about oneself also transferred to views of feeling unlovable by others, as described in the following tweets:

*...thinking that everyone hates me, even my friends/family/partner.
...a huge black cloud, drowning, sinking, hopeless. Demons pulling me under. Whispering "just give up, no one loves you."
...thinking everyone hates me/has a grudge against me when I haven't done anything to them.*

Along with negative views of oneself, hopelessness and helplessness also satiated this theme:

*...feeling stuck all the time.
...no options, no choices and no escape.
...internally drowning while everyone else seems to be staying afloat.*

Feelings of being invisible also came through in many of the tweets in this category, such as when one Twitter user stated:

...invisible. It's there but nobody can see.

Finally, putting others' needs above their own arose throughout the content of this theme, as is described in the following tweet:

...constantly helping people out of their problems and never being able to help myself.

Theme 2: Lifestyle Challenges

In addition to difficult thoughts and perceptions, lifestyle challenges were often mentioned (n=416 tweets). In this theme, Twitter users described problems with motivation, eating, sleeping, and other daily tasks. A large portion of the tweets in this category revealed difficulty with motivation:

*...wanting change but having no motivation to make a change.
...having no motivation to do absolutely anything.*

Table 1. MyDepressionLooksLike themes and descriptions.

Theme	Description	Sample tweet	Number of tweets
Dysfunctional thoughts	Thoughts about self that are negative, hopelessness, feeling invisible, and unlovable	<i>feeling eternally unloveable and hopeless</i>	498
Lifestyle challenges	Difficulty with eating, sleeping, motivation, and daily tasks	<i>staying in bed at all times because I've lost all motivation to do anything</i>	416
Social struggles	Struggling in social relationships, isolation, loneliness, and feeling like a burden to others	<i>isolating myself, then getting upset over being lonely. Constantly feeling like I'm annoying or a burden to everyone</i>	433
Hiding behind a mask	Pretending to be okay in front of others to hide the reality of one's depression	<i>a big smile that I wear everyday to hide the sad thoughts inside my head</i>	236
Apathy and sadness	Expressions of sadness and emptiness	<i>crying for no reason</i>	149
Suicidal thoughts and behaviors	Descriptions of self-harm and thoughts of death	<i>No interest in being awake. There is nothing in me that enjoys being alive. If given an option I'd choose death.</i>	110
Seeking relief	Both positive and negative means to alleviate the depression; descriptions of self-care as well as coping mechanisms such as alcohol and drugs	<i>Smiling big & drinking & smoking my problems away to feel numb to the pain something I manage with therapy, medication, good habits, and exercise. You can too.</i>	136

A significant number of Twitter users described difficulty getting out of bed:

...being so mentally exhausted that it turns into physical exhaustion and I literally can't get out of bed.

...not being able to make it out of the house the entire weekend because leaving bed is an impossible feat.

I think I just spent 36 straight hours in bed.

Parallel to being unable to get out of bed, respondents to the hashtag described a feeling of exhaustion:

Tiredness that is far deeper than muscle fatigue. It's like my very soul is exhausted.

...being so heavily exhausted that I can't even take care of myself or anyone/anything else.

Regarding sleeping and eating, users posted the following tweets:

...having no appetite for days on end, constantly hearing "you need to eat" and no one understanding that I can't.

...being constantly dehydrated because I can't even get out of bed to get a glass of water.

This also included aspects of hygiene and a lack of self-care:

...not remembering the last time I showered and not caring...being called gross when I tell someone.

Other daily tasks were described as being affected, as described in the following tweets:

...mold growing on dozens of dishes by my bed, not doing laundry for months.

Trouble with school and work was another aspect of this theme:

...a constant fear of failing school #mydepressionlooklike not having any motivation to get my work done.

...my boss telling me I'm not the same person he hired because my happiness is affected (sic) my work.

Theme 3: Social Struggles

Twitter users reported difficulty with social relationships (n=433 tweets). One Twitter user described it as pushing others away, longing for connection, loneliness, isolation, and feeling like a burden to others. Respondents to the hashtag revealed overall difficulty with social relationships:

...pressing the self-destruct button on relationships because I can't figure out a way to sustain them.

When describing their social struggles, users often expressed conflicted feelings and behaviors such as wanting closeness but instead pushing loved ones away. One user described this as:

...wanting to just have someone hold me and say it's ok just one time. But instead yelling at anyone who touches me.

Another Twitter user vividly painted this picture:

...screaming inside—"don't leave me alone" while simultaneously saying "I'll be fine."

This often revealed an underlying fear of judgment from others:

...pushing anyone and everyone away because being alone is the only guarantee of a judgment free space.

In addition to fear of judgment, fear of reaching out and asking for help also came up frequently throughout this theme:

...being scared to reach out to others because how can you make others happy when you can't even make yourself happy?

These difficulties with social relationships also lead to feelings of isolation and loneliness, as described in the following tweets:

...alienation and feeling so alone in the world that I have no one to talk to.

...feeling disconnected from everyone and everything you ever liked doing while aching for love and belonging.

Often this was something Twitter users seemed to describe as purposefully doing, as described below:

...literally dropping all my friends for months, showing up to school every day in sweats/a hoodie not talking to nobody.

...distancing myself from everyone I love.

Users also described feeling like a burden:

...wanting to socialize and then telling the person I don't want to see them cause (sic) I feel like a burden.

Respondents to the hashtag also described anger at others in their social relationships:

...anger an outburst because I keep everything inside I can't trust anyone with my feelings.

Theme 4: Hiding Behind a Mask

Descriptions of depression were also revealed as being hidden by putting on a mask (n=236 tweets). In this manner, Twitter users described hiding behind a mask to hide the reality of their depression:

always faking a smile and acting like everything is fine when it's not.

Some respondents to the hashtag described being so good at hiding their depression that they were able to keep it a secret for a long time:

...wouldn't even know I've been battling it for 5 years cause I'm so good at hiding it.

...cause I'd rather put a mask on than let people in to see how vulnerable or broken I am.

This illustrates why Twitter users may feel they need to put on a mask. In addition, Twitter users revealed other reasons, such as:

...a smile to avoid the "what's wrong" questions.

The tweets in this category also described smiling, laughing, and joking in an effort to mask their depression, as described in the following tweets:

...covered up by a big smile and funny jokes only if they knew about the emptiness within.

...me always joking and laughing to cover up the hurt and suffering that is imbedded within my spirit.

Theme 5: Apathy and Sadness

Twitter users described symptoms of crying spells and overall sadness and apathy (n=149 tweets). This theme described these emotional effects of what depression looks like. Tweets revealed crying spells and tearfulness. Many tweets described crying when alone:

tears begin to flow when I'm by myself.

Crying seemed to be described consistently throughout this theme:

...crying, crying, crying...oh did I forget to mention crying over EVERYTHING b/c every little thing cuts so much deeper.

Another tweet provides an example of feeling down:

...a "case of the Mondays"; always lurking, waiting to sneak up on me the minute I let my guard down.

In addition to sadness, feelings of emptiness and apathy were also included in this #MyDepressionLooksLike theme. Users tweeted about what depression looks like, describing it as follows:

...a hole carved into my chest and have nothing to fill that inner emptiness.

...feeling completely numb and emotionless.

A sense of the loss of emotion is also included in this emptiness, as indicated by the following tweet:

...the loss of all my former passion and hope.

Theme 6: Self-Harm and Suicidal Behaviors

Tweets also described self-harm and suicide (n=110 tweets). One individual described self-harm as:

...taking a blade to my skin just to have some sort of evidence of the pain I hold locked up inside.

This way of revealing emotional pain through self-harm was evidenced by another similar tweet:

...lines carved into my skin, to make emotional pain physical, visible.

One Twitter user described the self-harm of depression as:

...long sleeves in the summer time, people staring at my arms and wondering if it's contagious.

Thoughts of death also persisted throughout this category of tweets, as evident in the following:

...wanting to die 24/7.

...re-editing the same old suicide note.

Wishing for death was another way suicide crept up into these tweets:

...my bed in the darkness with nothing but my thoughts slowly killing me, hoping they will.

Wishing I was in heaven now. Not wanting to live anymore.

Theme 7: Seeking Relief

Many users described ways to find relief from their depression (n=136 tweets). This included both positive and negative means to alleviate depression, such as descriptions of self-care as well as adverse coping mechanisms such as alcohol and drugs. Finding a way to relieve symptoms, such as receiving professional services, was also an aspect of the tweets in this theme. Negative means to alleviate depression were expressed in the following tweets:

...trying to be productive but watching 5 hours of Netflix (sic) in bed—just so my mind turns off.

...a lot of shopping bags in my closet. I would rather shop the pain away than talk about it.

Other forms of adverse coping skills included alcohol and drugs, as expressed in the following tweet:

...excessive drinking and sleeping because reality sucks.

Medications were also described frequently throughout this theme, as expressed in the tweets below:

...the little green pill that somehow helps me get through every day. For you it's just life, for me it's a mission.

...7 medications a day.

In terms of more positive, hopeful ways of seeking relief, one Twitter user described:

And the power of prayer really helped myself to direct my energy towards a calmer path.

Another person tweeted that #MyDepressionLooksLike:

...a child I need to take care of daily—it's a part of me so I show myself love and kindness, even on the hardest days.

Discussion

Principal Findings

Tweets in response to the hashtag #MyDepressionLooksLike saturated various themes describing the inner world of individuals with depression. These themes reveal important information about how people talk about their experiences of depression on Twitter. Some of this included cognitive, lifestyle, and social implications of depression, as well as hiding the reality of it, experiencing sadness, seeking relief, and suicidal thoughts and behaviors.

The themes of this study reflect previous findings on depression. The theme, *dysfunctional thoughts*, included tweets that displayed users' difficulty with thoughts, such as feeling hopeless and unlovable. Prior literature reveals similar findings, such that people with depression have greater rumination in association with negative material [43,44]. The theme *lifestyle problems* revealed Twitter users' difficulty with daily activities such as eating, sleeping, exercising, working, and overall motivation. Problems with motivation have also been seen in

the literature on depression, such that lack of motivation is considered the number one barrier to employment in adults with a major thought or affective disorder [45]. The *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5) lists dysfunctional thoughts and lifestyle problems as symptoms of major depressive disorder (MDD) [13]. Interestingly, engaging on a social media platform such as Twitter may require less energy to connect with others compared with engaging face-to-face. Social media has also been found as a motivator of and barrier to exercise and an influencer of food choices and eating habits [46]. This makes the idea of depression and social media a two-sided coin, creating an easier environment to receive support but also potentially creating barriers to a healthy lifestyle.

In another example, tweets in the social struggles theme often displayed content steeped in isolation, pushing others away, but simultaneously wanting to be close to people. Users also described feeling like a burden, which has been indicated in prior literature [47]. Individuals who feel they are a burden to their family and friends may be more willing to disclose symptoms on an online platform in which they are more anonymous as opposed to Facebook where followers are often your real-world friends [48]. Research indicates that Twitter users are able to talk about mental health openly because they do not fear being judged and are able to vent and feel heard [8]. However, because of the format of Twitter, such as the character limit for tweets, it is possible that it may result in less ability to provide or receive social support compared with other social media outlets. Additionally, sharing negative tweets may lead to co-rumination among users [49]. These online social relationships may replicate in-person relationships with others, providing a much needed connection for those with depression [17]. People with depression or poorer mental health tend to use social media for more social support and emotional connection as opposed to individuals without depression who use it for information sharing [48,50]. It is also unclear whether social connections on Twitter result in the same sense of burden as compared with real-life social ties and how this could influence online communication [47].

Users also tweeted about self-harm and suicidal thoughts and behaviors, paralleling DSM-5 symptoms of MDD [13]. In a previous systematic review of young people using social media for discussing self-harm, the findings suggest that users were supported in the Web-based setting [51]. However, suicide and social media have gained increased attention as news reports reveal harrowing incidents of individuals live streaming their own suicide on sites such as Facebook [52]. Facebook has since initiated a suicide prevention page that offers live-chat support from mental health providers and is testing a suicide program that would use artificial intelligence methods to identify potential suicide or self-injury posts [53,54]. It may be difficult for social media sites to keep up with hashtags because of their ability to generate so much attention in such a short period, making it impossible for self-harm or suicide prevention to adequately take place [55]. However, a Twitter-specific suicide prevention app called the Samaritans Radar designed to detect users who may need help was closed shortly after launching because of vulnerability of those with mental health, including

opening this information up to cyber bullies [56]. These prevention attempts reveal potential avenues and controversies of providing support for self-harm and suicide in a Web-based community format. This is particularly important because of the evidence of suicide contagion, in which watching or hearing about suicide increases the likelihood of others engaging in suicidal behaviors [57,58]. Detecting concerns of suicide on Twitter in research raises important ethical questions. Twitter users do not consent to participate and are difficult or impossible to locate, making traditional means of disclosing risk unviable. This is an unresolved ethical dilemma that will need to be addressed as research of Twitter data continues.

Along with potentially providing support, social media platforms can provide guidance for self-management of health problems such as depression [17]. Twitter users may be posting on this hashtag to seek relief from symptoms. In addition to data provided in the description of the seeking relief theme, Twitter users shared information about exploratory treatments undergoing testing, including messages about the magic mushroom compound [59]. Interestingly, research reveals that online community users expect to receive more support than they are willing to provide [60,61]. This may mean their use of social media is a form of seeking relief in the first place. Literature also suggests that the emotional and instrumental support these communities provide actually influences patients' health states, such as improving from poor to fair outcomes [17]. It may also be that users benefit from sharing mental health experiences online in general, as well as communicating with other users about their experiences. However, in this study, we were unable to analyze these constructs.

Limitations

Information such as sex, age, relationship status, occupation, socioeconomic status, race, or religion of users was not available, which prevented researchers from drawing study conclusions based on sample characteristics. Furthermore, we were unable to gather information about the potential dialogue occurring between Twitter users, such as retweets and comments, because these retweets often did not include the original hashtag, making them difficult to capture. It is important to note that our sample did not include all tweets associated with the hashtag, making it possible that our data could miss other themes. It is also possible that the brief nature of tweets—140 characters—may limit what we understand about users' experiences. Finally, posts for the specific hashtag #MyDepressionLooksLike may represent a biased population of Twitter users, such as only those who identify with depression.

Future Directions

Our study examined the public discourse of depression and depression symptoms on Twitter. Given the role that social support and isolation play in depression and that Twitter removes some barriers for individuals with depression to connect with others, future research is needed to understand the public conversations Twitter users have with one another when users share about their struggles and methods for coping. Given the mixed findings on the effects of social media use, it is also possible that there are deleterious effects of using Twitter to

connect on sensitive topics such as depression. It would be useful to understand the benefits and consequences of engaging with the Twitter platform regarding mental health problems. Finally, more research is needed to understand how users' posts

about their depression affect their real-world relationships, given the benefits or consequences this could have for one's course of illness.

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Conflicts of Interest

None declared.

References

1. Pew Research Center. 2017. Social media facts sheet URL: <http://www.pewinternet.org/fact-sheet/social-media/> [accessed 2017-06-02] [WebCite Cache ID 6qvDCQsVB]
2. Internet Live Stats. 2017. Twitter usage statistics URL: <http://www.internetlivestats.com/twitter-statistics/> [accessed 2017-06-02] [WebCite Cache ID 6qvD6T535]
3. Twitter. 2017. Twitter usage/company facts URL: <https://about.twitter.com/company> [accessed 2017-06-02] [WebCite Cache ID 6qvDVODGy]
4. Grinberg N, Naaman M, Shaw B, Lotan G. Semantic Scholar. 2013. Extracting diurnal patterns of real world activity from social media URL: <https://pdfs.semanticscholar.org/64cb/361bfeff6f71f00ee8df4f8da07ae48503fa.pdf> [accessed 2017-09-29] [WebCite Cache ID 6tpeL6e2q]
5. Hingle M, Yoon D, Fowler J, Kobourov S, Schneider ML, Falk D, et al. Collection and visualization of dietary behavior and reasons for eating using Twitter. *J Med Internet Res* 2013;15(6):e125 [FREE Full text] [doi: [10.2196/jmir.2613](https://doi.org/10.2196/jmir.2613)] [Medline: [23796439](https://pubmed.ncbi.nlm.nih.gov/23796439/)]
6. Lamos V, Lansdall-Welfare T, Araya R, Cristianini N. Arxiv. 2013. Analysing mood patterns in the United Kingdom through twitter content URL: <https://arxiv.org/abs/1304.5507> [accessed 2017-09-29] [WebCite Cache ID 6tpePT3mR]
7. Murthy D, Bowman S, Gross AJ, McGarry M. Do we tweet differently from our mobile devices? a study of language differences on mobile and web-based twitter platforms. *J Commun* 2015 Aug 25;65(5):816-837. [doi: [10.1111/jcom.12176](https://doi.org/10.1111/jcom.12176)]
8. Berry N, Lobban F, Belousov M, Emsley R, Nenadic G, Bucci S. #WhyWeTweetMH: Understanding why people use twitter to discuss mental health problems. *J Med Internet Res* 2017 Apr 05;19(4):e107 [FREE Full text] [doi: [10.2196/jmir.6173](https://doi.org/10.2196/jmir.6173)] [Medline: [28381392](https://pubmed.ncbi.nlm.nih.gov/28381392/)]
9. Reavley NJ, Pilkington PD. Use of twitter to monitor attitudes toward depression and schizophrenia: an exploratory study. *PeerJ* 2014;2:e647 [FREE Full text] [doi: [10.7717/peerj.647](https://doi.org/10.7717/peerj.647)] [Medline: [25374786](https://pubmed.ncbi.nlm.nih.gov/25374786/)]
10. Shepherd A, Sanders C, Doyle M, Shaw J. Using social media for support and feedback by mental health service users: thematic analysis of a twitter conversation. *BMC Psychiatry* 2015;15:29 [FREE Full text] [doi: [10.1186/s12888-015-0408-y](https://doi.org/10.1186/s12888-015-0408-y)] [Medline: [25881089](https://pubmed.ncbi.nlm.nih.gov/25881089/)]
11. Mathers C. The Global Burden of Disease: 2004 Update. Geneva: World Health Organization; 2008.
12. Barney LJ, Griffiths KM, Jorm AF, Christensen H. Stigma about depression and its impact on help-seeking intentions. *Aust N Z J Psychiatry* 2006 Jan;40(1):51-54. [doi: [10.1080/j.1440-1614.2006.01741.x](https://doi.org/10.1080/j.1440-1614.2006.01741.x)] [Medline: [16403038](https://pubmed.ncbi.nlm.nih.gov/16403038/)]
13. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders (DSM-5®). Arlington, VA: American Psychiatric Association; 2013.
14. Slavich GM, O'Donovan A, Epel ES, Kemeny ME. Black sheep get the blues: a psychobiological model of social rejection and depression. *Neurosci Biobehav Rev* 2010 Sep;35(1):39-45 [FREE Full text] [doi: [10.1016/j.neubiorev.2010.01.003](https://doi.org/10.1016/j.neubiorev.2010.01.003)] [Medline: [20083138](https://pubmed.ncbi.nlm.nih.gov/20083138/)]
15. Cacioppo JT, Hughes ME, Waite LJ, Hawkley LC, Thisted RA. Loneliness as a specific risk factor for depressive symptoms: cross-sectional and longitudinal analyses. *Psychol Aging* 2006 Mar;21(1):140-151. [doi: [10.1037/0882-7974.21.1.140](https://doi.org/10.1037/0882-7974.21.1.140)] [Medline: [16594799](https://pubmed.ncbi.nlm.nih.gov/16594799/)]
16. Brinker J, Cheruvu VK. Social and emotional support as a protective factor against current depression among individuals with adverse childhood experiences. *Prev Med Rep* 2017 Mar;5:127-133 [FREE Full text] [doi: [10.1016/j.pmedr.2016.11.018](https://doi.org/10.1016/j.pmedr.2016.11.018)] [Medline: [27981026](https://pubmed.ncbi.nlm.nih.gov/27981026/)]
17. Yan L, Tan Y. Feeling blue? go online: an empirical study of social support among patients. *Inf Syst Res* 2014 Dec;25(4):690-709. [doi: [10.1287/isre.2014.0538](https://doi.org/10.1287/isre.2014.0538)]
18. Moreno MA, Jelenchick LA, Egan KG, Cox E, Young H, Gannon KE, et al. Feeling bad on facebook: depression disclosures by college students on a social networking site. *Depress Anxiety* 2011 Jun;28(6):447-455 [FREE Full text] [doi: [10.1002/da.20805](https://doi.org/10.1002/da.20805)] [Medline: [21400639](https://pubmed.ncbi.nlm.nih.gov/21400639/)]
19. Schwämmlein E, Wodzicki K. What to tell about me? self-presentation in online communities. *J Comput-Mediat Comm* 2012 Sep 13;17(4):387-407. [doi: [10.1111/j.1083-6101.2012.01582.x](https://doi.org/10.1111/j.1083-6101.2012.01582.x)]

20. Fox J, Moreland JJ. The dark side of social networking sites: an exploration of the relational and psychological stressors associated with Facebook use and affordances. *Comput Human Behav* 2015 Apr;45:168-176. [doi: [10.1016/j.chb.2014.11.083](https://doi.org/10.1016/j.chb.2014.11.083)]
21. Chou HG, Edge N. "They are happier and having better lives than I am": the impact of using facebook on perceptions of others' lives. *Cyberpsychol Behav Soc Netw* 2012 Feb;15(2):117-121. [doi: [10.1089/cyber.2011.0324](https://doi.org/10.1089/cyber.2011.0324)] [Medline: [22165917](https://pubmed.ncbi.nlm.nih.gov/22165917/)]
22. de Vries DA, Kühne R. Facebook and self-perception: individual susceptibility to negative social comparison on Facebook. *Personal Individ Differ* 2015 Nov;86:217-221. [doi: [10.1016/j.paid.2015.05.029](https://doi.org/10.1016/j.paid.2015.05.029)]
23. Frison E, Eggermont S. Exploring the relationships between different types of facebook use, perceived online social support, and adolescents depressed mood. *Soc Sci Comput Rev* 2015 Jan 21;34(2):153-171. [doi: [10.1177/0894439314567449](https://doi.org/10.1177/0894439314567449)]
24. Radovic A, Gmelin T, Stein BD, Miller E. Depressed adolescents' positive and negative use of social media. *J Adolesc* 2017 Feb;55:5-15 [FREE Full text] [doi: [10.1016/j.adolescence.2016.12.002](https://doi.org/10.1016/j.adolescence.2016.12.002)] [Medline: [27997851](https://pubmed.ncbi.nlm.nih.gov/27997851/)]
25. Schou AC, Billieux J, Griffiths MD, Kuss DJ, Demetrovics Z, Mazzoni E, et al. The relationship between addictive use of social media and video games and symptoms of psychiatric disorders: A large-scale cross-sectional study. *Psychol Addict Behav* 2016 Mar;30(2):252-262. [doi: [10.1037/adb0000160](https://doi.org/10.1037/adb0000160)] [Medline: [26999354](https://pubmed.ncbi.nlm.nih.gov/26999354/)]
26. Lin LY, Sidani JE, Shensa A, Radovic A, Miller E, Colditz JB, et al. Association between social media use and depression among U.S. young adults. *Depress Anxiety* 2016 Apr;33(4):323-331. [doi: [10.1002/da.22466](https://doi.org/10.1002/da.22466)] [Medline: [26783723](https://pubmed.ncbi.nlm.nih.gov/26783723/)]
27. Yang C. Instagram use, loneliness, and social comparison orientation: interact and browse on social media, but don't compare. *Cyberpsychol Behav Soc Netw* 2016 Dec;19(12):703-708. [doi: [10.1089/cyber.2016.0201](https://doi.org/10.1089/cyber.2016.0201)]
28. Woods HC, Scott H. #Sleepyteens: social media use in adolescence is associated with poor sleep quality, anxiety, depression and low self-esteem. *J Adolesc* 2016 Dec;51:41-49. [doi: [10.1016/j.adolescence.2016.05.008](https://doi.org/10.1016/j.adolescence.2016.05.008)] [Medline: [27294324](https://pubmed.ncbi.nlm.nih.gov/27294324/)]
29. Rosen L, Whaling K, Rab S, Carrier L, Cheever N. Is facebook creating "iDisorders"? the link between clinical symptoms of psychiatric disorders and technology use, attitudes and anxiety. *Comput Human Behav* 2013 May;29(3):1243-1254. [doi: [10.1016/j.chb.2012.11.012](https://doi.org/10.1016/j.chb.2012.11.012)]
30. Jelenchick LA, Eickhoff JC, Moreno MA. "Facebook depression?" social networking site use and depression in older adolescents. *J Adolesc Health* 2013 Jan;52(1):128-130. [doi: [10.1016/j.jadohealth.2012.05.008](https://doi.org/10.1016/j.jadohealth.2012.05.008)] [Medline: [23260846](https://pubmed.ncbi.nlm.nih.gov/23260846/)]
31. Twitter. 2017. Processing streaming data URL: <https://dev.twitter.com/streaming/overview/processing> [accessed 2017-06-02] [WebCite Cache ID 6qvDcqOja]
32. Cravens JD, Whiting JB, Aamar RO. Why I stayed/left: an analysis of voices of intimate partner violence on social media. *Contemp Fam Ther* 2015 Sep 25;37(4):372-385. [doi: [10.1007/s10591-015-9360-8](https://doi.org/10.1007/s10591-015-9360-8)]
33. Bruckman A. Gatech. 2002. Ethical guidelines for research online URL: <https://www.cc.gatech.edu/~asb/ethics/> [accessed 2017-08-13] [WebCite Cache ID 6shD525Bn]
34. Whitehead LC. Methodological and ethical issues in Internet-mediated research in the field of health: an integrated review of the literature. *Soc Sci Med* 2007 Aug;65(4):782-791. [doi: [10.1016/j.socscimed.2007.03.005](https://doi.org/10.1016/j.socscimed.2007.03.005)] [Medline: [17512105](https://pubmed.ncbi.nlm.nih.gov/17512105/)]
35. Krippendorff K. Content analysis: an introduction to its methodology. Thousand Oaks, CA: Sage; 2012.
36. Kondracki NL, Wellman NS, Amundson DR. Content analysis: review of methods and their applications in nutrition education. *J Nutr Educ Behav* 2002 Jul;34(4):224-230. [doi: [10.1016/s1499-4046\(06\)60097-3](https://doi.org/10.1016/s1499-4046(06)60097-3)]
37. Bowen GA. Grounded theory and sensitizing concepts. *IIQM* 2016 Nov 29;5(3):12-23. [doi: [10.1177/160940690600500304](https://doi.org/10.1177/160940690600500304)]
38. Mislove A, Lehmann S, Ahn Y, Onnela J, Rosenquist J. Mislove. 2011. Understanding the demographics of twitter users URL: <https://mislove.org/publications/Twitter-ICWSM.pdf> [accessed 2017-09-29] [WebCite Cache ID 6tpiJ6Hm7]
39. Pew Research Center. 2016. Social media update 2016 URL: <http://www.pewinternet.org/2016/11/11/social-media-update-2016/> [accessed 2017-06-02] [WebCite Cache ID 6qvDPLAZJ]
40. Duggan M, Ellison N, Lampe C, Lenhart A, Madden M. Social media update 2014. Pew Research Center 2015 Jan:1-17.
41. Goh J, Gao G, Agarwal R. The creation of social value: can an online health community reduce rural-urban health disparities? *Mis Quarterly*. *MIS Quarterly* 2016;40(1):247-263.
42. Liu Y, Kliman-Silver C, Mislove A. Mislove. 2014. The tweets they are a-changin: evolution of twitter users and behavior URL: <https://mislove.org/publications/Profiles-ICWSM.pdf> [accessed 2017-09-29] [WebCite Cache ID 6tpiSt6Nv]
43. Joormann J, Gotlib IH. Updating the contents of working memory in depression: interference from irrelevant negative material. *J Abnorm Psychol* 2008 Feb;117(1):182-192. [doi: [10.1037/0021-843X.117.1.182](https://doi.org/10.1037/0021-843X.117.1.182)] [Medline: [18266496](https://pubmed.ncbi.nlm.nih.gov/18266496/)]
44. Rimes KA, Watkins E. The effects of self-focused rumination on global negative self-judgements in depression. *Behav Res Ther* 2005 Dec;43(12):1673-1681. [doi: [10.1016/j.brat.2004.12.002](https://doi.org/10.1016/j.brat.2004.12.002)] [Medline: [16239157](https://pubmed.ncbi.nlm.nih.gov/16239157/)]
45. Braitman A, Counts P, Davenport R, Zurlinden B, Rogers M, Clauss J, et al. Comparison of barriers to employment for unemployed and employed clients in a case management program: An exploratory study. *Psychiatr Rehabil J* 1995;19(1):3-8. [doi: [10.1037/h0095466](https://doi.org/10.1037/h0095466)]
46. Vaterlaus JM, Patten EV, Roche C, Young JA. #Gettinghealthy: the perceived influence of social media on young adult health behaviors. *Comput Human Behav* 2015 Apr;45:151-157. [doi: [10.1016/j.chb.2014.12.013](https://doi.org/10.1016/j.chb.2014.12.013)]
47. Hames JL, Hagan CR, Joiner TE. Interpersonal processes in depression. *Annu Rev Clin Psychol* 2013 Mar;9:355-377. [doi: [10.1146/annurev-clinpsy-050212-185553](https://doi.org/10.1146/annurev-clinpsy-050212-185553)] [Medline: [23297787](https://pubmed.ncbi.nlm.nih.gov/23297787/)]
48. Park M, McDonald D, Cha M. Perception differences between the depressed and non-depressed users in twitter. 2013 Presented at: 7th International AAAI Conference on Weblogs and Social Media, ICWSM 2013; July 8-11, 2013; Cambridge, MA p. 217-226.

49. Davila J, Hershenberg R, Feinstein BA, Gorman K, Bhatia V, Starr LR. Frequency and quality of social networking among young adults: associations with depressive symptoms, rumination, and corumination. *Psychol Pop Media Cult* 2012 Apr 1;1(2):72-86 [FREE Full text] [doi: [10.1037/a0027512](https://doi.org/10.1037/a0027512)] [Medline: [24490122](https://pubmed.ncbi.nlm.nih.gov/24490122/)]
50. Sampasa-Kanyinga H, Lewis RF. Frequent use of social networking sites is associated with poor psychological functioning among children and adolescents. *Cyberpsychol Behav Soc Netw* 2015 Jul;18(7):380-385. [doi: [10.1089/cyber.2015.0055](https://doi.org/10.1089/cyber.2015.0055)] [Medline: [26167836](https://pubmed.ncbi.nlm.nih.gov/26167836/)]
51. Dyson MP, Hartling L, Shulhan J, Chisholm A, Milne A, Sundar P, et al. A systematic review of social media use to discuss and view deliberate self-harm acts. *PLoS One* 2016;11(5):e0155813 [FREE Full text] [doi: [10.1371/journal.pone.0155813](https://doi.org/10.1371/journal.pone.0155813)] [Medline: [27191728](https://pubmed.ncbi.nlm.nih.gov/27191728/)]
52. Dwoskin E, Timberg C. The Washington Post. 2017 Apr 17. Facebook wanted 'visceral' live video. It's getting live-streaming killers and suicides URL: https://www.washingtonpost.com/business/technology/facebook-wanted-visceral-live-video-its-getting-suicides-and-live-streaming-killers/2017/04/17/a6705662-239c-11e7-a1b3-faff0034e2de_story.html?utm_term=.71443347a823 [accessed 2017-06-02] [WebCite Cache ID 6qvCSeJBV]
53. Facebook. 2017. Building a safer community with new suicide prevention tools URL: <https://newsroom.fb.com/news/2017/03/building-a-safer-community-with-new-suicide-prevention-tools/> [accessed 2017-06-02] [WebCite Cache ID 6qvCka0uv]
54. Facebook. 2017. Suicide prevention URL: <https://www.facebook.com/help/594991777257121/> [accessed 2017-09-21] [WebCite Cache ID 6teAZchrw]
55. Moreno MA, Ton A, Selkie E, Evans Y. Secret society 123: understanding the language of self-harm on Instagram. *J Adolesc Health* 2016 Jan;58(1):78-84 [FREE Full text] [doi: [10.1016/j.jadohealth.2015.09.015](https://doi.org/10.1016/j.jadohealth.2015.09.015)] [Medline: [26707231](https://pubmed.ncbi.nlm.nih.gov/26707231/)]
56. BBC News. 2017. Samaritans pulls 'suicide watch' radar app URL: <http://www.bbc.com/news/technology-29962199> [accessed 2017-08-12] [WebCite Cache ID 6seszIr3V]
57. Cheng Q, Li H, Silenzio V, Caine ED. Suicide contagion: a systematic review of definitions and research utility. *PLoS One* 2014;9(9):e108724 [FREE Full text] [doi: [10.1371/journal.pone.0108724](https://doi.org/10.1371/journal.pone.0108724)] [Medline: [25259604](https://pubmed.ncbi.nlm.nih.gov/25259604/)]
58. Mueller AS, Abrutyn S. Suicidal disclosures among friends: using social network data to understand suicide contagion. *J Health Soc Behav* 2015 Mar;56(1):131-148 [FREE Full text] [doi: [10.1177/0022146514568793](https://doi.org/10.1177/0022146514568793)] [Medline: [25722129](https://pubmed.ncbi.nlm.nih.gov/25722129/)]
59. Carhart-Harris RL, Bolstridge M, Rucker J, Day CM, Erritzoe D, Kaelen M, et al. Psilocybin with psychological support for treatment-resistant depression: an open-label feasibility study. *Lancet Psychiatry* 2016 Jul;3(7):619-627. [doi: [10.1016/S2215-0366\(16\)30065-7](https://doi.org/10.1016/S2215-0366(16)30065-7)]
60. Fox S, Jones S. Pew Research Center. 2007. The social life of health information: Americans' pursuit of health takes place within a widening network of both online and offline sources URL: http://www.pewinternet.org/files/old-media/Files/Reports/2009/PIP_Health_2009.pdf [accessed 2017-09-29] [WebCite Cache ID 6tpiwJwmo]
61. Preece J, Nonnecke B, Andrews D. The top five reasons for lurking: improving community experiences for everyone. *Comput Human Behav* 2004 Mar;20(2):201-223. [doi: [10.1016/j.chb.2003.10.015](https://doi.org/10.1016/j.chb.2003.10.015)]

Abbreviations

API: application programming interface

DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

MDD: major depressive disorder

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Original Paper

A Transmedia Storytelling Intervention With Interactive Elements to Benefit Latinas' Mental Health: Feasibility, Acceptability, and Efficacy

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Abstract

Background: Latinos report higher rates of depression and anxiety than US whites but are less likely to receive care. Transmedia storytelling interventions accessible on the Internet via smartphones, tablets, and computers hold promise for reducing reluctance to explore or get help for symptoms because they are private, convenient, and can reach large numbers of people, including Latinas with mental health needs.

Objective: The purpose of this study was to examine the feasibility, acceptability, and preliminary efficacy of a mental health transmedia intervention for Latinas with elevated symptoms of depression, anxiety, or both.

Methods: A total of 28 symptomatic English-speaking Latina women aged 21 to 48 years participated in a 6-week study using a within-group design. All aspects of the study were completed via telephone or Internet. Participants used their personal devices to engage the Web-based transmedia intervention (in English) that included story-based videos, a data-informed psychotherapeutic video, an interactive video sequence, and a blog written from the point of view of one of the characters with links to mental health resources. Perceived confidence to get help and perceived importance for seeking immediate help were both measured using single-item questions. Participants completed surveys at baseline (via telephone) and 1 and 6 weeks after media engagement that measured various factors, including depression (Patient Health Questionnaire; PHQ-9 and PHQ-8) and anxiety (Generalized Anxiety Disorder scale; GAD-7). A telephone interview was conducted within 72 hours of media engagement. Action taken or intentions to get help (single-item question) and talking about the videos with others (single-item question) were measured 1 and 6 weeks after media engagement. Repeated measures analysis of variance was used to assess change in depression (PHQ-8) and anxiety (GAD-7) before transmedia engagement and 1 and 6 weeks after. Spearman correlations evaluated the association of confidence and importance of getting help with action taken, anxiety, and depression.

Results: All 28 Latinas (English speakers) who engaged with the transmedia remained in the 6-week study. Within 1 week of transmedia engagement, 39% of women took action to get help, and 82% discussed the media with others. Symptoms of depression ($F_{2,54}=9.0$, $P<.001$) and anxiety ($F_{2,54}=18.7$, $P<.001$) significantly reduced across time. Higher levels of confidence were significantly associated with actions taken at 1 ($P=.005$) and 6 weeks ($P=.04$), and higher levels of importance were significantly associated with actions taken at 1 ($P=.009$) and 6 weeks ($P=.003$). Higher levels of confidence were associated with lower levels of depression ($P=.04$) and anxiety ($P=.01$) at 6 weeks.

Conclusions: Preliminary findings indicate a culturally tailored mental health transmedia intervention is a feasible approach that holds promise for engaging large numbers of symptomatic English-speaking Latina women to begin the process of seeking help, as well as decreasing symptoms of anxiety and depression.

KEYWORDS

depression; anxiety; transmedia; Internet; mental health; mood disorders; smartphone

Introduction

Background

Latinos are the largest ethnic minority group in the United States [1], and they report more symptoms of depression (such as sadness or hopelessness) and more symptoms of anxiety (such as nervousness) compared with US whites [2]. Symptoms of anxiety often co-occur with symptoms of depression [3]. However, US Latinos receive less mental health care than whites [4], even if they have insurance [5,6], and often are not diagnosed despite distress [7]. In a large epidemiologic study, less than one-third of Latinos of Mexican descent with major depression received guideline concordant care [8]. Acculturation processes and social assimilation pressures associated with exposure to life in the United States lead to shifts in language usage from Spanish to English and contribute to intergenerational changes in Latino family stability and cohesiveness, bringing cultural stress that may influence mental health [9]. US-born or English-speaking Latinos report more anxiety and depressive symptoms [9,10], as well as risks for suicidal ideation and suicide attempts [11] compared with foreign-born or Spanish-speaking Latinos. Heilemann and colleagues found that women of Mexican descent aged 21 to 40 years who were born or grew up in the United States reported more depressive symptoms than their immigrant peers [12]. However, talking about a personal mental health problem [13] or receiving mental health treatment can be perceived as stigmatizing in Latino culture [14,15]. Women fear that if they take the step to get mental health care, they will end up being committed to a mental health institution [7] or that other people will think they are crazy. [16]. Despite difficulties in daily life, often only Latinas with the highest levels of symptoms seek professional help [17]. This occurs despite evidence that treatments have been effective in reducing symptoms of depression [18] and anxiety [19] among US Latinas. Barriers to seeking therapy for Latinas include being overwhelmed and feeling responsible to meet loved ones' needs before seeking resources for their own mental health needs [20]. The daily demands of women's busy lives as mothers, workers, or daughters [21] raise the need for finding help that is flexible in terms of access, timing, location, and cost. Social and cultural sensitivity of available services is key [22], but depressed ethnic minority women have been found to be less likely to perceive they have a need for mental health care [23]. Becoming aware that depression or anxiety is present and overcoming stigma related to emotional health is crucial to being able to consider using resources such as therapy. For this reason, useful strategies that are also entertaining such as storytelling, hold promise for attracting women to consider their situation and the options for help.

Storytelling Interventions

Although only able to reach a small audience, an attractive fotonovela booklet created by Cabassa and colleagues [24] was

used to help Latina adults overcome stigma for depression. The fotonovela portrayed a story with photos and captions, comic book style, about a fictitious Latina mother who was depressed; review of the booklet led to increased intentions to seek treatment in a sample of at-risk, mostly Spanish-speaking adult Latinas [25]. However, efforts targeting English-speaking Latinos to date are lacking, and the reach of paper interventions with booklets such as fotonovelas is limited. Entertainment education or "edutainment" [26] strategies that involve webnovela [27] and telenovela formats have used compelling characters to showcase a variety of sexual health issues that have influenced Latino audiences since the pioneering work of Miguel Sabido in telenovelas that aired in Mexico in the 1970s [28]. Importantly, a specific focus on mental health for adult Latinas has not yet been approached using the telenovela format as an edutainment strategy. However, telenovelas have been used in health intervention research with US Latinos on topics such as alcohol abuse prevention [29] home care service use for elders with chronic illnesses [30], breast cancer screening [31], prevention of stroke and heart disease [32], colorectal cancer screening [33], and dementia knowledge and attitudes [34].

Transmedia, a form of digital edutainment, moves beyond telenovela viewing and holds promise for innovative interventions because, as a communication technology, it offers a convenient methodology for reaching and affecting large numbers of individuals including those in need. As Latinos have the highest usage of smartphones among US adults (18-49 years) [35] and high Internet usage including both English (94%) and Spanish speakers (86%) [36], they are a prime audience for an innovative approach using transmedia. A compelling media package can be tailored to address mental health-oriented content specifically designed for a Latina audience. Transmedia involves digital storytelling, which is conveyed over multiple platforms [37] including smartphones, tablets, and computers. Content can be delivered via network TV, cable TV, or streaming services (Wi-Fi, Internet, or cellular networks). With transmedia, different parts of a story unfold across various platforms, allowing viewers to make choices about what parts of the story to engage with, how, and when. Thus, stories can become even more captivating as they extend beyond the traditional episodic format through video logs, blogs, websites, individual videos, or a miniseries of short bonus videos featuring characters who not only provide drama and entertainment but who also provide information or resource options. The timing of viewing is up to the viewer, but the higher their interest in the story and characters, the more they are likely to engage [37]. The options for engagement give transmedia an interactive dynamic controlled by the viewer [38,39]. The dynamic features of transmedia contrast with the more static nature of pamphlets, fotonovelas, or comic books and the more passive nature of film or television.

Transmedia: Storytelling Over Multiple Digital Platforms

Transmedia that includes health messages has become increasingly popular among the growing numbers of English-speaking Latinos in the United States through Wise Entertainment's hit show, *East Los High* that reached viewers in all 50 US states and 163 countries during its first season [26]. It combined episodic dramas with transmedia extension videos that convey [26] unique parts of the story. Each part contributes to the creation of an immersive media experience [37] that can be leveraged for purposes of health. Whereas *East Los High* has focused on sexual and reproductive health, no transmedia interventions to date have focused specifically on topics related to adult Latinas' emotional health experiences or dealing with symptoms of depression or anxiety. The demand for story-based media is increasing among US Latinos who, according to Nielsen's Digital Consumer Report [40], watch more digital media than the average American.

Goal of This Transmedia Intervention

With the goal of using transmedia in an intervention, we drew upon our previous research data to enhance understanding of key issues for English-speaking Latinas associated with their experiences of depression or anxiety, as well as resilience and coping. We used those deidentified data to create a transmedia intervention called "Catalina: Confronting My Emotions" that was offered to women struggling with mental health symptoms. The purpose of this study was to examine the feasibility of a mental health transmedia intervention for English-speaking Latinas with moderate-to-severe symptoms of depression or anxiety. The first aim was to examine feasibility in terms of implementation, demand, and acceptability of a 6 week "Catalina" transmedia intervention. The second aim was to test the preliminary efficacy of the transmedia intervention to spur change in symptoms, perceived confidence and perceived importance of seeking help, and actions taken to get help.

Methods

Development of the Media

With guidance from the University of California, Los Angeles Institutional Review Board (UCLA IRB), we used deidentified data from the Principal Investigator's (PI) previous mental health studies with English-speaking and second generation Latinas as groundwork for creating composite characters and a storyline. Then, the PI teamed up with a Latino writer-director from Hollywood who created the scripts (in English) for the drama. Content validity for scripts was obtained from a community advisory board of four mental health therapists in two waves of critique, with a focus on making the scripts realistic and culturally appropriate. All four therapists had experience working with English-speaking adult Latinas and two of the four were Latinas themselves. The script was revised after each wave of input from the therapists. Casting was done in Hollywood, Latino or Latina actors were hired, and the video scenes were filmed and edited. Theater testing was done using preliminary versions of the videos, with a community sample of 19 Latina adults. Feedback regarding relatability of the characters and cultural appropriateness of the storyline was

collected using focus groups and individual interviews. Feedback led to the final editing of the media. Simultaneously, a computer programmer collaborated with the PI to create an interactive feature and the Web page that was designed to match the look and feel of the videos. It included photos, captions, and links to all the videos and the resource-rich blog, including contact information and links to local and Web-based resources plus hotlines for mental health services.

Study Design

Approval was granted by the UCLA IRB for a mixed-methods study with a one-group pretest and posttest design in a particular geographic target zone (approximately 22-mile diameter) within a much larger metropolitan area of Southern California. Purposive sampling methods were used for community-based recruitment from May 2015 to August 2015. The research was designed so that participants could complete all aspects of the study entirely over the phone and Internet.

Participants

Inclusion criteria limited enrollment to those who self-identified as Latina women aged 21 to 55 years who read and spoke English and who scored above the threshold at screening for depression on the Patient Health Questionnaire (PHQ-9) [41] or the brief 7-item Generalized Anxiety Disorder scale (GAD-7) [42]. Additional inclusion criteria required participants to have access to the Internet via a smartphone, tablet, or computer. The study flier clarified that each step of the study would be done over the phone and the Internet using a smartphone, tablet, or computer and that it involved watching some videos including a television-like story featuring a Latina character.

A total of 63 women called the study phone. Of the 63 callers, 28 were ineligible based on the inclusion criteria, including 6 who expressed suicidal ideation (they were further screened and referred using a suicide protocol), 10 who scored below threshold for both depression and anxiety, 4 who did not speak English, 2 who did not identify as Latinas, 4 who did not complete the screening, and 2 who reported they had only called to inquire for a friend. Thus, 35 women moved on to be screened and met eligibility requirements. Of them, 4 did not complete the Web-based informed consent after screening, 2 consented but did not participate beyond giving consent, 1 consented but later contacted the research assistant (RA) to report she could not gain access to the Internet on her phone. A final total of 28 eligible women moved beyond consent, and all of them completed the study; that is, there was no attrition over the 6 weeks of data collection.

Procedure

Fliers were distributed at nine partner sites including women's health clinics, parenting centers, social service sites, and a large catholic church in the geographic target zone. The fliers, printed in color and featuring a photo of the Latina main character from the story, invited adult Latinas who were struggling with feelings of sadness or worry to call if they wanted to participate in a media-based study. After giving verbal consent, callers were screened by the RA, a psychiatric mental health nurse practitioner (second author). The RA administered the PHQ-9 [41] and the GAD-7 [42] at screening, documenting all answers

and scoring in real time. Subsequently, the data were entered into Statistical Package for the Social Sciences (SPSS, IBM Corp) for comparison to posttest answers. An IRB-approved protocol was followed for women who self-identified as having suicidal ideation; they were not enrolled. See [Figure 1](#) for the intervention protocol beginning with screening and moving from Web-based informed consent, to media engagement, and online surveys.

All enrolled participants were assigned a confidential identification number for deidentification purposes, and media was made accessible via a password protected “Catalina” website after they completed the Web-based informed consent using a link sent to them in a text message (short message service, SMS) or email. Participants first completed at time 1 the online survey and then accessed the website that included an introductory video along with a series of links that were sequentially arranged to guide the viewer. [Figure 2](#) displays screenshots of the smartphone view, including how the videos were numbered. The introduction video led to a 3-min overview video introducing the project. The first link after the “intro” led to a 14-min video that depicted a story featuring the main character named Catalina, a 28-year old Latina who was dealing with life challenges including symptoms of depression and anxiety in her daily life at home, at a party, and alone with a friend. The second and third links led to two shorter 4-min bonus videos that extended the story; one portrayed Catalina grappling with the decision to seek therapy, and the other showed her reflecting on her experience after having had a positive therapy session with a Latina nurse-therapist character whom we named Veronica Sanchez, RN. The fourth link led to a bonus video of Veronica alone speaking directly to the viewer as a Latina, a nurse, and a therapist and providing user-friendly psychoeducation about depression and anxiety, as well as information on treatment and help-seeking. The Latina character of Veronica was portrayed as a nurse who was a therapist because of the relatively high trust that the public [43] and Latinos have in nurses [44,45], including nurses as therapists who treat depression [21], to counteract the stigma associated with mental health care [13]. The bilingual actress who played Veronica did both English and Spanish versions of one specific psychoeducational bonus video so that participants could share the Spanish version with friends or family who did not speak English.

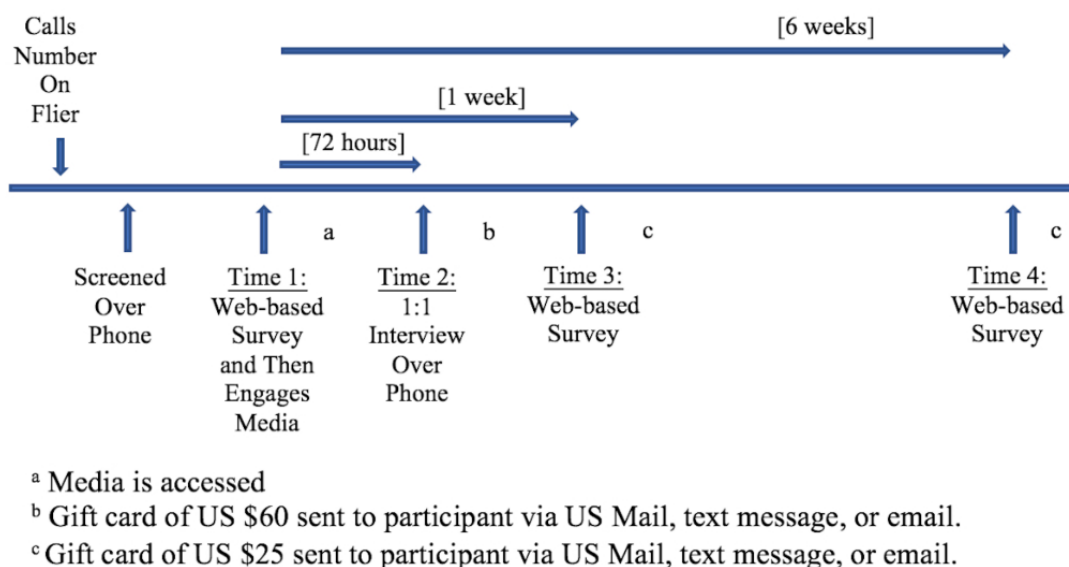
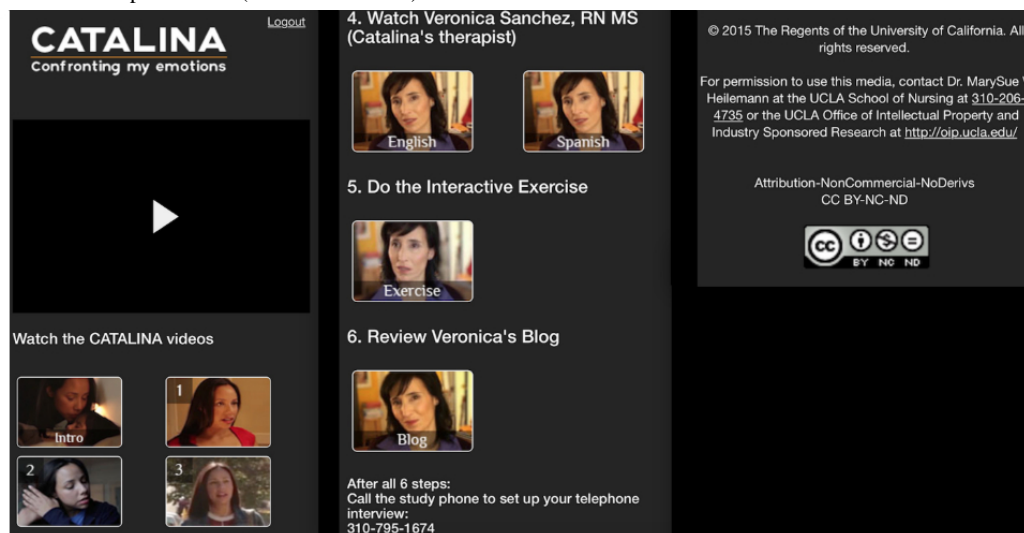
Link number five led to a series of coordinated short video segments wherein Veronica (the nurse-therapist character) directly asked the viewer specific questions inspired by motivational interviewing (MI) [46] in a sequence lasting about 6 min in total to spur participants’ thinking about themselves and their situation. For this interactive sequence, the viewer answered by choosing or clicking on a number and also by typing words into textboxes (see [Figure 3](#) for the script of

Web-based questions that women answered) and then clicking to go to the next video in the sequence. The aim of the successive videos and questions, controlled by the viewer, was to allow participants to move at their own pace while reflecting on how they were feeling or thinking [47]. At the end of the sequence, Veronica provided psychoeducation and explained how women could use their answers to reflect on their intentions. She then invited women to visit a blog that was accessible via the final (sixth) link; the blog included textual content written from Veronica’s point of view and featured names, addresses, and Internet links to various affordable mental health resources for individuals with low incomes, including local clinics and hotlines.

At all points, viewers were free to decide if and when they would click any links to engage with the surveys or media. The Web page included a reminder for participants to call the study phone after engaging with the media to schedule a one-to-one interview with the RA within 72 hours of media exposure. The qualitative telephone interview explored women’s perceptions of the media in a way that protected women’s privacy. As reported elsewhere (in process), the individual interviews were audiorecorded, transcribed, and analyzed. Participants were sent a text message 1 and 6 weeks after engaging in the media, which provided a link to Web-based surveys (time 3 and time 4) that included the PHQ-8 and GAD-7 plus survey questions about perceptions related to the importance of getting immediate help, confidence they could get help, and intentions or action taken. To compensate for their time, gift cards to a local retailer were mailed, emailed, or texted to participants at three points (see [Figure 1](#)).

Measurements and Instruments

As few studies have examined the integration of health information into transmedia storylines, Bowen’s [48] standard areas of feasibility were used to guide these analyses. Thus, our analyses included the criteria of: implementation, demand, acceptability, and limited efficacy. Implementation addressed ease of access and degree of engagement of the delivery of the intervention (how many women accessed the Web page, navigated the media site, and answered MI interactive questions by typing within answer boxes without needing assistance). Demand involved the extent to which the transmedia intervention was used (how many women watched and completed all minutes of each video). Acceptability involved suitability, attractiveness, or satisfaction of the intervention (answers to questions about relatability to the main character and desirability of seeing the nurse-therapist character and how many women used or shared Veronica’s blog). Limited efficacy involved the preliminary effectiveness of the transmedia intervention to reduce symptoms of depression and anxiety and to influence perceived importance of getting help and perceived confidence that they could seek help.

Figure 1. Timeline of data collection and gift card distribution time points.**Figure 2.** Screenshots of smartphone view (3 of 3 screenshots).**Figure 3.** Web-based questions for interactive video sequence based on Rollnick and Miller's (2008) motivational interviewing ruler.

1.	How important is it to you to get some help and feel better? (if 10 means it's very important to you to get some help, and 1 means it "doesn't really matter")
	1 __, 2 __, 3 __, 4 __, 5 __, 6 __, 7 __, 8 __, 9 __, 10 __
2.	Why isn't that number lower? (Type your answer below)
3.	How confident are you? How able do you think you are to take some action and get help for your feelings now? (How able do you think you are to take some action and get help for your feelings right now?)
	1 __, 2 __, 3 __, 4 __, 5 __, 6 __, 7 __, 8 __, 9 __, 10 __
4.	What would it take to raise that number? What would it take for your sense that you were able to actually DO something to get help, to go up a notch or two? What would it take to feel like you could "do it"? (Type your answer below)

Depressive Symptoms

The PHQ-9 [49] is a 9-item questionnaire for depression and was used at the time of initial screening to measure the severity of depression, including suicidal ideation experienced during the preceding 2 weeks. However, the PHQ-8 was used for two subsequent time points of the study without the ninth item about suicidal ideation (time 3 and time 4). Response options for the PHQ-9 and PHQ-8 are on a 4-point Likert scale and range from “not at all” to “nearly every day.” PHQ-9 scores indicating either moderate (≥ 10) or severe (≥ 15) depression represented study eligibility. The PHQ-9 for depression had good internal consistency reliability (Cronbach alpha=.86) [41] and good criterion validity ($r=.79$) in a sample of 3000 women from obstetrician or gynecologist clinics. In another study with 6000 patients, the PHQ-9 demonstrated good sensitivity (88.0%) and specificity (88.0%) to discriminate between depressed and nondepressed individuals at the cut-point of 10 or higher [49]. Merz and colleagues [50] did a study with a community-based sample of 479 Latinas and found the Cronbach alpha for the English version of the PHQ-9 to be .84 and for the Spanish version to be .85. Any response other than *not at all* for the suicidal ideation item on the scale indicated possible suicidal ideation [51], and therefore, for this study, a suicide risk assessment protocol was implemented if any woman endorsed this item.

After screening, the PHQ-8 was used to measure the severity of depression over the past 2 weeks [52]. For this study, the PHQ-8 was completed 1 and 6 weeks after engaging with the transmedia (time 3 and 4, respectively). Questionnaire items for the PHQ-8 are identical to those of the PHQ-9 except for the omission of the suicidal ideation item. Reliability was high in a sample of 32 Bolivian primary care patients (78%, 25/32 women) who were assessed by an automated telephonic depression self-care service using the PHQ-8 with a Cronbach alpha of .83 [53]. In a sample of 1022 coronary artery disease patients, the sensitivity and specificity for detecting major depression were similar for both the PHQ-9 (54% and 90%, respectively) and PHQ-8 (50% and 91%, respectively) [51]. Furthermore, a high correlation between the PHQ-9 and PHQ-8 scores ($r=.997$) was found [51].

Anxiety Symptoms

The GAD-7 is a 7-item questionnaire for anxiety and was used to screen for and measure the severity of anxiety over the preceding 2 weeks in this study [54]. Response options are on a 4-point Likert scale and range from *not at all* to *nearly every day*. GAD-7 scores indicating either moderate (≥ 10) or severe (≥ 15) anxiety represented study eligibility. Anxiety severity was assessed at screening and 1 and 6 weeks after engaging the transmedia intervention (time 3 and 4, respectively). In a study by Mills and colleagues [54] with a community sample of 436 Latinos, the GAD-7 had strong internal consistency reliability with a Cronbach alpha of .91 for the English version and .94 for the Spanish version.

Levels of Perceived Confidence and Importance

For the interactive video sequence with Veronica, questions were fashioned after Rollnick and Miller's [47] MI ruler and

were created to capture motivational dimensions for help-seeking behavior (see Figure 3). In one of the videos in the interactive sequence, a single-item question was used to measure women's perceptions of how important it was to get emotional help right now. Possible responses ranged from 1 to 10 with 1 meaning it was not very important and 10 meaning it was very important. Another single-item question with a 10-point range was used in the interactive sequence to measure women's perceptions of how confident they were in their ability to actually do something to get emotional support at this time (1 indicated they were not confident and 10 indicated they were very confident). Higher scores represented greater importance and greater confidence, respectively.

Behavior Change

Action taken and intentions to take action to get mental health care or support were assessed using Web-based surveys at time 3 and time 4 (see Figure 1), with a single question that had four possible answers. The answers ranged from (1) denial of action taken and no intention to act, to (2) denial of action but actively considering taking action to get help, to (3) denial of action but having certainty of intention to act in the future, to (4) affirmation that action had been taken to get support.

Relatability and Desirability

Included in the time 2 telephone interview (scheduled after engaging the transmedia intervention) was a single-item Likert question with a 10-point range that was used to measure how much the women related to the main character (Catalina). Possible responses ranged from 1 to 10, with 1 meaning they did not relate to her at all and 10 meaning they completely related to her. Another single-item Likert question was asked to measure how comfortable women would be seeing someone such as the nurse-therapist character (Veronica) for counseling (1 indicated there were not comfortable and 10 indicated they were very comfortable).

Impact of Transmedia

Women were asked if they thought about or talked about the videos with family members, friends, or anyone else since viewing the media. These questions were asked as part of the Web-based surveys 1 and 6 weeks after engaging with the media (time 3 and 4, respectively; see Figure 1). Possible answers included (1) No, (2) Yes, and (3) Choose not to answer.

Use of Blog

Participants were asked if and how they used Veronica's resource-rich blog about where to seek services for support or therapy. Actions taken and intentions to act were measured as part of the Web-based surveys 1 and 6 weeks after engaging with the media (time 3 and 4, respectively; see Figure 1). Possible answers were (1) No, (2) Yes, and (3) Choose not to answer. Another single-item question using the same answer choices was used to measure if women shared resources found on Veronica's blog with family, friends, or anyone in need at time 3 and time 4 (see Figure 1).

Access to and Engagement With Intervention Content

Web-based analytics tracking was used to measure the number of women who, without contacting the RA for assistance, (1)

accessed the transmedia intervention Web page, (2) accessed and watched all videos, (3) completed all minutes of each video, and (4) answered the Web-based MI interactive questions.

Data Analysis

Descriptive statistics were computed for sample characteristics. To assess feasibility in terms of implementation, descriptive statistics were used to compute how many women accessed, engaged, and navigated the Web page and answered the MI interactive questions (by typing within answer boxes) without assistance. To assess demand, descriptive statistics were used to compute how many women watched and completed all minutes of each video. To assess acceptability, descriptive statistics were used to compute relatability to the main character, desirability of seeing the nurse-therapist character, and the number of women who used or shared information on Veronica's blog. Limited efficacy was assessed using repeated measures analysis of variance to assess change over time for anxiety and depression symptoms and Spearman correlations to evaluate the association of perceived confidence and importance of getting immediate help with anxiety, depression, and action taken.

Results

Sample

Of the 28 participants who completed the Web-based consent form and accessed the media Web page (see [Figure 1](#)), 23 women (82%, 23/28) completed the telephone interview within 72 hours of viewing the transmedia, 4 (14%, 4/28) completed the interview within 6 days, but 1 completed the interview after 14 days. The average interview length was 45 min for each participant (range: 29-75 min). Participants were asked to complete surveys 1 and 6 weeks after viewing the transmedia (time 3 and 4, respectively). The average time between viewing and completion of the time 3 survey was 7.5 days (range: 6-16 days). The average time between viewing and the time 4 survey was 6 weeks (range: 6-7.5 weeks).

See [Table 1](#) for demographic information of the sample. The mean age was 29.2 (standard deviation 7.1.). More than half of the sample finished high school and attended some level of post high school education such as college or technical school. Most participants reported they found it difficult or very difficult to pay their weekly bills.

In terms of TV viewing habits, most participants reported that they watched TV shows about characters in a comedy or drama on a weekly basis. Over half of the sample watched story-based dramas or comedies several times weekly, and over three-quarters of the sample watched telenovelas on a weekly basis. In terms of the Internet, all participants reported that they watched videos, movies, or story-based shows via a smartphone, tablet, or computer on a weekly basis (see [Table 2](#)).

Intervention Feasibility

As noted above (see Participants), 1 woman enrolled in the study but did not have Internet access on her phone so did not

stay in the study. Of the 28 women who enrolled and had access to the Internet, all engaged the media using a smartphone, tablet or computer, and all stayed in the study throughout the 6 weeks.

Implementation

In terms of Bowen's feasibility criteria of implementation [48], all 28 women clicked the media link to engage with the videos without assistance from the RA. Likewise, all 28 typed in answers to the MI interactive questions without need for assistance.

Demand

The website tracker of user plays for each video showed that all 28 women in the sample watched all the videos. Of the total, 27 women completed all minutes of all videos; however, 1 woman stopped the 14-min video approximately 2.5 min before its ending.

Acceptability

The mean relatability score for how much women related to the main character (Catalina) was 6.95 on a 10-point scale. The mean desirability score for how comfortable women would be seeing the nurse-therapist character for counseling (Veronica) was 8.13 on a 10-point scale. Within 6 weeks of viewing, 20 of the 28 women (71%, 20/28) used or shared with others the blog or information from the blog.

Limited Efficacy Analysis

Depressive Symptoms

Depressive symptom levels decreased significantly across time ($F_{2,54}=9.0$, $P<.001$); there was a linear decrease ($F_{1,27}=14.2$, $P=.001$) with scores at screening significantly higher than at 1 week ($F_{1,27}=6.45$, $P=.02$) and 6 weeks after exposure to the media ($F_{1,27}=14.2$, $P=.001$; see [Table 3](#)). Even though results showed a continuing decrease across time, there was a slight lessening of the decrease from week 1 to week 6 after media exposure such that the 1- and 6-week scores were not significantly different ($F_{1,27}=3.9$, $P=.06$; see [Table 3](#) and [Figure 4](#)).

Anxiety Symptoms

For anxiety symptoms, there was a significant reduction across time ($F_{2,54}=18.7$, $P<.001$). A quadratic function also describes the pattern ($P=.008$) showing a "curve," with greater decrease between screening and 1 week post media than from 1 to 6 weeks after media exposure (see [Table 3](#)). Scores at screening were significantly higher than at 1 week post media exposure ($F_{1,17}=25.5$, $P<.001$) and at 6 weeks post media exposure ($F_{1,27}=23$, $P<.001$). Even though results showed a continuing decrease across time, there was a lessening of the decrease from week 1 to week 6 post media exposure such that the week 1 and week 6 scores were not significantly different ($F_{1,27}=1.4$, $P=.25$; see [Table 3](#) and [Figure 4](#)).

Table 1. Sample demographics (N=28).

Demographic variables	n (%)
Education	
Highest education level	
Some high school (but not all)	3 (10.7)
Graduated from high school or earned a general educational development certificate	7 (25)
Some technical, trade, or vocational school after high school	3 (10.7)
Attended some college	8 (28.6)
Graduated with an associate degree	1 (3.6)
Graduated with a bachelor's degree	3 (10.7)
Graduated with a master's degree	2 (7.1)
Chose not to answer the question	1 (3.6)
Finances	
Ability to meet weekly financial needs	
Not difficult	3 (10.7)
Somewhat difficult	6 (21.4)
Very difficult	19 (67.9)
Choose not to answer	
Mental health symptoms	
Depression and anxiety	
Depression: PHQ-9 ^a score ≥ 10	3 (10.7)
Anxiety: GAD-7 ^b score ≥ 10	4 (14.3)
Depression and anxiety scores each ≥ 10	21 (75)

^aPHQ-9: Patient Health Questionnaire 9-item.

^bGAD-7: Generalized Anxiety Disorder scale 7-item.

Figure 4. Mean depression (Patient Health Questionnaire 9-item, PHQ-9 or 8) and anxiety (Generalized Anxiety Disorder scale 7-item, GAD-7) scores at screening, 1 week (time 3) and 6 weeks (time 4) after engagement with the transmedia intervention (PHQ-9 at screening; PHQ-8 at time 3 and time 4).

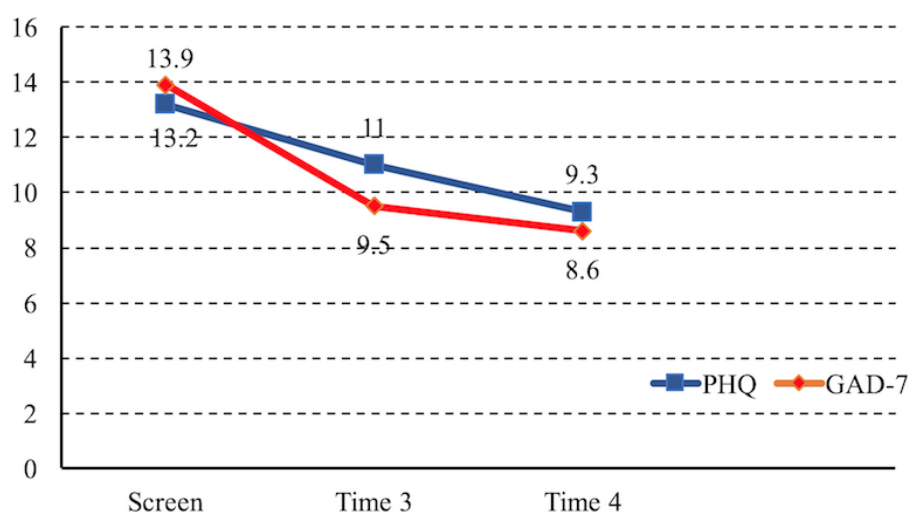


Table 2. Media viewing habits of sample using television (TV) and Internet (N=28).

Media viewing habits	n (%)
How often do you watch TV shows that are stories about characters in a situation comedy or drama?	
Never	1 (3.6)
Once a week	5 (17.9)
Several times a week	15 (53.6)
Everyday	7 (25)
How often do you watch telenovelas on TV?	
Never	6 (21.4)
Once a week	5 (17.9)
Several times a week	13 (46.4)
Everyday	4 (14.3)
How often do you watch videos from the Internet on your smartphone, tablet, or computer?	
Never	0
Once a week	7 (25)
Several times a week	12 (42.9)
Everyday	9 (32.1)
How often do you watch movies or story-based shows on your smartphone, tablet, or computer?	
Never	5 (17.9)
Once a week	8 (28.6)
Several times a week	9 (35.7)
Everyday	5 (17.9)

Table 3. Mean scores (standard deviation) for depression and anxiety (n=28) 1 and 6 weeks after engagement with transmedia intervention.

Mental health scores	Screening Mean (SD ^a)	1 week after media (time 3) Mean (SD)	6 weeks after media (time 4) Mean (SD)
Depression PHQ-9 ^b	13.2 (3.9)	-	-
Depression PHQ-8 ^c	-	11.0 (5.6)	9.3 (6.7)
Anxiety GAD-7 ^d	13.9 (3.4)	9.5 (4.6)	8.6 (6.1)

^aSD: standard deviation.

^bPHQ-9: Patient Health Questionnaire 9-item.

^cPHQ-8: Patient Health Questionnaire 8-item

^dGAD-7: Generalized Anxiety Disorder scale 7-item.

Perceived Confidence and Symptoms

Six weeks after media exposure, symptoms of depression and anxiety were both significantly correlated with perceived confidence that participants could take action to get immediate help. That is, higher levels of confidence were associated with lower levels of depression symptoms (Spearman ρ (rho): $-.399$, $P=.04$) and with lower levels of anxiety symptoms (Spearman ρ : $-.460$, $P=.01$).

Perceived Importance and Symptoms

Six weeks after media exposure, women's perceived level of importance of getting help for their emotions was not significantly correlated with anxiety symptoms (Spearman ρ : $-.288$, $P=.14$), nor was it significantly correlated with depression (Spearman ρ : $-.258$, $P=.19$). These moderate but nonsignificant

effects indicated that higher perceived levels of importance were associated with lower levels of depression and anxiety.

Intentions or Actions Taken to Seek Help

Within 1 week of media exposure, participants had changed their behavior. Specifically, 11 women (39%) reported they had already used the resources from the blog including links and contact information of local resources for support or therapy and hotline numbers. In addition, within 1 week, 25 women (89%, 25/28 of the sample) reported thinking about the videos during the week, and 23 women (82%, 23/28) reported they had already talked about the videos and transmedia with friends or family. Six weeks after exposure to the media, 8 women (28.5%, 8/28) reported they had used resources from the blog, and 21 women (75%, 21/28) reported they were still spending time

thinking about the videos. At time 4, a total of 22 women (79%, 22/28) reported they had talked about the videos since time 3 when they completed the last set of Web-based questions 5 weeks earlier.

Perceived Confidence and Intentions or Actions Taken to Seek Help

Women's level of perceived confidence in their ability to seek help was significantly associated with intentions or taking action to get help both 1 week after (Spearman ρ : .513, $P=.005$) and 6 weeks after engaging with the media (Spearman ρ : .410, $P=.04$). Higher levels of confidence were associated with higher levels of intentions or taking action to get help both 1 week and 6 weeks after engaging with the media.

Perceived Importance and Intentions or Action Taken to Seek Help

Women's perceptions of the importance of getting help for their emotions was significantly associated with intentions or taking action to get help both 1 week after (Spearman ρ : .487, $P=.009$) and 6 weeks after engaging with the media (Spearman ρ : .554, $P=.003$). Higher levels of importance were associated with higher levels of intentions or taking action to get help both 1 and 6 weeks after engaging with the media.

Discussion

Principal Findings

Preliminary findings indicate that an Internet-accessible transmedia storytelling intervention is a feasible approach for engaging and helping English-speaking Latina adults with symptoms of depression, anxiety, or both. Such interventions hold promise for reaching much larger numbers of Latinas, including those who are underserved but need help. To our knowledge, this is the first mental health transmedia intervention, and findings suggest that women found the intervention compelling, therapeutic, and resourceful. Participants engaged with all features of the intervention, and all of them remained in the study for the entire 6-week duration; there was no attrition after initiation of the study.

Importantly, women in our sample took action, and within 1 week, more than a third (39%, 11/28) used resources from the resource-rich blog. This included referral sites and hotlines that women used to gain knowledge about the available resources, to gather information, or to make an appointment for services. Moreover, the participants found the transmedia to be socially valuable, with the majority (82%, 23/28) sharing it with those in their social circle within days of viewing it for the first time. Rather than keeping their experience of the transmedia to themselves, most of the women in our sample told friends and family about the transmedia intervention without delay. These findings highlight the convenient and strategic design of the transmedia website. Participants who determined that they (or a friend) could benefit from services just as Catalina did, could readily access resources.

Finally, the intervention was therapeutic in that symptoms reduced after engagement with our transmedia storytelling intervention. Our 6-week intervention led to a statistically

significant improvement of the debilitating symptoms of depression and anxiety. This drop in symptom levels over the 6-week intervention illustrates how a digital storytelling intervention using the Internet can make a measurable difference in an individual's life. This is even more important because of our sample's vulnerability; 75% (21/28) of our Latina participants reported co-occurring depression and anxiety, which is commensurate with the literature [3]. Co-occurrence rates are estimated to be as high as 50% [55], which is associated with greater chronicity, psychiatric hospitalization, psychosocial disability, and suicide [56]. The reduction of symptoms and improvement in confidence for seeking mental health services was possible in just 1 week with the Catalina intervention, and symptoms further reduced through the 6-week point. This implies that further reduction of symptoms and further help seeking action may be possible if more story-based episodes, psychoeducational bonus videos, or media-based interactive exercises would be made available on an ongoing basis.

Compelling, story-based content that individuals find appropriate, desirable, and easily accessible via the Internet provides a way to reach thousands of people about topics that are often considered taboo. For example, the *East Los High* resource Web page associated with the show provided a hyperlink to Planned Parenthood, which was used 26,414 times during the first season and another 30,868 times in the 6 weeks after the season ended [26]. As mental health-related stigma within the Latino community has led to concealment of potential mental health problems, avoidance of seeking needed mental health services has been problematic [57,58]. Internet-based transmedia, however, offers a way to do discreet outreach to help symptomatic women overcome stigma-related barriers through a story that women find interesting. By considering how a fictitious character is dealing with their emotional issues, women can reflect in a low risk way on how they are feeling and consider ways to get help. Due to the individual nature of mental health challenges, our transmedia helped optimize privacy in that women used their own personal devices to access and explore the media at their own discretion without others having to know what they were doing. Women had control over when, where, and how long they engaged the media, which maximized their ability to use it at a time convenient for them. Overall, our findings indicate that the women were receptive to a Web-based psychotherapeutic intervention.

It is key for story-based edutainment to have realistic stories set in a believable world that is socioculturally relevant with a main character that viewers can relate to [59,60] and identify with [31]. We drew upon previous data, including findings from English-speaking Latinas treated for depression [18,20,21] to create the main character (Catalina) and the nurse-therapist character (Veronica). Likewise, the script for our intervention was based on deidentified data about real-life experiences of Latinas struggling with their emotions. It was edited on the basis of feedback from a team of therapists; subsequently, it was theater-tested with a community sample of Latina adults (manuscript in process) and edited again. These methodological steps were valuable in that results showed participants demonstrated strong character identification with the main character (Catalina). Furthermore, participants found the

nurse-therapist character (Veronica) to be highly acceptable as someone they would be comfortable seeing for mental health care. These scores suggest that participants shared certain key characteristics with Catalina and that they were attracted to the character of Veronica, portrayed as a Latina woman who was both a nurse and a therapist, in relation to an imagined working relationship [61]. Within the story, Catalina referred to Veronica as her therapist whom she saw as a capable health professional she could trust. Veronica was featured providing psychoeducational content, leading the interactive sequence using Rollnick and Miller's [46] MI ruler, offering participants guidance on how to interpret their answers, and inviting women to use her resource-rich blog. It is possible that the effectiveness of our transmedia intervention was enhanced because of the rapport women experienced with Veronica. It is likely she was perceived by participants not only as Catalina's confidante but potentially their own as well. As nurses are viewed as the most honest and ethical professionals [43] and as evidenced from previous research, a nurse who has specialized training as a therapist has been effective with depressed Latinas [21].

In conjunction with symptom reduction, transmedia storytelling interventions may also serve as catalysts that help women take action to seek mental health services. For our sample, both perceived confidence (self-efficacy) and importance were associated with increased actions taken to get help 1 and 6 weeks after viewing the media. On the basis of Bandura's social cognitive theory, self-efficacy is a psychological determinant of behavior change commonly targeted in health promotion interventions [62]. Other research on the ability to perform mental health care activities using the mental health self-efficacy scale offers support for linking confidence, self-efficacy, media, and mental health symptoms; Clarke and colleagues [63] studied a sample of adults suffering from mild-to-moderate symptoms of depression, anxiety, and stress and found that a Web-based psychotherapeutic intervention was associated with increased confidence for managing common mental health problems, along with a reduction in depression, anxiety, and stress [63]. Thus, if Catalina, who struggled similarly with life's daily obstacles and emotions in the story was able to find help, participants may also have felt confident in their ability to take risks to explore Web pages, make calls or appointments, and seek help.

Limitations

This was a feasibility study with a one-group pretest posttest design. Thus, results cannot be generalized beyond this sample until an attention control and usual care are added to the research, as necessary, to verify the efficacy for this transmedia intervention. With the surveys and the qualitative interview administered by the RA, a psychiatric mental health nurse practitioner, the possibility of a therapeutic effect exists.

Conclusions

Because telenovelas have long been enjoyed by Latina audiences and because of the success of *East Los High* [26], compelling transmedia dramas hold promise for reaching many Latinas who are at risk themselves or who know of someone who is. With the potential to reach thousands of women through Web-based content, the impact on women's knowledge of symptom management options could be sizable. The results of our study support the hypothesis that a transmedia intervention, informed by deidentified data composites from at-risk Latinas, can be developed and is able to affect symptoms and spur action. In addition to a randomized controlled trial, what remains to be studied are the enduring effects of the intervention such that participants continue to display enough confidence to seek and obtain the therapy they need.

Future implications of this study include advancements in the use of transmedia, such as further development of more interactive Web-based activities to access other evidence-based therapeutic help for women to make strides in managing their symptoms. This research and development may provide insight into how to refine and tailor future evidence-based Web-based treatment programs for Latinas. A recent review of Internet-based cognitive behavioral therapy (iCBT) supports the efficacy of iCBT to successfully treat depression and anxiety and particularly in overcoming the barriers that often preclude treatment [64]. Due to the privacy possible when engaging an intervention such as ours using transmedia via one's own personal smartphone, tablet or computer, such interventions may help women overcome stigma, increase confidence to seek care, or expand options for helpful resources to help them tolerate long wait-lists encountered when seeking needed therapy.

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Conflicts of Interest

None declared.

References

1. US Census. 2014. Hispanic heritage month 2014: Sept. 15–Oct. 15 URL: https://www.census.gov/content/dam/Census/newsroom/facts-for-features/2014/cb14ff-22_hispanic.pdf [accessed 2017-07-22] [WebCite Cache ID 6uDRCmv9W]
2. Schiller JS, Lucas JW, Ward BW, Peregoy JA. CDC. 2012. Summary health statistics for U.S. adults: National Health Interview Survey, 2010 URL: https://www.cdc.gov/nchs/data/series/sr_10/sr10_252.pdf [accessed 2017-07-19] [WebCite Cache ID 6sB3m45vW]

3. Kessler RC, Berglund P, Demler O, Jin R, Koretz D, Merikangas KR, National Comorbidity Survey Replication. The epidemiology of major depressive disorder: results from the National Comorbidity Survey Replication (NCS-R). *J Am Med Assoc* 2003 Jun 18;289(23):3095-3105. [doi: [10.1001/jama.289.23.3095](https://doi.org/10.1001/jama.289.23.3095)] [Medline: [12813115](https://pubmed.ncbi.nlm.nih.gov/12813115/)]
4. Cook BL, McGuire T, Miranda J. Measuring trends in mental health care disparities, 2000-2004. *Psychiatr Serv* 2007 Dec;58(12):1533-1540. [doi: [10.1176/ps.2007.58.12.1533](https://doi.org/10.1176/ps.2007.58.12.1533)] [Medline: [18048553](https://pubmed.ncbi.nlm.nih.gov/18048553/)]
5. Lagomasino IT, Dwight-Johnson M, Miranda J, Zhang L, Liao D, Duan N, et al. Disparities in depression treatment for Latinos and site of care. *Psychiatr Serv* 2005 Dec;56(12):1517-1523. [doi: [10.1176/appi.ps.56.12.1517](https://doi.org/10.1176/appi.ps.56.12.1517)] [Medline: [16339612](https://pubmed.ncbi.nlm.nih.gov/16339612/)]
6. Ojeda VD, McGuire TG. Gender and racial/ethnic differences in use of outpatient mental health and substance use services by depressed adults. *Psychiatr Q* 2006;77(3):211-222. [doi: [10.1007/s11126-006-9008-9](https://doi.org/10.1007/s11126-006-9008-9)] [Medline: [16927167](https://pubmed.ncbi.nlm.nih.gov/16927167/)]
7. Ko JY, Farr SL, Dietz PM, Robbins CL. Depression and treatment among U.S. pregnant and nonpregnant women of reproductive age, 2005-2009. *J Womens Health (Larchmt)* 2012 Aug;21(8):830-836 [FREE Full text] [doi: [10.1089/jwh.2011.3466](https://doi.org/10.1089/jwh.2011.3466)] [Medline: [22691031](https://pubmed.ncbi.nlm.nih.gov/22691031/)]
8. González HM, Vega WA, Williams DR, Tarraf W, West BT, Neighbors HW. Depression care in the United States: too little for too few. *Arch Gen Psychiatry* 2010 Jan;67(1):37-46 [FREE Full text] [doi: [10.1001/archgenpsychiatry.2009.168](https://doi.org/10.1001/archgenpsychiatry.2009.168)] [Medline: [20048221](https://pubmed.ncbi.nlm.nih.gov/20048221/)]
9. Vega WA, Sribney WM, Aguilar-Gaxiola S, Kolody B. 12-month prevalence of DSM-III-R psychiatric disorders among Mexican Americans: nativity, social assimilation, and age determinants. *J Nerv Ment Dis* 2004 Aug;192(8):532-541. [Medline: [15387155](https://pubmed.ncbi.nlm.nih.gov/15387155/)]
10. Alegría M, Canino G, Shrout PE, Woo M, Duan N, Vila D, et al. Prevalence of mental illness in immigrant and non-immigrant U.S. Latino groups. *Am J Psychiatry* 2008 Mar;165(3):359-369 [FREE Full text] [doi: [10.1176/appi.ajp.2007.07040704](https://doi.org/10.1176/appi.ajp.2007.07040704)] [Medline: [18245178](https://pubmed.ncbi.nlm.nih.gov/18245178/)]
11. Perez-Rodriguez MM, Baca-Garcia E, Oquendo MA, Wang S, Wall MM, Liu S, et al. Relationship between acculturation, discrimination, and suicidal ideation and attempts among US Hispanics in the National Epidemiologic Survey of Alcohol and Related Conditions. *J Clin Psychiatry* 2014 Apr;75(4):399-407. [doi: [10.4088/JCP.13m08548](https://doi.org/10.4088/JCP.13m08548)] [Medline: [24813407](https://pubmed.ncbi.nlm.nih.gov/24813407/)]
12. Heilemann MV, Lee KA, Kury FS. Strengths and vulnerabilities of women of Mexican descent in relation to depressive symptoms. *Nurs Res* 2002;51(3):175-182. [Medline: [12063416](https://pubmed.ncbi.nlm.nih.gov/12063416/)]
13. Nadeem E, Lange JM, Edge D, Fongwa M, Belin T, Miranda J. Does stigma keep poor young immigrant and U.S.-born Black and Latina women from seeking mental health care? *Psychiatr Serv* 2007 Dec;58(12):1547-1554. [doi: [10.1176/ps.2007.58.12.1547](https://doi.org/10.1176/ps.2007.58.12.1547)] [Medline: [18048555](https://pubmed.ncbi.nlm.nih.gov/18048555/)]
14. Hernandez MY, Organista KC. Qualitative exploration of an effective depression literacy fotonovela with at risk Latina immigrants. *Am J Community Psychol* 2015 Sep;56(1-2):79-88. [doi: [10.1007/s10464-015-9729-8](https://doi.org/10.1007/s10464-015-9729-8)] [Medline: [25987298](https://pubmed.ncbi.nlm.nih.gov/25987298/)]
15. Uebelacker LA, Marootian BA, Pirraglia PA, Primack J, Tighe PM, Haggarty R, et al. Barriers and facilitators of treatment for depression in a Latino community: a focus group study. *Community Ment Health J* 2012;48(1):114-126. [doi: [10.1007/s10597-011-9388-7](https://doi.org/10.1007/s10597-011-9388-7)] [Medline: [21267653](https://pubmed.ncbi.nlm.nih.gov/21267653/)]
16. Interian A, Martinez IE, Guarnaccia PJ, Vega WA, Escobar JJ. A qualitative analysis of the perception of stigma among Latinos receiving antidepressants. *Psychiatr Serv* 2007 Dec;58(12):1591-1594 [FREE Full text] [doi: [10.1176/ps.2007.58.12.1591](https://doi.org/10.1176/ps.2007.58.12.1591)] [Medline: [18048562](https://pubmed.ncbi.nlm.nih.gov/18048562/)]
17. Heilemann MV, Copeland D. Sources of emotional help sought by low income women of Mexican descent. *Issues Ment Health Nurs* 2005;26(2):185-204. [Medline: [15966112](https://pubmed.ncbi.nlm.nih.gov/15966112/)]
18. Heilemann MV, Pieters HC, Kehoe P, Yang Q. Schema therapy, motivational interviewing, and collaborative-mapping as treatment for depression among low income, second generation Latinas. *J Behav Ther Exp Psychiatry* 2011 Dec;42(4):473-480 [FREE Full text] [doi: [10.1016/j.jbtep.2011.05.001](https://doi.org/10.1016/j.jbtep.2011.05.001)] [Medline: [21619859](https://pubmed.ncbi.nlm.nih.gov/21619859/)]
19. Chavira DA, Golinelli D, Sherbourne C, Stein MB, Sullivan G, Bystritsky A, et al. Treatment engagement and response to CBT among Latinos with anxiety disorders in primary care. *J Consult Clin Psychol* 2014 Jun;82(3):392-403 [FREE Full text] [doi: [10.1037/a0036365](https://doi.org/10.1037/a0036365)] [Medline: [24660674](https://pubmed.ncbi.nlm.nih.gov/24660674/)]
20. Pieters HC, Heilemann MV. "I can't do it on my own": motivation to enter therapy for depression among low income, second generation, Latinas. *Issues Ment Health Nurs* 2010 Apr;31(4):279-287 [FREE Full text] [doi: [10.3109/01612840903308549](https://doi.org/10.3109/01612840903308549)] [Medline: [20218772](https://pubmed.ncbi.nlm.nih.gov/20218772/)]
21. Heilemann MV, Pieters HC, Dornig K. Reflections of low-income, second-generation Latinas about experiences in depression therapy. *Qual Health Res* 2016;26(10):1351-1365. [doi: [10.1177/1049732315624411](https://doi.org/10.1177/1049732315624411)]
22. Ishikawa RZ, Cardemil EV, Falmagne RJ. Help seeking and help receiving for emotional distress among Latino men and women. *Qual Health Res* 2010 Nov;20(11):1558-1572. [doi: [10.1177/1049732310369140](https://doi.org/10.1177/1049732310369140)] [Medline: [20448272](https://pubmed.ncbi.nlm.nih.gov/20448272/)]
23. Nadeem E, Lange JM, Miranda J. Mental health care preferences among low-income and minority women. *Arch Womens Ment Health* 2008 Jun;11(2):93-102 [FREE Full text] [doi: [10.1007/s00737-008-0002-0](https://doi.org/10.1007/s00737-008-0002-0)] [Medline: [18463940](https://pubmed.ncbi.nlm.nih.gov/18463940/)]
24. Cabassa LJ, Molina GB, Baron M. Depression fotonovela: development of a depression literacy tool for Latinos with limited English proficiency. *Health Promot Pract* 2012 Nov;13(6):747-754 [FREE Full text] [doi: [10.1177/1524839910367578](https://doi.org/10.1177/1524839910367578)] [Medline: [21051325](https://pubmed.ncbi.nlm.nih.gov/21051325/)]

25. Hernandez MY, Organista KC. Entertainment-education? A fotonovela? A new strategy to improve depression literacy and help-seeking behaviors in at-risk immigrant Latinas. *Am J Community Psychol* 2013 Dec;52(3-4):224-235. [doi: [10.1007/s10464-013-9587-1](https://doi.org/10.1007/s10464-013-9587-1)] [Medline: [23907442](#)]
26. Wang H, Singhal A. East los high: transmedia edutainment to promote the sexual and reproductive health of young Latina/o Americans. *Am J Public Health* 2016 Jun;106(6):1002-1010. [doi: [10.2105/AJPH.2016.303072](https://doi.org/10.2105/AJPH.2016.303072)] [Medline: [27077336](#)]
27. Andrade EL, Evans WD, Edberg MC, Cleary SD, Villalba R, Batista IC. Victor and Erika Webnovela: an innovative generation @ audience engagement strategy for prevention. *J Health Commun* 2015;20(12):1465-1472 [[FREE Full text](#)] [doi: [10.1080/10810730.2015.1018648](https://doi.org/10.1080/10810730.2015.1018648)] [Medline: [26252644](#)]
28. Population Media Center. 2017. Theory supporting Sabido URL: <https://www.populationmedia.org/2007/08/09/sex-soap-social-change-the-sabido-methodology/> [accessed 2017-07-21] [WebCite Cache ID 6sB4cigxK]
29. Lalonde B, Rabinowitz P, Shefsky ML, Washienko K. La Esperanza del Valle: alcohol prevention novelas for Hispanic youth and their families. *Health Educ Behav* 1997 Oct;24(5):587-602 [[FREE Full text](#)] [Medline: [9307895](#)]
30. Crist JD. Cafecitos and telenovelas: culturally competent interventions to facilitate Mexican American families' decisions to use home care services. *Geriatr Nurs* 2005;26(4):229-232. [Medline: [16173135](#)]
31. Wilkin HA, Valente TW, Murphy S, Cody MJ, Huang G, Beck V. Does entertainment-education work with Latinos in the United States? Identification and the effects of a telenovela breast cancer storyline. *J Health Commun* 2007;12(5):455-469. [doi: [10.1080/10810730701438690](https://doi.org/10.1080/10810730701438690)] [Medline: [17710596](#)]
32. Vaughn S. Stroke and heart disease prevention education via telenovela: a focus group's evaluation. *Rehabil Nurs* 2012;37(5):215-219. [doi: [10.1002/rnj.53](https://doi.org/10.1002/rnj.53)] [Medline: [22949274](#)]
33. Larkey LK, McClain D, Roe DJ, Hector RD, Lopez AM, Sillanpaa B, et al. Randomized controlled trial of storytelling compared to a personal risk tool intervention on colorectal cancer screening in low-income patients. *Am J Health Promot* 2015;30(2):e59-e70. [doi: [10.4278/ajhp.131111-QUAN-572](https://doi.org/10.4278/ajhp.131111-QUAN-572)] [Medline: [25615708](#)]
34. Grigsby TJ, Unger JB, Molina GB, Baron M. Evaluation of an audio-visual novela to improve beliefs, attitudes and knowledge toward dementia: a mixed-methods approach. *Clin Gerontol* 2017;40(2):130-138. [doi: [10.1080/07317115.2016.1211210](https://doi.org/10.1080/07317115.2016.1211210)] [Medline: [28452671](#)]
35. The Nielsen Company. 2016. Television is still top brass but viewing differences vary with age URL: <http://www.nielsen.com/us/en/insights/news/2016/television-is-still-top-%09brass-%09but-viewing-differences-vary-with-age.html> [accessed 2017-07-21] [WebCite Cache ID 6sB529Ali]
36. Brown A, López G, Lopez MH. Pew Research Center. 2016. Internet use among Hispanics URL: <http://www.pewhispanic.org/2016/07/20/1-internet-use-among-hispanics/> [accessed 2017-07-21] [WebCite Cache ID 6sB5lir09]
37. Jenkins H. *Convergence Culture: Where Old and New Media Collide*. New York: New York University Press; 2008.
38. Bernardo N. *The Producer's Guide to Transmedia: How to Develop, Fund, Produce and Distribute Compelling Stories Across Multiple Platforms*. London: BeActive Books; 2011.
39. Pratten R. *Getting Started in Transmedia Storytelling: A Practical Guide for Beginners*. London: CreateSpace Independent Publishing Platform; 2015.
40. The Nielsen Company. 2014. The US digital consumer report URL: <http://www.nielsen.com/us/en/insights/reports/2014/the-us-digital-consumer-%09report.html> [accessed 2017-07-22] [WebCite Cache ID 6sB69mjjU]
41. Spitzer RL, Williams JB, Kroenke K, Hornyak R, McMurray J. Validity and utility of the PRIME-MD patient health questionnaire in assessment of 3000 obstetric-gynecologic patients: the PRIME-MD Patient Health Questionnaire Obstetrics-Gynecology Study. *Am J Obstet Gynecol* 2000 Sep;183(3):759-769. [Medline: [10992206](#)]
42. Spitzer RL, Kroenke K, Williams JB, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med* 2006 May 22;166(10):1092-1097. [doi: [10.1001/archinte.166.10.1092](https://doi.org/10.1001/archinte.166.10.1092)] [Medline: [16717171](#)]
43. Gallup. 2016. Americans rate healthcare providers high on honesty, ethics URL: <http://www.gallup.com/poll/200057/americans-rate-healthcare-providers-high-honesty-ethics.aspx> [accessed 2017-07-23] [WebCite Cache ID 6sB8G9nNe]
44. Jones SM. Making me feel comfortable: developing trust in the nurse for Mexican Americans. *West J Nurs Res* 2015 Nov;37(11):1423-1440. [doi: [10.1177/0193945914541519](https://doi.org/10.1177/0193945914541519)] [Medline: [25012197](#)]
45. Kneipp SM, Lutz BJ, Means D. Reasons for enrollment, the informed consent process, and trust among low-income women participating in a community-based participatory research study. *Public Health Nurs* 2009;26(4):362-369. [doi: [10.1111/j.1525-1446.2009.00791.x](https://doi.org/10.1111/j.1525-1446.2009.00791.x)] [Medline: [19573215](#)]
46. Rollnick S, Miller WR, Butler CC. *Motivational Interviewing in Health Care: Helping Patients Change Behavior*. New York: The Guilford Press; 2008.
47. Miller WR, Rollnick S. *Motivational Interviewing: Preparing People for Change*. 2nd ed. New York: Guilford Press; 2002.
48. Bowen DJ, Kreuter M, Spring B, Cofta-Woerpel L, Linnan L, Weiner D, et al. How we design feasibility studies. *Am J Prev Med* 2009 May;36(5):452-457 [[FREE Full text](#)] [doi: [10.1016/j.amepre.2009.02.002](https://doi.org/10.1016/j.amepre.2009.02.002)] [Medline: [19362699](#)]
49. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med* 2001 Sep;16(9):606-613 [[FREE Full text](#)] [Medline: [11556941](#)]
50. Merz EL, Malcarne VL, Roesch SC, Riley N, Sadler GR. A multigroup confirmatory factor analysis of the Patient Health Questionnaire-9 among English- and Spanish-speaking Latinas. *Cultur Divers Ethnic Minor Psychol* 2011 Jul;17(3):309-316 [[FREE Full text](#)] [doi: [10.1037/a0023883](https://doi.org/10.1037/a0023883)] [Medline: [21787063](#)]

51. Razykov I, Ziegelstein RC, Whooley MA, Thombs BD. The PHQ-9 versus the PHQ-8--is item 9 useful for assessing suicide risk in coronary artery disease patients? Data from the Heart and Soul Study. *J Psychosom Res* 2012 Sep;73(3):163-168. [doi: [10.1016/j.jpsychores.2012.06.001](https://doi.org/10.1016/j.jpsychores.2012.06.001)] [Medline: [22850254](#)]
52. Kroenke K, Strine TW, Spitzer RL, Williams JB, Berry JT, Mokdad AH. The PHQ-8 as a measure of current depression in the general population. *J Affect Disord* 2009 Apr;114(1-3):163-173. [doi: [10.1016/j.jad.2008.06.026](https://doi.org/10.1016/j.jad.2008.06.026)] [Medline: [18752852](#)]
53. Janevic MR, Aruquipa Yujra AC, Marinec N, Aguilar J, Aikens JE, Tarrazona R, et al. Feasibility of an interactive voice response system for monitoring depressive symptoms in a lower-middle income Latin American country. *Int J Ment Health Syst* 2016 Sep 22;10:59 [FREE Full text] [doi: [10.1186/s13033-016-0093-3](https://doi.org/10.1186/s13033-016-0093-3)] [Medline: [27688798](#)]
54. Mills SD, Fox RS, Malcarne VL, Roesch SC, Champagne BR, Sadler GR. The psychometric properties of the generalized anxiety disorder-7 scale in Hispanic Americans with English or Spanish language preference. *Cultur Divers Ethnic Minor Psychol* 2014 Jul;20(3):463-468 [FREE Full text] [doi: [10.1037/a0036523](https://doi.org/10.1037/a0036523)] [Medline: [25045957](#)]
55. Fava M, Rankin MA, Wright EC, Alpert JE, Nierenberg AA, Pava J, et al. Anxiety disorders in major depression. *Compr Psychiatry* 2000;41(2):97-102. [Medline: [10741886](#)]
56. Hirschfeld RM. The comorbidity of major depression and anxiety disorders: recognition and management in primary care. *Prim Care Companion J Clin Psychiatry* 2001 Dec;3(6):244-254 [FREE Full text] [Medline: [15014592](#)]
57. Aguilar-Gaxiola S, Loera G, Mendez L, Sala M. UC Davis. 2012. Community-defined solutions for Latino mental health care disparities: California reducing disparities project, Latino strategic planning, workgroup population report URL: https://www.ucdmc.ucdavis.edu/newsroom/pdf/Latino_mental_health_report-6-25-2012-1.pdf [WebCite Cache ID 6sB8cis7Z]
58. Wong EC, Collins RL, Cerully J, Seelam R, Roth B. Rand. 2016. Racial and ethnic differences in mental illness stigma and discrimination among Californians experiencing mental health challenges URL: https://www.rand.org/pubs/research_reports/RR1441.html [accessed 2017-07-22] [WebCite Cache ID 6sBAC0Vtx]
59. Bandura A. Social cognitive theory of mass communication. *Media Psychol* 2001;3(3):265-299. [doi: [10.1207/S1532785XMEP0303_03](https://doi.org/10.1207/S1532785XMEP0303_03)]
60. Quintero Johnson JM, Harrison K, Quick BL. Understanding the effectiveness of the entertainment-education strategy: an investigation of how audience involvement, message processing, and message design influence health information recall. *J Health Commun* 2013;18(2):160-178. [doi: [10.1080/10810730.2012.688244](https://doi.org/10.1080/10810730.2012.688244)] [Medline: [23030409](#)]
61. Chory RM. Differences in television viewers' involvement: identification with and attraction to liked, disliked, and neutral characters. *Commun Res Rep* 2013;30(4):293-305. [doi: [10.1080/08824096.2013.837041](https://doi.org/10.1080/08824096.2013.837041)]
62. Glanz K, Rimer BK, Viswanath K. *Health Behavior and Health Education: Theory, Research, and Practice*. 4th ed. San Francisco: Jossey-Bass; 2008.
63. Clarke J, Proudfoot J, Birch MR, Whitton AE, Parker G, Manicavasagar V, et al. Effects of mental health self-efficacy on outcomes of a mobile phone and web intervention for mild-to-moderate depression, anxiety and stress: secondary analysis of a randomised controlled trial. *BMC Psychiatry* 2014 Sep 26;14:272 [FREE Full text] [doi: [10.1186/s12888-014-0272-1](https://doi.org/10.1186/s12888-014-0272-1)] [Medline: [25252853](#)]
64. Webb CA, Rosso IM, Rauch SL. Internet-based cognitive-behavioral therapy for depression: current progress and future directions. *Harv Rev Psychiatry* 2017;25(3):114-122. [Medline: [28475503](#)]

Abbreviations

GAD-7: Generalized Anxiety Disorder scale 7-item

iCBT: Internet-based cognitive behavioral therapy

MI: motivational interviewing

PHQ-9: Patient Health Questionnaire 9-item

RA: research assistant

SD: standard deviation

UCLA IRB: University of California, Los Angeles Institutional Review Board

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Original Paper

Pregnant Women's Perceptions of the Risks and Benefits of Disclosure During Web-Based Mental Health E-Screening Versus Paper-Based Screening: Randomized Controlled Trial

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Abstract

Background: Pregnant women's perceptions of the risks and benefits during mental health screening impact their willingness to disclose concerns. Early research in violence screening suggests that such perceptions may vary by mode of screening, whereby women view the anonymity of e-screening as less risky than other approaches. Understanding whether mode of screening influences perceptions of risk and benefit of disclosure is important in screening implementation.

Objective: The objective of this randomized controlled trial was to compare the perceptions of pregnant women randomized to a Web-based screening intervention group and a paper-based screening control group on the level of risk and benefit they perceive in disclosing mental health concerns to their prenatal care provider. A secondary objective was to identify factors associated with women's perceptions of risk and benefit of disclosure.

Methods: Pregnant women recruited from maternity clinics, hospitals, and prenatal classes were computer-randomized to a fully automated Web-based e-screening intervention group or a paper-based control. The intervention group completed the Antenatal Psychosocial Health Assessment and the Edinburgh Postnatal Depression Scale on a computer tablet, whereas the control group completed them on paper. The primary outcome was women's perceptions of the risk and benefits of mental health screening using the Disclosure Expectations Scale (DES). A complete analysis was conducted. Statistical significance was set at $P < .05$. We used t tests to compare the means of the risk and benefit subscales between groups.

Results: Of the 675 eligible women approached, 636 (94.2%) agreed to participate and were randomized to the intervention ($n=305$) and control ($n=331$) groups. There were no significant baseline differences between groups. The mode of screening was not associated with either perceived risk or benefit of screening. There were no differences in groups in the mean scores of the risk and benefit of disclosure subscales. Over three-quarters of women in both intervention and control groups perceived that mental health screening was beneficial. However, 43.1% (272/631) of women in both groups reported feeling very, moderately, or somewhat vulnerable during mental health screening. We found that women of low income, those treated previously for depression or anxiety, and those pregnant with their first child were more likely to perceive greater risk. However, these associations were very small.

Conclusions: Pregnant women in both the e-screening and paper-based screening groups perceived benefit and risk of disclosure similarly, suggesting that providers can implement the mode of screening that is most ideal for their clinical setting. Regardless of the mode of screening, a substantial number of women reported feeling vulnerable during mental health screening, highlighting the importance of the need to reduce women's vulnerability throughout the screening process with strategies such as addressing women's concerns, explaining the rationale for screening, and discussing how results will be used.

Trial Registration: Clinicaltrials.gov NCT01899534; <https://clinicaltrials.gov/ct2/show/NCT01899534> (Archived by WebCite at <http://www.webcitation.org/6tRktGC4M>)

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KEYWORDS

pregnancy; mental health; screening; prenatal care; computers

Introduction

Background

Recent studies reveal new evidence that untreated prenatal depression persists through the first 4 to 5 years postnatally, impacting child socioemotional and cognitive development [1-4]. Such evidence has been used to support recommendations for routine prenatal and postnatal mental health screening by international guidelines from the United Kingdom [5], Australia [6], and the United States [7,8], prompting major shifts in global perinatal mental health care. However, whereas the need for universal screening is clear, guidance surrounding its implementation is sparse.

One of the main considerations in implementation of routine perinatal mental health screening is the need for it to target the substantial, well-documented barriers to screening that have been reported by both women and perinatal providers [9-11]. For instance, a recent systematic review noted that even in universal screening programs comprising screening, algorithmic decision support, and direct referrals to psychiatry, depression tool screening scores were documented in only 39% of the visits [9,12]. Other studies have reported that barriers differ at each stage of perinatal mental health care (screening, referral, and treatment) [9,13], and targeting such barriers directly is the most effective approach for improving women's access to mental health treatment [9,13]. In evaluating the implementation of routine screening in outpatient obstetrics clinics at Massachusetts General Hospital (Boston, Massachusetts), investigators concluded that "efforts that are aimed at decreasing barriers to the detection, assessment, and referral of women for depression screening both before and after delivery can lead to high levels of mental health care use among women who screen positive." [14].

E-screening with accompanying computer-based algorithmic recommendations for treatment has potential to lessen the significant barriers that women and providers report surrounding screening and referral. Women and providers consistently report the need for support in recognizing perinatal depression and anxiety, and both feel challenged by time constraints and their discomfort in mental health discussions [9,13,15]. Providers describe the need for clear integration of screening within clinic

processes and infrastructure, an easy-to-use standardized screen, and systems that link patients readily to referrals [9,13]. Threaded through all of these concerns are women's perceptions about the risk versus the benefit of mental health screening.

Systematic reviews have suggested that women perceive risk in perinatal mental health screening, and guideline developers (including the Canadian Task Force on Preventive Health Care screening for depression) [16] have used that risk argument as a basis for not recommending routine mental health screening. However, few studies have generated strong empirical evidence on this subject [17]. Even more importantly, with the advent of novel mental health e-technologies, few studies have examined whether such perceptions vary by the mode of screening. For instance, whereas women cite risks of screening such as potentially being judged by a provider, feeling dismissed, or finding providers unsupportive, a significant implementation question is whether e-screening has potential to reduce such perceptions. On the basis of research by Renker et al [18,19] on computerized prenatal interpersonal violence screening in a demographically diverse sample of over 500 women and their reviews, e-screening may provide an anonymous venue that enables women to view the risks of screening as less daunting and the benefits more appealing [18,20-22]. Understanding whether e-screening impacts pregnant women's perceived risks of perinatal mental health screening warrants further exploration.

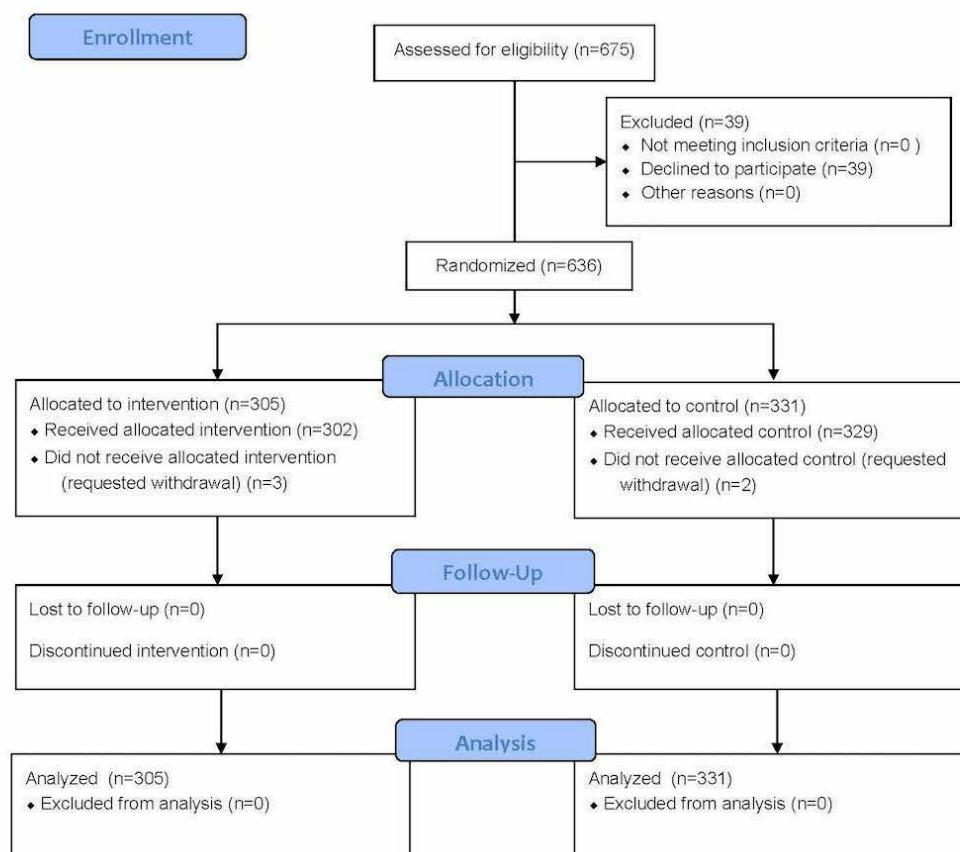
Objectives

The objective of this study was to compare pregnant women's perception of risk and benefit of disclosure of mental health concerns based on whether they were randomized to e-screening or paper-based screening. A secondary objective was to identify factors associated with women's perceptions of risk and benefit associated with disclosure during mental health screening.

Methods

Study Design

The study is a parallel-group, randomized controlled trial (RCT) (Figure 1). The methods have been previously published [23,24]. Approval for this study was granted by the Human Research Ethics Board at the University of Alberta.

Figure 1. Consort flow diagram.

Eligibility Criteria

Pregnant women were eligible for this trial if they were (1) able to speak or read English, (2) willing to be randomized to e-screening, and (3) willing to participate in a follow-up diagnostic interview within 1 week of recruitment. Because the Web-based screening tool was intended to be completed unassisted, it was designed for use by women with varying levels of computer literacy.

Setting and Recruitment

Setting and recruitment details have been published previously [23,24]. In brief, women were recruited from community-based family physician-led maternity clinics, a high-risk antenatal unit in a tertiary care center, and hospital-based prenatal classes in Edmonton, Alberta. The recruitment strategy aimed to include participants with diverse demographic and obstetrical characteristics. Trained research assistants used a standardized script to invite women to participate in the study. Once women completed the consent electronically on a computer tablet, the computer program designed by the Women's and Children's Health Research Institute automatically randomized them (1:1) to the intervention or control group. Thus, the research assistant was blinded to group allocation. Full details on consent procedures are found in the trial protocol [23].

Description of E-Screening Intervention and Control Groups

The intervention is described comprehensively in the protocol (with accompanying screenshots), as are details of the Antenatal

Psychosocial Health Assessment (ALPHA) [25-27] and the Edinburgh Postnatal Depression Scale (EPDS) [23]. Women randomized to the intervention group completed a full Web-based assessment with questions on psychosocial risk (ALPHA) [26,27] and current depression symptoms (EPDS) [28]. Women in the control group completed paper-based versions of the same screening tools (ALPHA and EPDS). Both groups completed the screening tools on a single occasion (recruitment).

Procedures

The details of the questionnaires and their development are described in the protocol [23] and the first trial paper [24]. Following consent and computer randomization, women in the intervention group completed the Web-based e-screening version of the ALPHA and EPDS on a computer tablet. They then proceeded to complete the Web-based baseline questionnaire. Women in the control group completed the Web-based consent on the tablet; thereafter, they were given the paper-based versions of the ALPHA and EPDS. Once finished, they returned to the tablet to complete the Web-based baseline questionnaire. One week after recruitment, women in both groups were telephoned by a trained research assistant (blinded to group allocation) to complete a Mini-International Neuropsychiatric Interview (MINI, Version 6.0.0) [29]. No data were stored on the tablets. Upon submission, survey data were sent to a secure server housed in the Faculty of Medicine and Dentistry at the University of Alberta.

Safety Protocol

Women who met criteria for a mood or anxiety disorder on the MINI or scored 13 or more on the EPDS were referred by the research assistant to the hospital-based reproductive mental health.

Sample Size

Because no data were available to guide estimation of a minimal clinically important difference in true cases detected through e-screening, we used a CI approach [30]. We based the sample size calculation on 85% of women with a score of 4 to 8 on the risk subscale of the Disclosure Expectations Scale (DES) and 85% of women with a score of 16 to 20 on the utility subscale of the DES. Using a margin of error of 0.05 and 25% estimated loss to follow-up, we calculated that 261 women per group ($N=542$) were required [23]. At a final sample size of 636, the study was sufficiently powered to detect differences in the outcomes between groups if they exist.

Measurement of Outcomes

We measured women's views of the risk and benefits of e-screening using the 8-item DES. The DES comprises 2 subscales, the risk subscale (items 1, 2, 4, and 5) and the utility subscale (items 3, 6, 7, and 8), designed to identify the perceived risks and benefits of psychological care. Convergent validity of the subscales has been demonstrated with other measures of self-disclosure, as well as psychological distress and intention to seek mental health care [31]. Instructions preceding the DES asked women to consider each question within the context of discussing mental health problems with their prenatal care provider. The risk subscale assesses the level of risk and consequences women perceive in self-disclosing mental health concerns and is based on the notion that the "potential dangers of opening up to another person may seem to some individuals worse than their actual problem" [31]. The utility subscale measures the perceived value of disclosure. Participants responded to each item on a 5-point Likert scale from "very" to "not at all." The individual scale items are given with their sample distributions in [Multimedia Appendix 1](#).

Analysis

Because there was a little data missing, we conducted a completer analysis (vs intention-to-treat analysis). Baseline differences of the groups were assessed using frequencies (95% CIs) and means (standard deviations [SD]) and compared using independent t tests (means) and chi-square tests (%) to assess the effectiveness of randomization. Statistical significance for all analyses and final models was set at $P<.05$. We used chi-square tests to compare proportions of women in each group responding to the subscale items.

Before the multivariable analysis, we conducted bivariate analyses to identify independent factors that were significantly associated with each of the outcomes at $P<.20$, estimating unadjusted odds ratios and their 95% CIs. Those variables were entered in the final multivariable models simultaneously, where $P<.05$ defined factors that were significantly associated with the outcomes in the final models.

Results

Sample Characteristics

Of the 675 eligible women approached from August 2013 to January 2015, 636 agreed to participate (participation rate: 94.2%, 636/675) and were randomized to the intervention ($n=305$) and control ($n=331$) groups. A total of 5 women withdrew from the study following group allocation: 3 in the intervention group and 2 in the control group (see [Figure 1](#)). There were no statistically significant differences at baseline between the two groups.

[Table 1](#) shows that the majority of pregnant women were between 25 and 34 years of age, partnered, white, had incomes of Can \$80,000 or more, had at least some postsecondary education and were pregnant with their first child. One-quarter of participants had been diagnosed and treated for a mental health concern before recruitment. The majority of women were comfortable using laptops, computer tablets, and smartphones. Missing data were less than 3.0% (19/636) for all variables, with the majority having less than 1.5% (10/636); thus, data imputation was not used.

Primary and Secondary Objectives

Primary Objectives

Perceived Risk and Benefit of Disclosure: Description of Items of the Risk and Utility Subscales

There were no significant differences between groups on any of the items of the risk or benefit subscales of the DES ([Multimedia Appendix 1](#)). In terms of risk, the item with the most endorsements was "How vulnerable would you feel if you disclosed something very personal to your doctor or nurse that you have never told anyone before," with 42.4% (128/302) of women in the e-screening group and 43.8% (144/329) in the paper-based group indicating disclosure of a mental health concern would make them feel somewhat, moderately, or very vulnerable ([Multimedia Appendix 1](#)). This was followed by women endorsing that they would perceive disclosure as somewhat or moderately or very "risky" (e-screening 34.4% [104/302]; paper 35.3% [116/329]), "worrisome" (e-screening 29.5% [89/302]; paper 32.5% [107/329]), and "difficult" (e-screening 22.2% [67/302]; paper 21.0% [69/329]) ([Multimedia Appendix 1](#)).

From a benefits perspective, the majority of women in both groups felt they would get a useful response from their provider if they disclosed their concerns (e-screening 81.1% [245/302]; paper 83.9% [276/329]), and it would be beneficial to do so (e-screening 83.1% [251/302]; paper 81.5% [268/329]). Additionally, 76.8% (485/631) of women felt that it would be helpful to talk to their provider about a mental health problem (e-screening 76.2% [230/302]; paper 77.5% [255/329]), and it would feel better to have the opportunity to discuss their feelings of anxiety or depression with them (e-screening 70.9% [214/302]; paper 77.5% [255/329]).

Table 1. Sample characteristics (N=636).

Characteristics	Full sample (N=636 ^a)	Paper-based screening group (n=331 ^a)	E-screening group (n=305 ^a)	P value ^b
Recruitment site, n (%)				
Community-based clinic	423 (67.8)	224 (70.0)	199 (65.5)	.47
High-risk antenatal unit	70 (11.2)	34 (10.6)	36 (11.8)	
Prenatal class, n (%)	131 (21.0)	62 (19.4)	69 (22.7)	
Age, n (%)				
<25 years	88 (13.9)	50 (15.2)	38 (12.5)	.51
25-34 years	459 (72.2)	233 (70.6)	226 (74.6)	
35+	86 (13.6)	47 (14.2)	39 (12.9)	
Income, n (%)				
Below \$40,000	97 (15.4)	52 (15.8)	45 (14.9)	.81
\$40,000-\$79,999	139 (22.0)	75 (22.8)	64 (21.2)	
\$80,000 or more	395 (62.6)	202 (61.4)	193 (63.9)	
Education, n (%)				
High school or less	100 (15.8)	57 (17.3)	43 (14.2)	.29
Some postsecondary or more	531 (84.2)	272 (82.7)	259 (85.8)	
Marital status, n (%)				
Unpartnered	27 (4.3)	14 (4.3)	13 (4.3)	.98
Partnered	604 (95.7)	315 (95.7)	289 (95.7)	
Ethnicity, n (%)				
Not white	169 (26.8)	91 (27.7)	78 (25.8)	.60
white	462 (73.2)	238 (72.3)	224 (74.2)	
Born in Canada, n (%)				
No	119 (18.9)	66 (20.1)	53 (17.5)	.42
Yes	512 (81.1)	263 (79.9)	249 (82.5)	
Ever diagnosed with depression, anxiety, or any other kind of emotional concern, n (%)				
Yes	164 (25.9)	86 (26.1)	78 (25.7)	.91
No	470 (74.1)	244 (73.9)	226 (74.3)	
Ever treated for depression, anxiety, or any other kind of emotional concern, n (%)				
Yes	179 (28.2)	92 (27.9)	87 (28.6)	.84
No	455 (71.8)	238 (72.1)	217 (71.4)	
Pregnant before, n (%)				
First child	426 (69.3)	213 (68.5)	213 (70.1)	.67
Not first child	189 (30.7)	98 (31.5)	91 (29.9)	
Weeks gestation, mean (SD ^c)	9.00 (6.46)	8.61 (6.08)	9.39 (6.80)	.22
Used fertility treatments to become pregnant, n (%)				
Yes	35 (5.5)	17 (5.2)	18 (5.9)	.67
No	599 (94.5)	313 (94.8)	286 (94.1)	
ACEs^d score n (%)				
Score greater than or equal to 4	113 (18.0)	64 (19.5)	49 (16.3)	.31

Characteristics	Full sample (N=636 ^a)	Paper-based screening group (n=331 ^a)	E-screening group (n=305 ^a)	P value ^b
Score less than 4	516 (82.0)	265 (80.5)	251 (83.7)	
I am comfortable using a computer or laptop, n (%)				
Very comfortable	591 (93.7)	311 (94.5)	280 (92.7)	.45
Somewhat comfortable	36 (5.7)	17 (5.2)	19 (6.3)	
Not very comfortable	4 (0.6)	1 (0.3)	3 (1.0)	
I am comfortable using a computer tablet (eg, iPad), n (%)				
Very comfortable	530 (84.0)	280 (85.1)	250 (82.8)	.64
Somewhat comfortable	89 (14.1)	44 (13.4)	45 (14.9)	
Not very comfortable	12 (1.9)	5 (1.5)	7 (2.3)	
I am comfortable using a mobile phone, n (%)				
Very comfortable	546 (86.5)	286 (86.9)	260 (86.1)	.32
Somewhat comfortable	70 (11.1)	38 (11.6)	32 (10.6)	
Not very comfortable	15 (2.4)	5 (1.5)	10 (3.3)	

^aSome demographic data missing.

^bComparison of control and intervention groups: χ^2 statistic used for variables with three or more categories; two-tailed *t* test used for variables with estimated means.

^cSD: standard deviation.

^dACEs: adverse childhood experiences.

Perceived Risk and Benefit of Disclosure: Mean Scores of the Risk and Utility Subscales

There were no statistically significant differences between the e-screening and paper-based groups on the mean (SD) scores of the risk subscale (mean=8.51, SD=3.59 vs mean=8.57, SD=3.73) nor the utility (benefit) subscale (mean=14.11, SD=4.05 vs mean=14.17, SD=4.03) (Table 2).

Secondary Outcome

Factors Associated With Perceiving Risk in Disclosure of Prenatal Mental Health Problems

Among the twelve independent variables that we tested (including mode of screening), five variables were significantly associated with perceived risk of disclosing prenatal mental health problems: income, marital status, previously treated for depression or anxiety, born in Canada, and parity (data not

shown). In the final multivariable linear regression model (Table 3), low income, being treated previously for depression or anxiety, and being pregnant with the first child were significantly associated with perceiving greater risk in disclosing mental health concerns. On the basis of the partial eta squared, the effect size for each of these variables in terms of their contributions to risk of disclosure is very small.

Factors Associated With Perceiving Benefit in Disclosure of Prenatal Mental Health Problems

In bivariate analyses, age (under 25 years) and nulliparity were significantly associated with the perceived benefit of disclosure based on the utility subscale of the DES. No variables were significant in the final multiple linear regression model of factors associated with pregnant women perceiving benefit in disclosing mental health problems to their prenatal care providers (Table 4).

Table 2. Mean scores of risk and benefit subscales of the Disclosure Expectations Scale (N=629).

Primary outcome	Overall, mean (SD)	Paper, mean (SD)	E-screening, mean (SD)	<i>t</i> statistic (degrees of freedom)	P value ^a
Risk score	8.54 (3.66)	8.57 (3.73)	8.51 (3.59)	0.222 (629)	.82
Benefit score	14.14 (4.03)	14.17 (4.03)	14.11 (4.05)	0.189 (629)	.85

^aComparison of control and intervention groups: χ^2 statistic used for variables with three or more categories; two-tailed *t* test used for variables with estimated means.

Table 3. Multiple linear regression of factors associated with perceiving risk in disclosure of prenatal mental health problems.

Variable ^a	Beta (95% CI)	Standard error	Beta	P value	Partial eta squared ^b
Income (less than Can \$40,000)	1.11 (0.25-1.98)	0.44	.11	.01	0.010
Marital status (unpartnered)	.69 (–0.77 to 2.16)	0.75	.04	.35	0.001
Treated previously for depression anxiety (treated) ^c	.84 (0.19-1.49)	0.33	.10	.01	0.010
Born in Canada (No) ^c	–.76 (–1.55 to 0.03)	0.40	–.08	.06	0.006
Parity (first child)	.85 (0.23-1.46)	0.31	.11	.007	0.012

^aIndependent variables with $P < .20$ were entered simultaneously into the final model, including income, marital status, previously treated for depression or anxiety, born in Canada, and parity. The supplementary table of the univariate analysis is available from the corresponding author.

^bOn the basis of guidelines [32], a partial eta squared of >0.01 is a small effect size, >0.06 is medium, and >0.14 is large.

^c“Diagnosed and treated previously for depression or anxiety” were highly correlated and could not be entered into the same model (Pearson $r = .85$). Similarly, “born in Canada” and “ethnicity” were highly correlated (Pearson $r = .60$) and not entered together.

Table 4. Multiple linear regression of factors associated with pregnant women perceiving benefit in disclosure of prenatal mental health problems.

Variable ^a	B (95% CI)	Standard error	Beta	P value	Partial eta squared ^b
Age (under 25 years)	–.77 (–1.68 to 0.15)	0.47	–.07	.10	0.004
Parity (first child)	.21 (–0.49 to 0.90)	0.35	.02	.56	0.001

^aIndependent variables with $P < .20$ were entered simultaneously into the final model, including maternal age and parity. The supplementary table of the univariate analysis is available from the corresponding author.

^bOn the basis of guidelines [32], a partial eta squared of >0.01 is a small effect size, >0.06 is medium, and >0.14 is large.

Discussion

Interpretation

This trial adds substantially to the limited evidence on implementation of screening during the perinatal period by providing data on women’s views of the benefits and risks of disclosure of mental health concerns by mode of screening. In this study, 76.8 (485/631) of women perceived that mental health screening was beneficial. However, 21.6% (136/631) to 43.1% (272/631) of women perceived that disclosure held some degree of risk in that they viewed it as risky and worrisome, reporting that it made them feel vulnerable. There were no differences in groups in the mean scores of the risk and benefit of disclosure subscales. In multivariable linear regression analyses, we found that women of low income, those who had been treated previously for depression or anxiety, and those pregnant with their first child were more likely to perceive a greater risk in disclosing mental health concerns compared with women of higher income, who had never been treated for mental health problems, and who were multiparous. We found no factors that were associated with perceiving benefit in screening. Mode of screening (paper-based vs e-screening) was not significantly associated with either perceived risk or benefit of screening.

Overall, pregnant women perceived both paper-based and e-mental health screening to be beneficial. These findings are consistent with our cross-sectional study (N=460), where 97.6% (449/460) of pregnant women surveyed reported that they were very or somewhat comfortable with completing paper-based screening at home (92.3%, 425/460) or in a maternity clinic (90.4%, 416/460), as well as computer-based (86.0%, 395/460) screening [33]. They are also consistent with the study’s finding

that 97.3% (448/460) of pregnant women were comfortable with provider-initiated screening, whereas only two-thirds were comfortable with self-initiating discussions about their mental health concerns. Others have also reported a general acceptability of routine mental health screening in Australia, following the initiation of universal prenatal screening through the National Depression Initiative [34–37] and in the United States in hospital-based [14] and regional perinatal screening programs [38].

Women’s views of the benefits of screening did not vary by mode of screening. This result indicates that the way women were screened (paper or e-screening) did not influence the value of screening that women perceived in terms of its overall benefit, usefulness, helpfulness, or contribution in making them feel better. This positive finding suggests that whatever mode of screening providers choose to implement in their clinical settings will be viewed as beneficial by women. Similarly, the nonsignificant difference in the mean scores of the risk subscale reveals that women in the paper-based and e-screening groups viewed the degree of risk of disclosure similarly. On one hand, this is positive in that the providers can be assured that the risk that women perceive is independent of the mode of screening they choose to employ in their clinical settings.

However, it is concerning that 43.1% (272/631) of women find screening a vulnerable process. Again, that a similar number of women in both groups reported some degree of vulnerability indicates that this was unrelated to the way the screening questions were delivered and more likely linked to other aspects of the screening process such as the way screening is introduced or debriefed, provider characteristics, or the provider-client relationship. Several studies have shown the importance of provider characteristics and relationships on screening, including

being heard and trusting the provider [39], the ability of the provider to make a connection, being empathetic [40] and being a “good fit” (eg, we “clicked”) [13] were key aspects of successful treatment, whereas friendly, sensitive, warm, and caring attributes facilitated the screening process [41]. Conversely, negative experiences with perinatal health care providers have also been shown as detrimental to addressing perinatal depression, including women having their concerns dismissed, perceiving that their provider was inadequately prepared to assess and discuss perinatal depression, being unprepared for the process or the nature of the questions, feeling anxious and vulnerable when raising distressing histories, and seeing the screening process as intrusive [42]. Our own studies mirror these findings. We reported that women who had a relationship with their provider that fostered honesty were less likely to be deterred by potential barriers to screening [15,33,43], and those who had a sensitive and caring and interested provider were more likely to engage in screening [15,33,43]. These studies all support the conclusion that “the way in which clinicians interact with patients about depression might strongly influence patient responses” [39]. Our research has also shown that women were more likely to engage in screening if certain aspects of the process were in place, such as having an explanation about why some sensitive questions were asked, knowing what to expect if she revealed emotional struggles, being reassured that other women also have prenatal emotional problems, and knowing that talking about emotional health is a part of routine prenatal care [15].

We might have seen a difference in vulnerability by screening mode if we had included a face-to-face screening arm. For instance, qualitative studies of postpartum women have reported that face-to-face screening and discussions around treatment make women feel significantly vulnerable [44,45]. The findings of this study support the importance of the screening process as a whole, in that the mode of screening alone (e-screening vs paper) does not seem to mitigate the vulnerability that women experience during mental health screening.

Although the effect sizes were small, the findings that women of low income, those who had been treated previously for depression or anxiety, and those pregnant with their first child were more likely to perceive a greater risk in disclosing mental health concerns are important in identifying potential subgroups of women who may find screening a more vulnerable process. Given that our sample was quite demographically homogeneous, further research on the views of screening among these subgroups of women is warranted.

Of importance, this study demonstrated that mode of screening was not associated with perceived risk of screening. This finding is positive in light of how little we know about how women perceive e-screening and suggests that e-screening is a viable option for delivering mental health screening. Finally, that no subgroups of women were identified as perceiving greater or less benefit from screening suggests that all women, regardless of demographics or previous mental health history, find mental health screening beneficial. Mode of screening was also not identified as having an impact on perceived benefit, indicating that women find equal benefit from screening regardless of whether the questions are delivered on paper or tablet.

Limitations

Our sample was quite demographically homogeneous with the majority of women being partnered and well educated, as well as being born in Canada. However, our findings suggest that some subgroups of women may perceive mental health screening as more vulnerable. Future research should explore such women’s views of mental health screening in greater depth.

Conclusions

Women in this sample generally perceived mental health assessment as beneficial. However, a substantial number of them felt vulnerable during the screening process for mental health issues, and their perceptions were not mitigated by the mode of screening. Mode of screening was not related to women’s perceptions of the risk or benefit of screening.

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Authors' Contributions

DK, MA, SVZ, and AB designed the study. DK, MA, SVZ, SM, GM, and AB reviewed and contributed to the final grant. DK and SVZ managed the trial, whereas DK, SVZ, MA, and LV monitored trial processes. DK, RG, AB, and LV designed, conducted, and interpreted the analysis. DK led the writing of the manuscript. All authors were involved and contributed equally in the interpretation of findings and the critical review of the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Risks and benefits of disclosure of paper-based versus e-screening (N=631).

[PDF File (Adobe PDF File), 61KB - [mental_v4i4e42_app1.pdf](#)]

Multimedia Appendix 2

CONSORT - EHEALTH checklist (V.1.6.1).

[PDF File (Adobe PDF File), 768KB - [mental_v4i4e42_app2.pdf](#)]

References

- Kingston D. Policywise. 2011. The effects of prenatal and postpartum maternal psychological distress on child development: a systematic review URL: <https://policywise.com/wp-content/uploads/resources/2016/07/TheEffectsofPrenatalandPostpartumMaternalPsychologicalDistressonChildDevelopmentASystematicReviewpdf-Kingston-Dawn.pdf> [accessed 2017-09-07] [WebCite Cache ID 6tIBnkOTu]
- van der Waerden J, Galéra C, Larroque B, Saurel-Cubizolles M, Sutter-Dallay A, Melchior M, EDEN Mother-Child Cohort Study Group. Maternal depression trajectories and children's behavior at age 5 years. *J Pediatr* 2015 Jun;166(6):1440-8.e1. [doi: [10.1016/j.jpeds.2015.03.002](#)] [Medline: [25866387](#)]
- Giallo R, Woolhouse H, Gartland D, Hiscock H, Brown S. The emotional-behavioural functioning of children exposed to maternal depressive symptoms across pregnancy and early childhood: a prospective Australian pregnancy cohort study. *Eur Child Adolesc Psychiatry* 2015 Oct;24(10):1233-1244. [doi: [10.1007/s00787-014-0672-2](#)] [Medline: [25572869](#)]
- Kingston D, Tough S, Whitfield H. Prenatal and postpartum maternal psychological distress and infant development: a systematic review. *Child Psychiatry Hum Dev* 2012 Oct;43(5):683-714. [doi: [10.1007/s10578-012-0291-4](#)] [Medline: [22407278](#)]
- NICE. NICE. 2014. Antenatal and postnatal mental health: clinical management and service guidance URL: <https://www.nice.org.uk/guidance/cg192> [accessed 2017-09-07] [WebCite Cache ID 6tIByXniC]
- Austin M, Highet N. NLA. 2011. Clinical practice guidelines for depression and related disorders - anxiety, bipolar disorder and puerperal psychosis - in the perinatal period [electronic resource] : a guideline for primary care health professionals / Australian Institute of Health and Welfare URL: <http://trove.nla.gov.au/work/38884367?selectedversion=NBD46738572> [accessed 2017-09-07] [WebCite Cache ID 6tICJPoBq]
- O'Connor E, Rossom RC, Henninger M, Groom HC, Burda BU. Primary care screening for and treatment of depression in pregnant and postpartum women: evidence report and systematic review for the US preventive services task force. *JAMA* 2016 Jan 26;315(4):388-406. [doi: [10.1001/jama.2015.18948](#)] [Medline: [26813212](#)]
- Siu AL, Bibbins-Domingo K, Grossman DC, Baumann LC, Davidson KW, Ebell M, et al. Screening for depression in adults: US preventive services task force recommendation statement. *JAMA* 2016 Jan 26;315(4):380-387. [doi: [10.1001/jama.2015.18392](#)] [Medline: [26813211](#)]
- Byatt N, Simas TA, Lundquist RS, Johnson JV, Ziedonis DM. Strategies for improving perinatal depression treatment in North American outpatient obstetric settings. *J Psychosom Obstet Gynaecol* 2012 Dec;33(4):143-161. [doi: [10.3109/0167482X.2012.728649](#)] [Medline: [23194018](#)]
- Kerker BD, Storfer-Isser A, Stein RE, Garner A, Szilagyi M, O Connor KG, et al. Identifying maternal depression in pediatric primary care: changes over a decade. *J Dev Behav Pediatr* 2016;37(2):113-120. [doi: [10.1097/DBP.0000000000000255](#)] [Medline: [26836638](#)]
- Leddy M, Haaga D, Gray J, Schulkin J. Postpartum mental health screening and diagnosis by obstetrician-gynecologists. *J Psychosom Obstet Gynaecol* 2011 Mar;32(1):27-34. [doi: [10.3109/0167482X.2010.547639](#)] [Medline: [21261561](#)]
- Delatte R, Cao H, Meltzer-Brody S, Menard MK. Universal screening for postpartum depression: an inquiry into provider attitudes and practice. *Am J Obstet Gynecol* 2009 May;200(5):e63-e64. [doi: [10.1016/j.ajog.2008.12.022](#)] [Medline: [19285644](#)]
- Kim J, La PL, Corcoran M, Magasi S, Batza J, Silver R. Barriers to mental health treatment among obstetric patients at risk for depression. *Am J Obstet Gynecol* 2010 Mar;202(3):312.e1-312.e5. [doi: [10.1016/j.ajog.2010.01.004](#)] [Medline: [20207252](#)]
- Venkatesh KK, Nadel H, Blewett D, Freeman MP, Kaimal AJ, Riley LE. Implementation of universal screening for depression during pregnancy: feasibility and impact on obstetric care. *Am J Obstet Gynecol* 2016 Oct;215(4):517.e1-517.e8. [doi: [10.1016/j.ajog.2016.05.024](#)] [Medline: [27210067](#)]
- Kingston D, Austin M, Heaman M, McDonald S, Lasiuk G, Sword W, et al. Barriers and facilitators of mental health screening in pregnancy. *J Affect Disord* 2015 Nov 1;186:350-357. [doi: [10.1016/j.jad.2015.06.029](#)] [Medline: [26281038](#)]
- Canadian Task Force on Preventive Health Care, Joffres M, Jaramillo A, Dickinson J, Lewin G, Pottie K, et al. Recommendations on screening for depression in adults. *CMAJ* 2013 Jun 11;185(9):775-782 [FREE Full text] [doi: [10.1503/cmaj.130403](#)] [Medline: [23670157](#)]

17. Thombs BD, Arthurs E, Coronado-Montoya S, Roseman M, Delisle VC, Leavens A, et al. Depression screening and patient outcomes in pregnancy or postpartum: a systematic review. *J Psychosom Res* 2014 Jun;76(6):433-446. [doi: [10.1016/j.jpsychores.2014.01.006](https://doi.org/10.1016/j.jpsychores.2014.01.006)] [Medline: [24840137](#)]
18. Renker PR. Breaking the barriers: the promise of computer-assisted screening for intimate partner violence. *J Midwifery Womens Health* 2008;53(6):496-503. [doi: [10.1016/j.jmwh.2008.07.017](https://doi.org/10.1016/j.jmwh.2008.07.017)] [Medline: [18984505](#)]
19. Renker PR, Tonkin P. Women's views of prenatal violence screening: acceptability and confidentiality issues. *Obstet Gynecol* 2006 Feb;107(2 Pt 1):348-354. [doi: [10.1097/01.AOG.0000195356.90589.c5](https://doi.org/10.1097/01.AOG.0000195356.90589.c5)] [Medline: [16449123](#)]
20. Locke SE, Kowaloff HB, Hoff RG, Safran C, Popovsky MA, Cotton DJ, et al. Computer interview for screening blood donors for risk of HIV transmission. *MD Comput* 1994;11(1):26-32. [Medline: [8145632](#)]
21. MacMillan HL, Wathen CN, Jamieson E, Boyle M, McNutt L, Worster A, et al. Approaches to screening for intimate partner violence in health care settings: a randomized trial. *JAMA* 2006 Aug 2;296(5):530-536. [doi: [10.1001/jama.296.5.530](https://doi.org/10.1001/jama.296.5.530)] [Medline: [16882959](#)]
22. Turner CF, Ku L, Rogers SM, Lindberg LD, Pleck JH, Sonenstein FL. Adolescent sexual behavior, drug use, and violence: increased reporting with computer survey technology. *Science* 1998 May 08;280(5365):867-873 [FREE Full text] [Medline: [9572724](#)]
23. Kingston D, McDonald S, Biringer A, Austin M, Hegadoren K, McDonald S, et al. Comparing the feasibility, acceptability, clinical-, and cost-effectiveness of mental health e-screening to paper-based screening on the detection of depression, anxiety, and psychosocial risk in pregnant women: a study protocol of a randomized, parallel-group, superiority trial. *Trials* 2014 Jan 02;15:3 [FREE Full text] [doi: [10.1186/1745-6215-15-3](https://doi.org/10.1186/1745-6215-15-3)] [Medline: [24383441](#)]
24. Kingston D, Austin M, Veldhuyzen van Zanten S, Harvalik P, Giallo R, McDonald SD, et al. Pregnant women's views on the feasibility and acceptability of web-based mental health e-screening versus paper-based screening: a randomized controlled trial. *J Med Internet Res* 2017 Apr 07;19(4):e88 [FREE Full text] [doi: [10.2196/jmir.6866](https://doi.org/10.2196/jmir.6866)] [Medline: [28389421](#)]
25. Blackmore ER, Carroll J, Reid A, Biringer A, Glazier RH, Midmer D, et al. The use of the antenatal psychosocial health assessment (ALPHA) tool in the detection of psychosocial risk factors for postpartum depression: a randomized controlled trial. *J Obstet Gynaecol Can* 2006 Oct;28(10):873-878. [Medline: [17140502](#)]
26. Carroll JC, Reid AJ, Biringer A, Midmer D, Glazier RH, Wilson L, et al. Effectiveness of the antenatal psychosocial health assessment (ALPHA) form in detecting psychosocial concerns: a randomized controlled trial. *CMAJ* 2005 Aug 2;173(3):253-259 [FREE Full text] [doi: [10.1503/cmaj.1040610](https://doi.org/10.1503/cmaj.1040610)] [Medline: [16076821](#)]
27. Reid AJ, Biringer A, Carroll JD, Midmer D, Wilson LM, Chalmers B, et al. Using the ALPHA form in practice to assess antenatal psychosocial health. *Antenatal psychosocial health assessment*. *CMAJ* 1998 Sep 22;159(6):677-684 [FREE Full text] [Medline: [9780969](#)]
28. Cox JL, Holden JM, Sagovsky R. Detection of postnatal depression. Development of the 10-item Edinburgh postnatal depression scale. *Br J Psychiatry* 1987 Jun;150:782-786. [Medline: [3651732](#)]
29. Chan A, Tetzlaff JM, Gøtzsche PC, Altman DG, Mann H, Berlin JA, et al. SPIRIT 2013 explanation and elaboration: guidance for protocols of clinical trials. *BMJ* 2013;346:e7586 [FREE Full text] [Medline: [23303884](#)]
30. Thabane L, Ma J, Chu R, Cheng J, Ismaila A, Rios LP, et al. A tutorial on pilot studies: the what, why and how. *BMC Med Res Methodol* 2010;10:1 [FREE Full text] [doi: [10.1186/1471-2288-10-1](https://doi.org/10.1186/1471-2288-10-1)] [Medline: [20053272](#)]
31. Vogel DL, Wester SR. To seek help or not to seek help: The risks of self-disclosure. *J Couns Psychol* 2003;50(3):351-361. [doi: [10.1037/0022-0167.50.3.351](https://doi.org/10.1037/0022-0167.50.3.351)]
32. Bannion W. *The 7 Steps of Data Analysis: A Manual for Conducting a Quantitative Research Study*. New York: Whisperer Press; 2013:1-353.
33. Kingston DE, Biringer A, McDonald SW, Heaman MI, Lasiuk GC, Hegadoren KM, et al. Preferences for mental health screening among pregnant women: a cross-sectional study. *Am J Prev Med* 2015 Oct;49(4):e35-e43. [doi: [10.1016/j.amepre.2015.03.026](https://doi.org/10.1016/j.amepre.2015.03.026)] [Medline: [26143952](#)]
34. Buist A, Condon J, Brooks J, Speelman C, Milgrom J, Hayes B, et al. Acceptability of routine screening for perinatal depression. *J Affect Disord* 2006 Jul;93(1-3):233-237. [doi: [10.1016/j.jad.2006.02.019](https://doi.org/10.1016/j.jad.2006.02.019)] [Medline: [16647761](#)]
35. Buist A, Ellwood D, Brooks J, Milgrom J, Hayes BA, Sved-Williams A, et al. National program for depression associated with childbirth: the Australian experience. *Best Pract Res Clin Obstet Gynaecol* 2007 Apr;21(2):193-206. [doi: [10.1016/j.bpobgyn.2006.11.003](https://doi.org/10.1016/j.bpobgyn.2006.11.003)] [Medline: [17175198](#)]
36. Gemmill A, Leigh B, Ericksen J, Milgrom J. A survey of the clinical acceptability of screening for postnatal depression in depressed and non-depressed women. *BMC Public Health* 2006 Aug 17;6:211 [FREE Full text] [doi: [10.1186/1471-2458-6-211](https://doi.org/10.1186/1471-2458-6-211)] [Medline: [16914061](#)]
37. Matthey S, White T, Phillips J, Taouk R, Chee TT, Barnett B. Acceptability of routine antenatal psychosocial assessments to women from English and non-English speaking backgrounds. *Arch Womens Ment Health* 2005 Sep;8(3):171-180. [doi: [10.1007/s00737-005-0076-x](https://doi.org/10.1007/s00737-005-0076-x)] [Medline: [15915317](#)]
38. Byatt N, Biebel K, Moore ST, Sarvet B, Ravech M, Allison J, et al. Improving perinatal depression care: the Massachusetts child psychiatry access Project for moms. *Gen Hosp Psychiatry* 2016;40:12-17. [doi: [10.1016/j.genhosppsy.2016.03.002](https://doi.org/10.1016/j.genhosppsy.2016.03.002)] [Medline: [27079616](#)]

39. Henshaw EJ, Flynn HA, Himle JA, O'Mahen HA, Forman J, Fedock G. Patient preferences for clinician interactional style in treatment of perinatal depression. *Qual Health Res* 2011 Jul;21(7):936-951. [doi: [10.1177/1049732311403499](https://doi.org/10.1177/1049732311403499)] [Medline: [21429945](https://pubmed.ncbi.nlm.nih.gov/21429945/)]
40. Bennett HA, Boon HS, Romans SE, Grootendorst P. Becoming the best mom that I can: women's experiences of managing depression during pregnancy--a qualitative study. *BMC Womens Health* 2007 Sep 11;7:13 [FREE Full text] [doi: [10.1186/1472-6874-7-13](https://doi.org/10.1186/1472-6874-7-13)] [Medline: [17848199](https://pubmed.ncbi.nlm.nih.gov/17848199/)]
41. Rollans M, Schmied V, Kemp L, Meade T. Digging over that old ground: an Australian perspective of women's experience of psychosocial assessment and depression screening in pregnancy and following birth. *BMC Womens Health* 2013 Apr 09;13:18 [FREE Full text] [doi: [10.1186/1472-6874-13-18](https://doi.org/10.1186/1472-6874-13-18)] [Medline: [23570282](https://pubmed.ncbi.nlm.nih.gov/23570282/)]
42. Byatt N, Biebel K, Friedman L, Debordes-Jackson G, Ziedonis D, Pbert L. Patient's views on depression care in obstetric settings: how do they compare to the views of perinatal health care professionals? *Gen Hosp Psychiatry* 2013;35(6):598-604 [FREE Full text] [doi: [10.1016/j.genhosppsych.2013.07.011](https://doi.org/10.1016/j.genhosppsych.2013.07.011)] [Medline: [23969144](https://pubmed.ncbi.nlm.nih.gov/23969144/)]
43. Kingston DE, Biringer A, Toosi A, Heaman MI, Lasiuk GC, McDonald SW, et al. Disclosure during prenatal mental health screening. *J Affect Disord* 2015 Nov 1;186:90-94. [doi: [10.1016/j.jad.2015.07.003](https://doi.org/10.1016/j.jad.2015.07.003)] [Medline: [26233318](https://pubmed.ncbi.nlm.nih.gov/26233318/)]
44. Poole H, Mason L, Osborn T. Women's views of being screened for postnatal depression. *Community Pract* 2006 Nov;79(11):363-367. [Medline: [17100363](https://pubmed.ncbi.nlm.nih.gov/17100363/)]
45. Flynn H, Henshaw E, O'Mahen H, Forman J. Patient perspectives on improving the depression referral processes in obstetrics settings: a qualitative study. *Gen Hosp Psychiatry* 2010;32(1):9-16 [FREE Full text] [doi: [10.1016/j.genhosppsych.2009.07.005](https://doi.org/10.1016/j.genhosppsych.2009.07.005)] [Medline: [20114123](https://pubmed.ncbi.nlm.nih.gov/20114123/)]

Abbreviations

ALPHA: Antenatal Psychosocial Health Assessment
DES: Disclosure Expectations Scale
EPDS: Edinburgh Postnatal Depression Scale
MINI: Mini-International Neuropsychiatric Interview
NHMRC: National Health and Medical Research Council
RCT: randomized controlled trial
SD: standard deviation

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Original Paper

A Web-Based Study of Dog Ownership and Depression Among People Living With HIV

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Abstract

Background: People living with human immunodeficiency virus (PLHIV) are approximately twice as likely to be depressed compared with HIV-negative individuals. Depression is consistently associated with low antiretroviral therapy (ART) adherence, an important step within the HIV care continuum related to HIV disease progression and overall health. One factor that may have positive psychosocial benefits and promote ART adherence is dog ownership. Research indicates that dog ownership is associated with lower depression, and initial evidence suggests its positive impact on psychosocial outcomes for PLHIV.

Objective: The aim of our study was to expand the existing research by examining the relationship between current dog ownership and depression for a sample of PLHIV while controlling for demographic characteristics and other potential confounders.

Methods: Participants aged 18 years or older and who self-reported an HIV diagnosis were recruited via social media into *When Dogs Heal*, a cross-sectional Web-based survey to collect data among adult PLHIV. The research visit was conducted via a Web-based survey, and there was no in-person interaction with the participant. Primary outcome measures included demographic questions (age, race, ethnicity, gender, and sexual orientation), pet ownership (type of pet owned and current dog ownership), depression (Center for Epidemiologic Studies Depression Scale, 10 items), and resilience (Resilience Research Centre Adult Resilience Measure, 28 items).

Results: A total of 252 participants were enrolled into the study in January 2016, with a final analytic sample of 199 participants. Mean age was 49 years, 86.4% (172/199) of participants were male, and 80.4% (160/199) were white. Current dog ownership was prevalent among the sample (68.3%, 136/199). Bivariate analysis indicated that there was no significant relationship between depression and demographic characteristics (age, race, ethnicity, gender, and sexual orientation), with $P > .05$. The multivariate logistic regression, including age, race, ethnicity, gender, resilience, and current dog ownership, was significant, with $P < .001$. Of the 6 predictor variables, only 2 were statistically significant: dog ownership and resilience. Noncurrent dog owners had 3 times higher odds of depression in comparison with current dog owners: odds ratio 3.01; 95% CI 1.54-6.21.

Conclusions: Growing evidence suggests that dog ownership reduces the likelihood of depression and, therefore, may confer long-term health benefits on PLHIV. Future studies should explore whether dog-specific interventions are a feasible and efficacious intervention to improve outcomes among PLHIV.

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KEYWORDS

HIV; depression; pet-human bonding

Introduction

In the United States, 1.1 million people are living with human immunodeficiency virus (HIV), with the highest burden among men who have sex with men (MSM), particularly racial and ethnic minority MSM [1]. The improved life expectancy of individuals living with HIV, largely because of antiretroviral therapy (ART) [2] and the shift to treatment as prevention [3], has increased the focus in the United States on linkage to care, engagement, and retention in medical care (including medication adherence), and viral suppression across the HIV care continuum. Among people living with HIV (PLHIV), a high level of ART adherence (at least 80%) may be needed to suppress viral replication and avoid resistance [4-6]; suboptimal adherence can lead to disease progression and decreased life expectancy for HIV-related disease [7-9]. Although the goal in the United States is suppression of the virus in 80% of infected individuals, in the most recent analysis, only 55% of PLHIV were virally suppressed [3,10].

Depression and depressive symptoms are consistently associated with poor ART adherence and overall HIV disease progression—even in a post-ART era [11-15]. Notably, depressive symptoms are prevalent among PLHIV [16-18]. Although it is estimated that approximately 16.1% of all Americans have been diagnosed with depression in their lifetime [19], one large national study (N=1560) found that 63% of PLHIV have experienced depressive symptoms (ie, depressive symptoms lasting 2 weeks or longer in their lifetime) [20]. In addition, Ciesla and Roberts's meta-analysis revealed that PLHIV are almost 2 times more likely to have had a recent major depressive episode (as measured by a diagnostic clinical interview) compared with HIV-negative individuals [21]. Interventions targeting depressive symptoms, particularly mild to moderate symptoms, are warranted and may help to improve HIV-specific health outcomes more generally [22].

One factor that may ameliorate depressive symptoms, promote ART adherence, and potentially assist in improving other HIV-related health outcomes is pet ownership. Pet ownership, in particular dog ownership, has been linked to multiple positive physical, psychological, and psychosocial health outcomes [23]. Evidence from studies exploring pet ownership and other animal-assisted interventions (AAIs) suggest positive physical health outcomes include cardiovascular benefits [24-26], increased physical activity [27-31], reduced cortisol levels [32], and lower blood pressure [33,34], particularly in response to stress [24,32,33,35,36]. Dog ownership is also associated with improved psychological outcomes, including lower depression [37-39], decreased loneliness [30,38,40], and improved general psychological well-being [29,38]. Additionally, evidence suggests that pet dogs facilitate social interactions [30,41-43], act as a catalyst in building social networks [30,43,44], and act as a conduit for building social capital [30,45].

Dog-specific AAIs have been shown to benefit those living with chronic health conditions in particular. Hospitalized pediatric

cancer patients who undergo animal-facilitated therapy with dogs show improved psychological health, decreased worry, and less fear [46,47]. In a review of related literature, Urbanski and Lazenby concluded that, overall, animal-facilitated therapy benefits children living with chronic illnesses, including those who are immunocompromised [48]. An increasing number of people with diabetes are acquiring diabetic alert dogs (DADs) for hypoglycemia detection. Although the evidence demonstrating DADs' ability to accurately detect hypoglycemia is limited and inconclusive, studies indicate that there are positive psychosocial outcomes, including decreased worry [49,50]. The first study to evaluate the objective reliability of DADs in a real-world environment found that despite the 12% positive predictive value, using DADs was feasible and participants were very satisfied with their dog [51]. One vulnerable population with a long-term health condition that may benefit from AAIs with pet dogs is PLHIV.

Similar to the general population, a small body of research suggests positive benefits of pet ownership among PLHIV, including stress reduction and improvement in mood and well-being, particularly for those with less social support [52-56]. One of the first studies to examine the impact of companion animals on PLHIV was a small descriptive study from 1991 [52]. Drawing themes from interviews with a small sample of gay men with HIV/AIDS (acquired immune deficiency syndrome), companion animals were found to provide social support, a means to reduce stress, and a sense of purpose because of the continuous care that participants needed to provide to their pet [52].

The first methodologically rigorous investigation into pet ownership in a sample of gay and bisexual men used data from the Multicenter AIDS Cohort Study, an ongoing observational study of the natural history of HIV/AIDS [57]. Siegel et al analyzed data from 1872 participants of which 708 (38%) were HIV-positive and 214 (11%) had AIDS [55]. For those diagnosed with AIDS, having a pet was associated with less depression, especially among those with lower social support [55]. More recently, a study conducted in 2011 with male US military veterans living with HIV/AIDS found dog ownership positively influenced well-being through companionship, sense of responsibility, and stress reduction [53]. Another cross-sectional study conducted in 2011 among 128 PLHIV in Australia (92% male, 87% nonheterosexual) found that those living with a companion animal (the most common was a dog) had higher levels of emotional well-being and decreased HIV-related negative social interactions compared with those without a companion animal [56].

In sum, initial evidence suggests that dog ownership is associated with positive psychosocial outcomes for PLHIV. In the study described herein, we sought to update this evidence and extend it to a broad target population of PLHIV in the United States. On the basis of prior findings, we hypothesized that among PLHIV, current dog ownership would be associated with fewer depressive symptoms, controlling for demographic

characteristics and other potential confounders. Given the potential for dog ownership to reflect a resilient response to stress (eg, drawing on social capital and social interaction), we also measured and included an indicator of resilience in our models to control for its potential confounding of the dog ownership and depression relationship.

Methods

Participants and Procedure

The study *When Dogs Heal* utilized an open cross-sectional Web-based survey to collect data among adult PLHIV. To recruit participants, messages were posted to social media platforms (eg, Facebook and Twitter) by the principal investigator, who posted about the study one time on each platform. Participants were incentivized to participate by offering a chance to win an Apple iPad. Eligibility criteria included being ≥ 18 years old and self-reporting an HIV diagnosis; dog ownership was not a requirement to enroll. Interested individuals were directed to a Web link with the study screener, consent statement, and survey. The survey was thoroughly tested by study staff before data collection. Upon clicking the link, volunteers were instructed to complete a series of screening questions and, if eligible, proceeded through the consent process before completing the study questionnaire. The survey questionnaire was deployed using Qualtrics, a Web-based data collection software tool based out of Seattle, WA and Provo, UT. Qualtrics utilizes transport layer security (TLS) encryption for all transmitted data and services are hosted by secure data centers. Participants were able to review and change their previous answers through a back button and were typically shown 1 question per page. Browser cookies and Internal Protocol (IP) address were used to prevent duplicate responses from the same individual. This study was approved by the institutional review board at the study site.

Measures

Participants first completed a brief set of demographic questions indicating their primary race (Asian/Pacific Islander, black/African American, white, Latino/Hispanic, other, or multiracial), ethnicity (Spanish/Hispanic/Latino/a), sex assigned at birth (male or female), current gender identity (male, female, or transgender), age, and whether or not they ever owned a pet (yes or no). Participants who reported having ever owned a dog were asked whether they currently owned a dog.

Depression was measured using the shortened Center for Epidemiologic Studies Depression Scale (CES-D10) [58,59]. This 10-item self-report measure of depressive symptoms in the prior week uses a 4-point frequency response scale. This measure has demonstrated excellent reliability and validity in prior research [58,60], as well as in this study ($\alpha=.90$). The CES-D10 was scored by summing the 10 items,

with higher scores indicating increased depressive symptoms. Per scoring criteria, a cut-off score of 10 or greater was used to determine whether the participant met the criteria for depression.

Resiliency, a potential confounding variable, was measured with the Resilience Research Centre Adult Resilience Measure (RRC-ARM), an adapted version of the Child and Youth Resilience Measure (CYRM-28) [61,62]. The 28-item instrument measures the resources available to individuals that may boost their ability to sustain their well-being through individual resources or capabilities, relationship with primary caregivers, and contextual factors that facilitate a sense of belonging [62]. Cronbach alpha for the 3 subscales of the CYRM-28 range from .794 to .833 and subscale correlations range from .555 to .705 [63]. This sample yielded an alpha of .90. An overall resiliency score was created by averaging across all items to achieve a score 1-5, where higher scores indicate higher levels of resilience.

Data Analysis

We used descriptive statistics, including measures of central tendency and dispersion, to characterize the sample. We assessed simple associations between variables using Pearson correlations or chi-square tests, with significance level set at $\alpha < .05$. A multivariable logistic regression analysis assessed the log odds that a participant would meet criteria for depression based on current dog ownership, controlling for age, race, ethnicity, and gender, as well as resilience. Due to low cell numbers, the race variable was dichotomized for analysis (white vs nonwhite). Data were analyzed using SPSS statistics version 24 (IBM Corporation).

Results

Participant Characteristics

In total, 356 data cases were downloaded from Qualtrics, of which 29 cases had a duplicate IP address. The data cases that were most complete were kept in the final dataset, leaving 327 unique volunteers who clicked the survey link; 15 cases that contained no data were deleted (ie, a volunteer clicked the link but did not proceed past the first screen). A total of 28 cases were deleted for not meeting eligibility criteria. Of the participants who were eligible, 32 did not enroll in the study.

A total of 252 adults living with HIV were enrolled into the study in January 2016, yielding a participation rate of 77.1% (252/327). Completion of the study survey took approximately 15 min on average. A total of 51 cases were withdrawn from analysis for largely incomplete responses. The completion rate for the survey was 79.8% (201/252). An additional 2 participants who reported transgender status were removed from the sample because of small cell size for analysis, that is, to minimize the number of variables in analytical models. The final analytic sample included 199 PLHIV.

Table 1. Sample characteristics of adult people living with human immunodeficiency virus (N=199).

Characteristic	Number
Age at baseline, mean (SD)	48.72 (10.68)
Age at HIV diagnosis, mean (SD)	31.89 (9.43)
Years since human immunodeficiency virus (HIV) diagnosis ^a , mean (SD)	16.87 (10.05)
Gender	
Male, n (%)	172 (86.4)
Female, n (%)	27 (13.6)
Race	
Black/African American, n (%)	9 (4.5)
White, n (%)	160 (80.4)
Latino/Hispanic, n (%)	9 (4.5)
Asian/Pacific Islander, n (%)	7 (3.5)
Other and multiracial, n (%)	14 (7.0)
Ethnicity	
Hispanic/Spanish/Latino/a, n (%)	18 (9.0)
Not Hispanic/Spanish/Latino/a, n (%)	181 (91.0)
Sexual orientation	
Homosexual/gay, n (%)	165 (82.9)
Bisexual, n (%)	8 (4.0)
Heterosexual/straight, n (%)	23 (11.6)
Other, n (%)	3 (1.5)
Ever owned a pet	
Yes, n (%)	194 (97.5)
No, n (%)	5 (2.5)
Ever owned a dog	
Yes, n (%)	184 (92.5)
No, n (%)	15 (7.5)
Acquired dog before or after HIV diagnosis^a	
Before, n (%)	57 (31.1)
After, n (%)	126 (68.9)
Dog type	
Companion or household pet, n (%)	168 (91.3)
Therapy dog, n (%)	14 (7.6)
Official service dog, n (%)	2 (1.1)
Current dog ownership	
Yes, n (%)	136 (68.3)
No, n (%)	63 (31.7)

^aOne participant declined to answer this question.

Table 1 summarizes the characteristics of the sample. The mean age was 48.72 years (standard deviation, SD 10.68; range 21-73) with the mean age at HIV diagnosis of 31.89 years (SD 9.43; range 15-67). The average number of years since HIV diagnosis was 16.87 (SD 10.05; range 0-38). Most participants were male

(86.4%, 172/199), white (80.4%, 160/199), not Hispanic/Spanish/Latino/a (91.0%, 181/199), and homosexual or gay (82.9%, 165/199). The vast majority of the sample reported lifetime pet ownership (97.5%, 194/199), with the most commonly reported pet being a dog (92.5%, 184/199). Of the

participants who reported ever having owned a dog, 68.9% (126/183) reported they got their dog after their HIV diagnosis, and 91.3% (168/184) indicated it was a household pet as compared with a therapy dog or official service dog. Current dog ownership was prevalent among the sample (68.3%, 136/199).

Bivariate Analysis

Chi-square tests (with Fisher exact test as needed for low cell sizes) and Pearson correlations indicated that there was no significant relationship between depression and demographic characteristics (N=199): age ($r=-.08$, $P=.28$), race ($\chi^2_1=1.8$, $P=.21$), ethnicity ($\chi^2_1<0.1$, $P>.99$), gender ($\chi^2_1=0.5$, $P=.54$), and sexual orientation ($\chi^2_1=0.6$, $P=.51$). Resilience was

moderately and negatively correlated with depression ($r=-0.31$, $P<.001$) (data not shown).

Multivariate Regression

Table 2 presents the results of the multivariable logistic regression model. Although not significant in bivariate analysis, we retained age, race, ethnicity, and gender in the model for substantive reasons. The logistic regression model was statistically significant, $\chi^2_6=37.206$, $P<.001$. Of the 6 predictor variables, only 2 were statistically significant: dog ownership and resilience. Noncurrent dog owners had 3 times higher odds of depression in comparison with current dog owners (OR 3.01, 95% CI 1.54-6.21), controlling for demographic factors and resilience.

Table 2. Multivariable logistic regression of depression on pet ownership among people living with human immunodeficiency virus (N=199).

Predictor Variables	Beta	Standard error	P value	Odds ratio (95% CI)
Age	-.026	0.015	.08	0.974 (0.946-1.004)
Race (white)	-.687	0.460	.14	0.503 (0.204-1.239)
Ethnicity (Hispanic)	-.203	0.605	.74	0.816 (0.249-2.671)
Gender (male)	-.508	0.500	.31	0.602 (0.226-1.602)
Resilience	-1.201	0.291	<.001	0.301 (0.170-0.533)
Current dog ownership (no)	1.130	0.355	.001	3.095 (1.542-6.213)
Constant	6.427	1.622	<.001	618.620

Discussion

Principal Findings

This study explored the impact of current dog ownership on depression for a sample of adult PLHIV. It was hypothesized that among PLHIV, current dog ownership would be associated with decreased likelihood of meeting depressive criteria. Our hypothesis was supported in that noncurrent dog ownership was significantly and positively associated with depression, controlling for the potential influence of resilience and other demographic factors. Individuals who were not current dog owners had 3 times higher odds of depression compared with current dog owners. This finding adds to and updates prior findings regarding the potential positive impact of dog ownership on depression in PLHIV.

This is a notable finding as depression is the most common psychiatric disorder associated with HIV disease [64]. Depression influences not only the psychological health of PLHIV but is a correlate of overall HIV disease progression as well. Support for or promotion of dog adoption and ownership may be a novel intervention to positively impact depression and, in turn, positively affect other HIV-related health outcomes. The growing adoption of dogs for diabetes-specific intervention and related research will inform feasibility and potential efficacy for PLHIV. The high satisfaction reported by dog owners in DAD programs provides preliminary evidence that full-time dog adoption may be feasible for other populations with chronic illnesses, such as PLHIV. Although research to date suggests benefits of dog ownership among PLHIV, longitudinal and intervention research is needed to establish whether or not dog

adoption is effective in reducing psychological symptoms and promoting overall health.

Although little research has been done on the potential mechanisms of action, dog ownership may impact depression and overall psychological health among PLHIV through bolstering social support networks. Pet dogs may act as a source of social support that can supplement existing support networks or fill network voids for vulnerable populations [24,30,35-39,44,52,65]. Allen and colleagues found evidence that pets, specifically dogs, act as sources of nonevaluative social support when faced with a stressor. This nonevaluative social support may facilitate better and faster physiological responses to mental stress over and above spousal and friend support [24,35,36]. The numerous positive associations of social support for PLHIV, including reduced depression, have been well documented [66,67]. Dog ownership may provide a unique type of social support for PLHIV that positively impacts depression over and above their existing social support networks.

Beyond ameliorating depressive symptoms, dog ownership may also have an effect on other important factors related to health outcomes for PLHIV, including ART adherence. As noted earlier, depression is consistently associated with suboptimal ART adherence. Inadequate social support is also routinely found to be correlated with poor ART adherence [68,69]. One additional mechanism through which dog ownership may influence ART adherence is through the routinization associated with pet care, which reflects the extent to which one's life is organized and follows a predictable pattern [52-54,70]. Routinization has been found to be an important factor in facilitating ART adherence [71-75]. Preliminary evidence

suggests that pets may facilitate the adoption of daily routines into which ART regimens can be incorporated [52-56]. Daily and continuous care for the dog through walking and feeding can provide a source of social interaction and give PLHIV a sense of purpose while establishing a healthy routine for themselves. One qualitative study on routinization found that even when participants were experiencing homelessness, having at least one recurring daily activity was associated with >70% adherence to ART; among the daily activities discussed was walking their dog [56]. Although ART adherence and routinization were not measured in this study, future studies should explore these factors, in addition to social support, as potential mediators of dog ownership on health outcomes for PLHIV.

Limitations

Several limitations of this study should be noted. The data are cross-sectional in nature and therefore causality cannot be inferred. For example, we measured depressive symptoms over the past 7 days, meaning we do not have data regarding onset of depression or whether depressive symptoms preceded or

followed dog companionship. Additionally, only participants with access to the Internet were able to enroll. Although the vast majority of Americans report having access to the Internet, Internet adoption is still closely dependent on income and education [76]. This sample comprised mostly middle-aged, nonheterosexual white men who had been infected for more than 10 years (on average), which is not reflective of the current trends in HIV incidence among younger racial and ethnic minorities. Therefore, findings may not generalize to younger and recently infected PLHIV.

Conclusions

In conclusion, growing evidence suggests that dog ownership reduces the likelihood of depression and, therefore, may confer long-term health benefits on PLHIV. Given this evidence, testing of dog-specific AAIs to reduce depressive symptoms as well as to improve HIV-related health outcomes is a logical next step. Given the relatively low rate of viral suppression in PLHIV in comparison with national targets, innovative interventions are needed to reach goals established under the national HIV/AIDS strategy.

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Conflicts of Interest

None declared.

References

1. Centers for Disease Control and Prevention. CDC. Atlanta, GA; 2017. HIV in the United States: At A Glance URL: <https://www.cdc.gov/hiv/pdf/statistics/overview/cdc-hiv-us-ataglance.pdf> [accessed 2017-10-27] [WebCite Cache ID 6uWyjGiL9]
2. Centers for Disease Control and Prevention. CDC. Atlanta, GA; 2013. HIV Surveillance Report, 2013; vol. 25 URL: <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2013-vol-25.pdf> [accessed 2017-10-27] [WebCite Cache ID 6uWzgnZ5E]
3. White House Office of National AIDS Policy. Washington, DC; 2015. National HIV/AIDS strategy for the United States: Updated to 2020 URL: <https://files.hiv.gov/s3fs-public/nhas-update.pdf> [WebCite Cache ID 6uX0PqRHg]
4. Osterberg L, Blaschke T. Adherence to medication. *N Engl J Med* 2005 Aug 4;353(5):487-497. [doi: [10.1056/NEJMr050100](https://doi.org/10.1056/NEJMr050100)] [Medline: [16079372](https://pubmed.ncbi.nlm.nih.gov/16079372/)]
5. Bangsberg DR. Less than 95% adherence to nonnucleoside reverse-transcriptase inhibitor therapy can lead to viral suppression. *Clin Infect Dis* 2006 Oct 01;43(7):939-941. [doi: [10.1086/507526](https://doi.org/10.1086/507526)] [Medline: [16941380](https://pubmed.ncbi.nlm.nih.gov/16941380/)]
6. Parienti J, Das-Douglas M, Massari V, Guzman D, Deeks SG, Verdon R, et al. Not all missed doses are the same: sustained NNRTI treatment interruptions predict HIV rebound at low-to-moderate adherence levels. *PLoS One* 2008 Jul 30;3(7):e2783 [FREE Full text] [doi: [10.1371/journal.pone.0002783](https://doi.org/10.1371/journal.pone.0002783)] [Medline: [18665246](https://pubmed.ncbi.nlm.nih.gov/18665246/)]
7. Gross R, Bilker WB, Friedman HM, Strom BL. Effect of adherence to newly initiated antiretroviral therapy on plasma viral load. *AIDS* 2001 Nov 09;15(16):2109-2117. [Medline: [11684930](https://pubmed.ncbi.nlm.nih.gov/11684930/)]
8. Lafeuillade A, Tamalet C, Pellegrino P, de Micco P, Vignoli C, Quilichini R. Correlation between surrogate markers, viral load, and disease progression in HIV-1 infection. *J Acquir Immune Defic Syndr* 1994 Oct;7(10):1028-1033. [Medline: [7916049](https://pubmed.ncbi.nlm.nih.gov/7916049/)]
9. McNabb J, Ross JW, Abriola K, Turley C, Nightingale CH, Nicolau DP. Adherence to highly active antiretroviral therapy predicts virologic outcome at an inner-city human immunodeficiency virus clinic. *Clin Infect Dis* 2001 Sep 01;33(5):700-705. [doi: [10.1086/322590](https://doi.org/10.1086/322590)] [Medline: [11486292](https://pubmed.ncbi.nlm.nih.gov/11486292/)]
10. Centers for Disease Control and Prevention. CDC. 2017. Selected National HIV Prevention and Care Outcomes in the United States 2017 URL: <https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-national-hiv-care-outcomes.pdf> [accessed 2017-10-27] [WebCite Cache ID 6uX38Wncr]
11. Beer L, Skarbinski J. Adherence to antiretroviral therapy among HIV-infected adults in the United States. *AIDS Educ Prev* 2014 Dec;26(6):521-537 [FREE Full text] [doi: [10.1521/aeap.2014.26.6.521](https://doi.org/10.1521/aeap.2014.26.6.521)] [Medline: [25490733](https://pubmed.ncbi.nlm.nih.gov/25490733/)]

12. Farinpour R, Miller EN, Satz P, Selnes OA, Cohen BA, Becker JT, et al. Psychosocial risk factors of HIV morbidity and mortality: findings from the Multicenter AIDS Cohort Study (MACS). *J Clin Exp Neuropsychol* 2003 Aug;25(5):654-670. [doi: [10.1076/jcen.25.5.654.14577](https://doi.org/10.1076/jcen.25.5.654.14577)] [Medline: [12815503](https://pubmed.ncbi.nlm.nih.gov/12815503/)]
13. Gonzalez JS, Batchelder AW, Psaros C, Safren SA. Depression and HIV/AIDS treatment nonadherence: a review and meta-analysis. *J Acquir Immune Defic Syndr* 2011 Oct 01;58(2):181-187 [FREE Full text] [doi: [10.1097/QAI.0b013e31822d490a](https://doi.org/10.1097/QAI.0b013e31822d490a)] [Medline: [21857529](https://pubmed.ncbi.nlm.nih.gov/21857529/)]
14. Leserman J. Role of depression, stress, and trauma in HIV disease progression. *Psychosom Med* 2008 Jun;70(5):539-545. [doi: [10.1097/PSY.0b013e3181777a5f](https://doi.org/10.1097/PSY.0b013e3181777a5f)] [Medline: [18519880](https://pubmed.ncbi.nlm.nih.gov/18519880/)]
15. Starace F, Ammassari A, Trotta MP, Murri R, De Longis P, Izzo C, AdICoNA Study Group. NeuroICoNA Study Group. Depression is a risk factor for suboptimal adherence to highly active antiretroviral therapy. *J Acquir Immune Defic Syndr* 2002 Dec 15;31(Suppl 3):S136-S139. [Medline: [12562037](https://pubmed.ncbi.nlm.nih.gov/12562037/)]
16. Bhatia MS, Munjal S. Prevalence of depression in people living with HIV/AIDS undergoing ART and factors associated with it. *J Clin Diagn Res* 2014 Oct;8(10):WC01-WC04 [FREE Full text] [doi: [10.7860/JCDR/2014/7725.4927](https://doi.org/10.7860/JCDR/2014/7725.4927)] [Medline: [25478433](https://pubmed.ncbi.nlm.nih.gov/25478433/)]
17. Bing EG, Burnam MA, Longshore D, Fleishman JA, Sherbourne CD, London AS, et al. Psychiatric disorders and drug use among human immunodeficiency virus-infected adults in the United States. *Arch Gen Psychiatry* 2001 Aug;58(8):721-728. [Medline: [11483137](https://pubmed.ncbi.nlm.nih.gov/11483137/)]
18. Israelski DM, Prentiss DE, Lubega S, Balmas G, Garcia P, Muhammad M, et al. Psychiatric co-morbidity in vulnerable populations receiving primary care for HIV/AIDS. *AIDS Care* 2007 Feb;19(2):220-225. [doi: [10.1080/09540120600774230](https://doi.org/10.1080/09540120600774230)] [Medline: [17364402](https://pubmed.ncbi.nlm.nih.gov/17364402/)]
19. Centers for Disease Control and Prevention. CDC. Atlanta, GA; 2011. Mental Illness Surveillance Among Adults in the United States. Suppl. vol. 60 URL: <https://www.cdc.gov/mmwr/pdf/other/su6003.pdf> [accessed 2017-10-27] [WebCite Cache ID 6uXCBIeq4]
20. Badiie J, Moore DJ, Atkinson JH, Vaida F, Gerard M, Duarte NA, et al. Lifetime suicidal ideation and attempt are common among HIV+ individuals. *J Affect Disord* 2012 Feb;136(3):993-999 [FREE Full text] [doi: [10.1016/j.jad.2011.06.044](https://doi.org/10.1016/j.jad.2011.06.044)] [Medline: [21784531](https://pubmed.ncbi.nlm.nih.gov/21784531/)]
21. Ciesla JA, Roberts JE. Meta-analysis of the relationship between HIV infection and risk for depressive disorders. *Am J Psychiatry* 2001 May;158(5):725-730. [doi: [10.1176/appi.ajp.158.5.725](https://doi.org/10.1176/appi.ajp.158.5.725)] [Medline: [11329393](https://pubmed.ncbi.nlm.nih.gov/11329393/)]
22. Simoni JM, Safren SA, Manhart LE, Lyda K, Grossman CI, Rao D, et al. Challenges in addressing depression in HIV research: assessment, cultural context, and methods. *AIDS Behav* 2011 Feb;15(2):376-388 [FREE Full text] [doi: [10.1007/s10461-010-9836-3](https://doi.org/10.1007/s10461-010-9836-3)] [Medline: [21046221](https://pubmed.ncbi.nlm.nih.gov/21046221/)]
23. Matchock RL. Pet ownership and physical health. *Curr Opin Psychiatry* 2015 Sep;28(5):386-392. [doi: [10.1097/YCO.000000000000183](https://doi.org/10.1097/YCO.000000000000183)] [Medline: [26164613](https://pubmed.ncbi.nlm.nih.gov/26164613/)]
24. Allen K, Blascovich J, Mendes WB. Cardiovascular reactivity and the presence of pets, friends, and spouses: the truth about cats and dogs. *Psychosom Med* 2002;64(5):727-739. [Medline: [12271103](https://pubmed.ncbi.nlm.nih.gov/12271103/)]
25. Arhant-Sudhir K, Arhant-Sudhir R, Sudhir K. Pet ownership and cardiovascular risk reduction: supporting evidence, conflicting data and underlying mechanisms. *Clin Exp Pharmacol Physiol* 2011 Nov;38(11):734-738. [doi: [10.1111/j.1440-1681.2011.05583.x](https://doi.org/10.1111/j.1440-1681.2011.05583.x)] [Medline: [21824172](https://pubmed.ncbi.nlm.nih.gov/21824172/)]
26. Levine GN, Allen K, Braun LT, Christian HE, Friedmann E, Taubert KA, American Heart Association Council on Clinical Cardiology, Council on Cardiovascular and Stroke Nursing. Pet ownership and cardiovascular risk: a scientific statement from the American Heart Association. *Circulation* 2013 Jun 11;127(23):2353-2363 [FREE Full text] [doi: [10.1161/CIR.0b013e31829201e1](https://doi.org/10.1161/CIR.0b013e31829201e1)] [Medline: [23661721](https://pubmed.ncbi.nlm.nih.gov/23661721/)]
27. Cutt H, Giles-Corti B, Knuiman M, Burke V. Dog ownership, health and physical activity: a critical review of the literature. *Health Place* 2007 Mar;13(1):261-272. [doi: [10.1016/j.healthplace.2006.01.003](https://doi.org/10.1016/j.healthplace.2006.01.003)] [Medline: [16503185](https://pubmed.ncbi.nlm.nih.gov/16503185/)]
28. Gretebeck KA, Radius K, Black DR, Gretebeck RJ, Ziemba R, Glickman LT. Dog ownership, functional ability, and walking in community-dwelling older adults. *J Phys Act Health* 2013 Jul;10(5):646-655. [Medline: [23307529](https://pubmed.ncbi.nlm.nih.gov/23307529/)]
29. Serpell J. Beneficial effects of pet ownership on some aspects of human health and behaviour. *J R Soc Med* 1991 Dec;84(12):717-720 [FREE Full text] [Medline: [1774745](https://pubmed.ncbi.nlm.nih.gov/1774745/)]
30. Wood L, Giles-Corti B, Bulsara M. The pet connection: pets as a conduit for social capital? *Soc Sci Med* 2005 Sep;61(6):1159-1173. [doi: [10.1016/j.socscimed.2005.01.017](https://doi.org/10.1016/j.socscimed.2005.01.017)] [Medline: [15970228](https://pubmed.ncbi.nlm.nih.gov/15970228/)]
31. Feng Z, Dibben C, Witham MD, Donnan PT, Vadiveloo T, Sniehotta F, et al. Dog ownership and physical activity in later life: a cross-sectional observational study. *Prev Med* 2014 Sep;66:101-106. [doi: [10.1016/j.ypmed.2014.06.004](https://doi.org/10.1016/j.ypmed.2014.06.004)] [Medline: [24931433](https://pubmed.ncbi.nlm.nih.gov/24931433/)]
32. Polheber JP, Matchock RL. The presence of a dog attenuates cortisol and heart rate in the Trier Social Stress Test compared to human friends. *J Behav Med* 2014 Oct;37(5):860-867. [doi: [10.1007/s10865-013-9546-1](https://doi.org/10.1007/s10865-013-9546-1)] [Medline: [24170391](https://pubmed.ncbi.nlm.nih.gov/24170391/)]
33. Friedmann E, Katcher AH, Thomas SA, Lynch JJ, Messent PR. Social interaction and blood pressure. Influence of animal companions. *J Nerv Ment Dis* 1983 Aug;171(8):461-465. [Medline: [6875529](https://pubmed.ncbi.nlm.nih.gov/6875529/)]
34. Krause-Parello CA, Kolassa J. Pet therapy: enhancing social and cardiovascular wellness in community dwelling older adults. *J Community Health Nurs* 2016;33(1):1-10. [doi: [10.1080/07370016.2016.1120587](https://doi.org/10.1080/07370016.2016.1120587)] [Medline: [26813050](https://pubmed.ncbi.nlm.nih.gov/26813050/)]

35. Allen K, Shykoff BE, Izzo Jr JL. Pet ownership, but not ace inhibitor therapy, blunts home blood pressure responses to mental stress. *Hypertension* 2001 Oct;38(4):815-820 [FREE Full text] [Medline: [11641292](#)]
36. Allen KM, Blascovich J, Tomaka J, Kelsey RM. Presence of human friends and pet dogs as moderators of autonomic responses to stress in women. *J Pers Soc Psychol* 1991 Oct;61(4):582-589. [Medline: [1960650](#)]
37. Le Roux MC, Kemp R. Effect of a companion dog on depression and anxiety levels of elderly residents in a long-term care facility. *Psychogeriatrics* 2009;9(1):23-26. [doi: [10.1111/j.1479-8301.2009.00268.x](#)]
38. McConnell AR, Brown CM, Shoda TM, Stayton LE, Martin CE. Friends with benefits: on the positive consequences of pet ownership. *J Pers Soc Psychol* 2011 Dec;101(6):1239-1252. [doi: [10.1037/a0024506](#)] [Medline: [21728449](#)]
39. Siegel JM. Stressful life events and use of physician services among the elderly: the moderating role of pet ownership. *J Pers Soc Psychol* 1990 Jun;58(6):1081-1086. [Medline: [2391640](#)]
40. Stanley IH, Conwell Y, Bowen C, Van Orden KA. Pet ownership may attenuate loneliness among older adult primary care patients who live alone. *Aging Ment Health* 2014;18(3):394-399 [FREE Full text] [doi: [10.1080/13607863.2013.837147](#)] [Medline: [24047314](#)]
41. McNicholas J, Collis GM. Dogs as catalysts for social interactions: robustness of the effect. *Br J Psychol* 2000 Feb;91 (Pt 1):61-70. [Medline: [10717771](#)]
42. Robins DM, Sanders CR, Cahill SE. Dogs and their people: pet-facilitated interaction in a public setting. *J Contemp Ethnogr* 1991;20(1):3-25. [doi: [10.1177/089124191020001001](#)]
43. Wood L, Martin K, Christian H, Nathan A, Lauritsen C, Houghton S, et al. The pet factor--companion animals as a conduit for getting to know people, friendship formation and social support. *PLoS One* 2015;10(4):e0122085 [FREE Full text] [doi: [10.1371/journal.pone.0122085](#)] [Medline: [25924013](#)]
44. Knight S, Edwards V. In the company of wolves: the physical, social, and psychological benefits of dog ownership. *J Aging Health* 2008 Jun;20(4):437-455. [doi: [10.1177/0898264308315875](#)] [Medline: [18448686](#)]
45. Wood L, Martin K, Christian H, Houghton S, Kawachi I, Vallesi S, et al. Social capital and pet ownership - A tale of four cities. *SSM Popul Health* 2017;3:442-447. [doi: [10.1016/j.ssmph.2017.05.002](#)]
46. Gagnon J, Bouchard F, Landry M, Belles-Isles M, Fortier M, Fillion L. Implementing a hospital-based animal therapy program for children with cancer: a descriptive study. *Can Oncol Nurs J* 2004;14(4):217-222. [Medline: [15635895](#)]
47. Chubak J, Hawkes R, Dudzik C, Foose-Foster JM, Eaton L, Johnson RH, et al. Pilot study of therapy dog visits for inpatient youth with cancer. *J Pediatr Oncol Nurs* 2017;34(5):331-341. [doi: [10.1177/1043454217712983](#)] [Medline: [28614971](#)]
48. Urbanski BL, Lazenby M. Distress among hospitalized pediatric cancer patients modified by pet-therapy intervention to improve quality of life. *J Pediatr Oncol Nurs* 2012;29(5):272-282. [doi: [10.1177/1043454212455697](#)] [Medline: [22907682](#)]
49. Gonder-Frederick L, Rice P, Warren D, Vajda K, Shepard J. Diabetic alert dogs: a preliminary survey of current users. *Diabetes Care* 2013 Apr;36(4):e47 [FREE Full text] [doi: [10.2337/dc12-1998](#)] [Medline: [23520374](#)]
50. Weber KS, Roden M, Müssig K. Do dogs sense hypoglycaemia? *Diabet Med* 2016 Jul;33(7):934-938. [doi: [10.1111/dme.12975](#)] [Medline: [26433211](#)]
51. Los EA, Ramsey KL, Guttman-Bauman I, Ahmann AJ. Reliability of trained dogs to alert to hypoglycemia in patients with type 1 diabetes. *J Diabetes Sci Technol* 2017 May;11(3):506-512 [FREE Full text] [doi: [10.1177/1932296816666537](#)] [Medline: [27573791](#)]
52. Carmack BJ. The role of companion animals for persons with AIDS/HIV. *Holist Nurs Pract* 1991 Jan;5(2):24-31. [Medline: [1984013](#)]
53. Kruger KS, Stern SL, Anstead G, Finley EP. Perceptions of companion dog benefits on well-being of US military veterans with HIV/AIDS. *South Med J* 2014 Mar;107(3):188-193. [doi: [10.1097/SMJ.0000000000000078](#)] [Medline: [24937339](#)]
54. Saberi P, Neilands TB, Johnson MO. Association between dog guardianship and HIV clinical outcomes. *J Int Assoc Provid AIDS Care* 2014;13(4):300-304. [Medline: [25513022](#)]
55. Siegel JM, Angulo FJ, Detels R, Wesch J, Mullen A. AIDS diagnosis and depression in the Multicenter AIDS Cohort Study: the ameliorating impact of pet ownership. *AIDS Care* 1999 Apr;11(2):157-170. [doi: [10.1080/09540129948054](#)] [Medline: [10474619](#)]
56. Hutton VE. Companion animals and wellbeing when living with HIV in Australia. *Anthrozoös* 2014;27(3):407-421.
57. Kaslow RA, Ostrow DG, Detels R, Phair JP, Polk BF, Rinaldo Jr CR. The Multicenter AIDS Cohort study: rationale, organization, and selected characteristics of the participants. *Am J Epidemiol* 1987 Aug;126(2):310-318. [Medline: [3300281](#)]
58. Andresen EM, Malmgren JA, Carter WB, Patrick DL. Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *Am J Prev Med* 1994 Mar;10(2):77-84. [Medline: [8037935](#)]
59. Radloff LS. The CES-D Scale: a self-report depression scale for research in the general population. *Appl Psychol Meas* 1977 Jun 01;1(3):385-401. [doi: [10.1177/014662167700100306](#)]
60. Miller WC, Anton HA, Townson AF. Measurement properties of the CESD scale among individuals with spinal cord injury. *Spinal Cord* 2008 Apr;46(4):287-292. [doi: [10.1038/sj.sc.3102127](#)] [Medline: [17909558](#)]
61. Ungar M, Liebenberg L. Assessing resilience across cultures using mixed methods: construction of the child and youth resilience measure. *J Mix Methods Res* 2011 Apr;5(2):126-149. [doi: [10.1177/1558689811400607](#)]

62. Resilience Research Centre. Halifax, Nova Scotia; 2016. The Resilience Research Centre Adult Resilience Measure (RRC-ARM) User's Manual URL: <http://www.resilienceresearch.org/files/CYRM/Adult%20-%20CYRM%20Manual.pdf> [WebCite Cache ID 6uXEFTpx]
63. Liebenberg L, Ungar M, Vijver FV. Validation of the Child and Youth Resilience Measure-28 (CYRM-28) among Canadian youth. *Res Soc Work Pract* 2011 Nov 24;22(2):219-226. [doi: [10.1177/1049731511428619](https://doi.org/10.1177/1049731511428619)]
64. American Psychiatric Association. Arlington, VA; 2012. HIV and Clinical Depression URL: <https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/Professional-Topics/HIV-Psychiatry/FactSheet-Depression-2012.pdf> [WebCite Cache ID 6uXETOZuN]
65. Allen K. Are pets a healthy pleasure? The influence of pets on blood pressure. *Curr Dir Psychol Sci* 2003;12(6):236-239. [doi: [10.1046/j.0963-7214.2003.01269.x](https://doi.org/10.1046/j.0963-7214.2003.01269.x)]
66. McClure JB, Catz SL, Prejean J, Brantley PJ, Jones GN. Factors associated with depression in a heterogeneous HIV-infected sample. *J Psychosom Res* 1996 Apr;40(4):407-415. [Medline: [8736421](https://pubmed.ncbi.nlm.nih.gov/8736421/)]
67. McDowell TL, Serovich JM. The effect of perceived and actual social support on the mental health of HIV-positive persons. *AIDS Care* 2007 Nov;19(10):1223-1229 [FREE Full text] [doi: [10.1080/09540120701402830](https://doi.org/10.1080/09540120701402830)] [Medline: [18071966](https://pubmed.ncbi.nlm.nih.gov/18071966/)]
68. Ammassari A, Trotta MP, Murri R, Castelli F, Narciso P, Noto P, AdICoNA Study Group. Correlates and predictors of adherence to highly active antiretroviral therapy: overview of published literature. *J Acquir Immune Defic Syndr* 2002 Dec 15;31(Suppl 3):S123-S127. [Medline: [12562034](https://pubmed.ncbi.nlm.nih.gov/12562034/)]
69. Gonzalez JS, Penedo FJ, Antoni MH, Durán RE, McPherson-Baker S, Ironson G, et al. Social support, positive states of mind, and HIV treatment adherence in men and women living with HIV/AIDS. *Health Psychol* 2004 Jul;23(4):413-418. [doi: [10.1037/0278-6133.23.4.413](https://doi.org/10.1037/0278-6133.23.4.413)] [Medline: [15264978](https://pubmed.ncbi.nlm.nih.gov/15264978/)]
70. Dembicki D, Anderson J. Pet ownership may be a factor in improved health of the elderly. *J Nutr Elder* 1996;15(3):15-31. [doi: [10.1300/J052v15n03_02](https://doi.org/10.1300/J052v15n03_02)] [Medline: [8948954](https://pubmed.ncbi.nlm.nih.gov/8948954/)]
71. Roberts K. Barriers to and facilitators of HIV-positive patients' adherence to antiretroviral treatment regimens. *AIDS Patient Care STDS* 2000 Mar;14(3):155-168. [doi: [10.1089/108729100317948](https://doi.org/10.1089/108729100317948)] [Medline: [10763545](https://pubmed.ncbi.nlm.nih.gov/10763545/)]
72. Ryan G, Wagner G. Pill taking 'routinization': a critical factor to understanding episodic medication adherence. *AIDS Care* 2003 Dec;15(6):795-806. [doi: [10.1080/09540120310001618649](https://doi.org/10.1080/09540120310001618649)] [Medline: [14617501](https://pubmed.ncbi.nlm.nih.gov/14617501/)]
73. Wagner G, Ryan G. Relationship between routinization of daily behaviors and medication adherence in HIV-positive drug users. *AIDS Patient Care STDS* 2004 Jul;18(7):385-393. [doi: [10.1089/1087291041518238](https://doi.org/10.1089/1087291041518238)] [Medline: [15307927](https://pubmed.ncbi.nlm.nih.gov/15307927/)]
74. Vaughan C, Wagner G, Miyashiro L, Ryan G, Scott J. The role of the home environment and routinization in ART adherence. *J Int Assoc Physicians AIDS Care (Chic)* 2011 Apr 20;10(3):176-182. [doi: [10.1177/1545109711399365](https://doi.org/10.1177/1545109711399365)] [Medline: [21508293](https://pubmed.ncbi.nlm.nih.gov/21508293/)]
75. Saberi P, Comfort M, Johnson MO. The relationship between daily organization and adherence to antiretroviral therapy. *J Acquir Immune Defic Syndr* 2012;61(1):e3-e6. [doi: [10.1097/QAI.0b013e318261faf2](https://doi.org/10.1097/QAI.0b013e318261faf2)]
76. Tomer A, Kane J. Brookings. Washinton, DC; 2015. Broadband Adoption Rates and Gaps in U.S. Metropolitan Areas URL: <https://www.brookings.edu/wp-content/uploads/2016/07/Broadband-Tomer-Kane-12315.pdf> [accessed 2017-10-25] [WebCite Cache ID 6uXEwoYad]

Abbreviations

AAI: animal-assisted intervention
AIDS: acquired immune deficiency syndrome
ART: antiretroviral therapy
CES: Center for Epidemiologic Studies
DAD: diabetic alert dog
HIV: human immunodeficiency virus
IP: Internet Protocol
MSM: men who have sex with men
PLHIV: people living with HIV
RRC: Resilience Research Centre
TLS: transport layer security

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Viewpoint

Partners in Parenting: A Multi-Level Web-Based Approach to Support Parents in Prevention and Early Intervention for Adolescent Depression and Anxiety

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Abstract

Depression and anxiety disorders in young people are a global health concern. Various risk and protective factors for these disorders are potentially modifiable by parents, underscoring the important role parents play in reducing the risk and impact of these disorders in their adolescent children. However, cost-effective, evidence-based interventions for parents that can be widely disseminated are lacking. In this paper, we propose a multi-level public health approach involving a Web-based parenting intervention, Partners in Parenting (PIP). We describe the components of the Web-based intervention and how each component was developed. Development of the intervention was guided by principles of the persuasive systems design model to maximize parental engagement and adherence. A consumer-engagement approach was used, including consultation with parents and adolescents about the content and presentation of the intervention. The PIP intervention can be used at varying levels of intensity to tailor to the different needs of parents across the population. Challenges and opportunities for the use of the intervention are discussed. The PIP Web-based intervention was developed to address the dearth of evidence-based resources to support parents in their important role in their adolescents' mental health. The proposed public health approach utilizes this intervention at varying levels of intensity based on parents' needs. Evaluation of each separate level of the model is ongoing. Further evaluation of the whole approach is required to assess the utility of the intervention as a public health approach, as well as its broader effects on adolescent functioning and socioeconomic outcomes.

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KEYWORDS

family; tailored; internet; mental health; preventive health services

Introduction

Overview

Depression and anxiety disorders are the largest contributors to disease burden in young people globally [1]. Research evidence highlights that parents have an important role in reducing the

risk and impact of these disorders in their adolescents; however, cost-effective, evidence-based interventions for parents that can be widely disseminated are lacking. In this paper, we propose a multi-level public health approach involving a Web-based parenting intervention to address this dearth of resources for parents across all levels of this continuum [2].

Depression and Anxiety Disorders in Youth Are a Global Health Concern

In young people aged between 13 to 17 years, lifetime prevalence rates of depression and anxiety disorders are 18% and 38%, respectively [3]. Early onset disorders, especially if untreated, tend to become chronic or relapsing, increase suicide risk, and forecast a wide range of psychosocial and vocational impairments [4-6]. Although intervention efforts for these disorders continue to progress, and rates of professional help seeking have increased [7], a large proportion of the burden of disease is still unavertable even with optimal treatment [8]. There is, hence, a strong need for an effective, integrated approach to reduce the prevalence and impact of these disorders, especially for young people. As the incidence of these disorders peaks during adolescence [9,10], adolescence is a particularly opportune time to target prevention and early intervention (referring to treatment and maintenance early in the course of disorder).

Parents Have an Important Role in Prevention and Early Intervention

There are various reasons why the family, particularly parents, is a strategic setting for targeting prevention and early intervention for youth depression and anxiety (also known as internalizing) disorders. First, young people see their family, especially their parents, as important in their lives, especially when it comes to their own mental health. Various national surveys have found that parents are the most commonly mentioned source of help young people would turn to if and when they have mental health difficulties [11,12]. Second, parents are intrinsically motivated to take action for their child's well-being and may possess the wisdom and life experience to help them appreciate the value of prevention and early intervention [13]. Third, most adolescents still live with their parents (or at least one parent), and this proximity affords parents the opportunities to notice significant changes in their child's mental health and behavior. As argued by proponents of family process [14] and family system [15] models, this proximity underscores the importance of parents in the development and maintenance of youth internalizing problems. Fourth, international policies and action plans related to mental health have recognized the importance of upskilling parents for the goal of prevention and promotion of child and youth mental and emotional well-being [16-19].

Finally, there is now robust evidence delineating risk and protective factors for adolescent anxiety and depressive disorders [20,21]. Importantly, some of these factors are within parents' control or influence and are potentially modifiable [22]. These include factors that involve the family system (eg, interparental conflict [23]), can be detected early by parents (eg, behaviorally inhibited temperament [20]), or are directly socialized or modeled by parents (eg, parental responses to child emotions [24]). However, findings from a national survey of Australian parents revealed that parents' knowledge about their role in reducing risk of depression in adolescents is less than optimal [25], highlighting a need to equip parents through more effective translation of evidence into preventive resources.

Moreover, a substantial body of research has demonstrated the various ways in which parenting behaviors may inadvertently maintain or exacerbate depression and anxiety disorders in young people [14,15,26,27]. For instance, as proposed by reciprocal relationship models, adolescent anxiety may elicit overprotective responses from parents, which in turn reinforces and maintains adolescent anxiety [28]. Parental modeling of anxiety [14] or maladaptive strategies to manage their own emotions [29] may also contribute to the maintenance of adolescent internalizing problems.

The rest of this paper presents the rationale for developing Partners in Parenting (PIP), an individually tailored Web-based intervention for parents of adolescents. We then describe the intervention development process and explain how the various components were designed to facilitate the proposed multi-level approach to empower parents to reduce the risk and impact of depression and anxiety disorders in their adolescent children.

Rationale for Developing the Partners in Parenting Intervention

Below, we describe the three key reasons that motivated the development of the PIP and the proposed multi-level approach.

Need to Involve Parents Across the Mental Health Intervention Continuum

Existing research evidence demonstrates the value of involving parents across the mental health intervention continuum, which includes prevention (universal, selective, and indicated), treatment (case identification and standard treatment for known disorders), and maintenance (strategies to reduce relapse and recurrence, and the disability associated with the disorder) [2].

Preventive parenting interventions can be *universal* (ie, delivered to all parents regardless of risk), *selective* (targeting parents whose children have known risk factors), or *indicated* (targeting parents whose children show signs or symptoms of emerging disorders) [2]. Although universal programs tend to have smaller effects than selective or indicated programs at the level of the individual, they can have a great public health impact because they reach a larger proportion of the population and have the potential to shift the population mean levels of depression and anxiety symptoms [30]. Notably, in a recent systematic review and meta-analysis of preventive parenting interventions (where most of the intervention was with the parent, rather than targeting primarily the child or involving the whole family), there was no evidence that the type of prevention (universal, selective, or indicated) moderated intervention effects [31]. When trying to engage parents in prevention of youth mental health problems, universal approaches can increase acceptability because they minimize the perceived stigma that some parents fear would be attached to themselves as a "bad" parent or to their child as having problems needing intervention [32]. On the other hand, according to the widely used Health Belief Model [33]—which explains why individuals engage in health-related behaviors—parents whose child has known risk factors (selective prevention) or early signs of difficulties (indicated prevention) may be more motivated to participate in preventive parenting programs because of heightened "perceived susceptibility" of their child.

Parents have an important role in facilitating case identification and professional help-seeking for adolescents. Parents are often the first to detect changes in their child's mental health and serve as an important conduit to adolescents engaging in appropriate treatment [34]. Given the evidence for parenting-related risk, protective, and maintenance factors in adolescent internalizing disorders [14,15,31], parents also have an important role in the maintenance component of the mental health intervention continuum.

Hence, we propose a multi-level public health approach involving the PIP Web-based intervention that incorporates universal, selective, and indicated prevention components, as well as treatment and maintenance components to maximize the strengths of all components to meet the needs and preferences of different families.

Prevention and Early Intervention Programs Fail to Adequately Involve Parents

One important limitation of existing prevention and early intervention programs for adolescent internalizing disorders is the inadequate level and nature of parental involvement. Specifically, whereas some interventions include a parent component, this usually involves teaching parents what their child is being taught, rather than targeting modifiable parenting risk, protective, or maintenance factors [14,23]. In particular, given that most existing treatments utilize cognitive behavioral therapy (CBT) approaches that primarily target cognitions and behaviors at the individual (adolescent) level, parental involvement often takes the form of supporting the child's implementation of strategies taught in session [35,36]. In many existing interventions, where a parent component exists, it tends to comprise a small proportion of the intervention, with the majority of the intervention targeting the young person [35-40].

In contrast to the increasing number of interventions targeting young people primarily [35,36,38-40], the aforementioned review of preventive parenting interventions found only three out of 51 interventions that were designed for parents of adolescents [31]. Notably, whereas preventive parenting interventions were found to have beneficial effects on the child's internalizing outcomes lasting up to 11 years post intervention [31], the evidence base for preventive interventions targeting young people directly suggests that intervention effects may last less than 2 years [38-40]. These findings underscore the need to provide parents of adolescents with more evidence-based parenting support, to reduce their adolescent's risk of internalizing disorders.

The dearth of interventions for adolescent depression and anxiety disorders that directly target parenting factors [35,36] stands in stark contrast to the myriad of family-based intervention programs for externalizing or substance use disorders in young people [15]. This lag in research translation is particularly notable given that meta-analyses of parenting factors have found comparable effect sizes for associations with youth externalizing problems (up to 6% [41], or up to 11% for delinquency [42]), substance use problems (eg, alcohol misuse, up to 7% [43]), and internalizing problems (up to 16% [23]). Moreover, evidence to date indicates no difference in treatment outcome between individual, group, and family or parental

formats of CBT approaches for child and adolescent anxiety disorders [44].

Efforts to translate research evidence on the role of parenting in the maintenance of adolescent depression and anxiety may be deterred by the equivocal evidence to date regarding whether parental involvement in adolescent treatment enhances treatment effects [15,45]. However, given the dearth of treatment interventions for adolescent internalizing disorders that target parenting-related maintenance factors, it remains to be ascertained whether such an intervention will indeed enhance treatment effects. Nonetheless, professional help-seeking for adolescent depression or anxiety is often facilitated by parents [34] who want to help but do not always know how [15] and may inadvertently contribute to the maintenance of their child's difficulties [27]. Hence, the PIP intervention was developed to address the need for an intervention that targets evidence-based parenting-related risk, protective, and maintenance factors and empowers parents to reduce the risk and impact of internalizing problems in their adolescent children.

Potential of the Web-Based Platform to Address Some Limitations of Existing Parenting Interventions

Another limitation of existing parenting interventions is that many are not well-used, even when available, because of barriers such as scheduling difficulties or privacy concerns [46]. With the increasing reach of the Internet, the use of Web-based media has been recommended as one key way to increase participation rates in preventive interventions [47]. For example, in Australia, the 2016 national census found that 97% of households with children younger than 15 years have Internet access [48]. However, based on the recent systematic review [31] and a search of major clinical trial registries, there is currently no widely accessible, tailored Web-based parenting intervention for prevention or early intervention for adolescent depression and anxiety disorders. Yet, Web-based interventions hold great promise because they have the potential to overcome the aforementioned barriers of existing face-to-face programs because of their anonymity, flexibility, and accessibility. Furthermore, the computerized delivery of a well-designed and well-maintained program guarantees implementation fidelity [49]. A Web-based parenting program also complements the use of the Internet as a popular source of information on mental health and parenting [7,50]. Moreover, a recent Web-based survey suggests that the majority of parents would find such a program useful [51].

Web-based interventions have now demonstrated effectiveness [49] and cost-effectiveness [52] for the treatment of depression and anxiety disorders. Promising evidence is also emerging for online prevention programs targeting young people directly [53], as well as parents of younger children [54,55]. The potential efficacy of Web-based prevention programs that target parents of adolescents remains largely untapped, but such programs would comprise a promising public health approach to preventing adolescent depression and anxiety that is potentially lower in cost per individual than existing programs [56].

An important limitation of existing prevention and treatment interventions for adolescent internalizing disorders is that they

only focus on one or a few parenting risk, protective, or maintenance factors for adolescent depression and anxiety [14,15,31,45]. This narrow focus approach means that programs may not adequately address the range of modifiable parenting factors for adolescent depression and anxiety that are relevant for each parent or family. The capacity of digital technology to automatically tailor a Web-based intervention to each user offers a potential solution to this limitation. Automated tailoring is beneficial when it involves screening each parent across all evidence-based risk, protective, and maintenance factors to ensure a more thorough coverage of areas that may be important to target in the intervention. In doing so, the program has greater breadth without imposing unnecessary burden on parents (because of the inclusion of less-relevant topics). Importantly, a tailored Web-based intervention provides some personalization of the program for the parent without requiring the costly involvement of trained professionals, hence increasing the intervention's perceived relevance [57], effectiveness [58], and potential for scalability and sustainability [57].

The Partners in Parenting Intervention

The PIP intervention comprises three components: (1) a parenting scale that assesses the parent's current parenting practices and beliefs against the recommendations of the parenting guidelines; (2) an automatically generated, individually tailored feedback report based on each parent's responses to the scale; and (3) a set of interactive Web-based modules to support parental behavior change.

To access PIP, parents register by creating an account using their email address and a self-selected password and providing basic demographic information about themselves and their child. To personalize the intervention to each parent, parents are asked to identify one target child to focus on when completing the intervention. All components of PIP are then personalized with the child's name and gender and the parent's name. Parents then complete the parenting scale to receive their tailored feedback report, before reviewing the selection of modules recommended specifically for them, alongside other modules (out of the nine) that are also available but were not recommended for them (because they were already considered concordant with the guidelines' recommendations in those areas of parenting). At this point, parents can apply their own preferences by accepting or deselecting recommended modules and selecting any additional modules that were not recommended before locking in their selection and starting their personalized program. One module is unlocked every 7 days, in a predetermined order (because each subsequent module is designed to build on the content of preceding modules), until the parent has completed all of the modules in their program. The 7-day interval encourages parents to focus on achieving the goal they had set from their most recently completed module before proceeding to the next module. Parents receive an automated email informing them that their next module is available and reminding them of the goal(s) they had previously selected but not yet marked as achieved on their personalized dashboard. Each module takes 15 to 25 min to complete depending on the module and the way parents choose to engage with it. After completing all of their modules, parents gain access to all modules,

including those they had not initially selected (see [Multimedia Appendix 1](#) for screenshots).

Development of the Partners in Parenting Intervention

Overview

The development of PIP involved three phases that were modeled after the related Parenting Strategies intervention to prevent adolescent alcohol misuse [59]. The Center for eHealth Research (CeHRes) roadmap for the development of electronic health (eHealth) technologies [60] guided the process of user-centered design. Specifically, the first two phases comprised a research translation process to develop a set of guidelines that represent the range of risk and protective factors to target in the intervention (akin to CeHRes Contextual Inquiry activities—identifying user needs and possible solutions). Phase 3 was guided by the consumer-engagement approach for developing parenting programs (CeHRes Value Specification—determining what users value) [61], and the intervention's Web-based technological features were designed to fulfill the principles of the Persuasive Systems Design (PSD) model (CeHRes Design—iterative process of building, testing, and refining prototypes and incorporating persuasive techniques) [62]. Considerations about the PIP implementation model were inherent throughout the development process (CeHRes Operationalization—introduction, adoption, and employment of the technology in practice).

Phase 1. Identifying Parental Factors to Target in the Intervention

To identify the range of modifiable parental factors to target in the intervention, the first phase involved a comprehensive systematic review and meta-analysis of risk and protective factors for adolescent depression and anxiety disorders that parents can potentially modify or influence [23]. Synthesizing longitudinal, retrospective, and cross-sectional evidence, the review identified a sound evidence base for three protective parental factors for depression (warmth, autonomy granting, and monitoring), and one for anxiety (warmth). In addition, three risk factors for both outcomes were also identified: interparental conflict, overinvolvement, and aversiveness [23].

Phase 2. Translating the Research Evidence Into Actionable Strategies

To translate this evidence base into actionable strategies, we employed the Delphi method to develop a set of expert consensus guidelines [63]. The Delphi method is a systematic way to determine expert consensus about questions that cannot be appropriately or adequately addressed using experimental or epidemiological methods [64]. This phase involved a systematic literature search of both academic and lay information, which identified 402 unique recommendations for parents to reduce the risk of depression or anxiety in their adolescent. An international panel of 23 clinical and research experts independently rated these recommendations over three survey rounds. Panel members were provided with brief summaries of the evidence from the systematic review of research evidence [23] to consider when rating the items.

The resulting guidelines, *How to prevent depression and clinical anxiety in your teenager: Strategies for parents* (henceforth “the Guidelines”; [65]) presents 190 parenting strategies that were endorsed by $\geq 90\%$ (21/23) of experts as important or essential for the prevention of adolescent depression and anxiety disorders. These strategies were thematically organized under 11 subheadings, as shown in Table 1.

The Guidelines [65] represent evidence-based and expert-endorsed strategies that parents can use to reduce their adolescent’s risk of depression and anxiety problems. A recent study evaluating user perceptions of the Guidelines indicated high levels of satisfaction, and the majority of users endorsed the potential value of Web-based parenting interventions based on the guidelines. Most parent users also reported attempting to make changes in their parenting as a result of reading the Guidelines [51]. Albeit a preliminary and uncontrolled evaluation study, these findings suggest the utility of the Guidelines as a basic, universal prevention strategy for parents of adolescents.

Phase 3. Developing the Web-Based Intervention

The Persuasive Systems Design Model

To support parents in the implementation of the Guidelines, and to individually tailor the Guidelines’ recommendations to each parent, phase 3 involved developing the three aforementioned components: (1) a self-assessment parenting scale, (2) a tailored feedback report, and (3) a set of interactive Web-based modules.

Design of the Web-based components of PIP was guided by the PSD model [62] that proposes to purposefully use technology to influence behavior change. In particular, the key features of PIP were designed to fulfill the principles of the PSD model in the primary task, dialogue, and system credibility categories (see Multimedia Appendix 2) [62].

Intervention Components

First, we developed a criterion-referenced parenting scale, called the Parenting to Reduce Adolescent Depression and Anxiety Scale (PRADAS), which assesses parents’ concordance with the nine domains of parenting addressed in the nine subheadings of the Guidelines (the “criterion”; see [66] for more details). The PRADAS represents the screening assessment that facilitates the tailoring of the intervention to each parent [57].

Next, we wrote automated feedback messages for all possible combinations of responses to the 79 items in the PRADAS. This involved creating a scoring system and feedback flowchart linking the response options for each item to the appropriate feedback message based on the predetermined scoring algorithm. Feedback messages highlight the parent’s parenting strengths and provide specific strategies to further improve their parenting, to adhere more closely to the recommendations of the Guidelines. Feedback messages are intentionally written to be brief, with the aim of motivating behavior change by identifying areas to change and providing specific means for action (PSD tunneling principle, [62]). The recommended behavior change is then supported by corresponding modules (see below) that are specifically recommended for each parent to build on the

strategies presented in the personalized feedback. The tailoring of every feedback message increases the perceived relevance of the intervention and allows the intervention to cover the range of factors that represent areas for improvement for each parent. The PRADAS content and feedback messages were initially drafted by a postgraduate student with graduate qualifications in psychology (MCB) and evaluated by the research team (comprising MCB, MBHY, AFJ, and KAL) to ensure their fidelity to the Guidelines.

Finally, the development of the interactive modules first involved a mapping of topics to the nine domains of parenting addressed in the Guidelines (see Table 1). Modules feature full colored illustrations, interactive activities, real-life vignettes, audio clips, troubleshooting tips, goal setting exercises, and an end-of-module quiz with immediate feedback to consolidate learning of each module’s key messages. Features of the modules were selected to fulfill PSD principles, and as part of the consumer-engagement approach [61], taken to develop both PIP and the earlier alcohol misuse prevention intervention [59]. Module content was based on the Guidelines but drew on other relevant evidence-based content as required. A psychologist undertaking postgraduate research (JMG) drafted the initial modules, which were then reviewed and revised through meetings involving the research team (comprising JMG, MBHY, AFJ, and KAL). Module content was evaluated to ensure its consistency and fidelity with the Guidelines, as well as other relevant best practice and credible resources.

Attention was paid to ensure that all components of the intervention were optimized to engage parent users, following the PSD principles as far as possible (as outlined in Multimedia Appendix 2). As part of a consumer-engagement approach to developing the intervention [61], we also consulted with parent and adolescent stakeholders to ensure that the various components of the intervention fulfilled the PSD principles as intended and were acceptable to target end users (see below).

Stakeholder Consultations—Parents

We recruited a reference group of 22 parents with adolescent children (aged 11-18 years) through staff e-newsletters at Monash University and the University of Melbourne, local high schools, and via online networks. Participants were mostly mothers (86.4%, 19/22), in the age range of 45 to 59 years, married or de facto, employed, Australian-born, English-speaking, and highly educated (at least an undergraduate qualification) and had 2 or 3 children. Parents attended one of three repeated 2-hour workshops (n=7 or 8 per workshop) where drafts of the PRADAS, feedback messages, and one module prototype (drafted as a Microsoft PowerPoint presentation) were presented for discussion. Parents were consulted on the language used in the PRADAS and feedback messages, and the logic, relevance, and usefulness of the feedback messages. They also provided feedback and input into the degree of interactivity and the tone and amount of content in the modules. Parents provided specific suggestions for rewording instructions and messages that could be misinterpreted or trigger unintended negative reactions from parents. Wherever possible, we incorporated parents’ feedback into all components of the intervention.

Table 1. Guidelines topics, corresponding subsections of the parenting scale and personalized feedback report, title of interactive modules, outline of content, and rationale for their inclusion.

Guidelines topic	Corresponding subsection of the parenting scale and feedback report	Title of interactive module	Outline of content	Rationale for inclusion
You can reduce your child's risk of developing depression and clinical anxiety	N/A ^a ; Not included in parenting scale or feedback report	N/A; No module on this topic	Psychoeducation about the role of parents in the prevention of adolescent depression and anxiety	Endorsed by experts
Establish and maintain a good relationship with your teenager	Your relationship with your teenager	Connect	Acknowledges the challenge of connecting with adolescent children, and provides specific tips on how to do this	Sound research evidence that parental "warmth" is protective against both anxiety and depression; endorsed by experts
Be involved and support increasing autonomy	Your involvement in your teenager's life	Nurture roots and inspire wings	Helps parents establish the important balance between staying involved and interested in their adolescent's life, while encouraging increasing age-appropriate autonomy	Sound research evidence that overinvolvement is a risk factor for depression, and autonomy granting and monitoring are protective factors; endorsed by experts
Encourage supportive relationships	Your teenager's relationships with others	Good friends, supportive relationships	Provides strategies for parents to support their adolescent's social skills development	Emerging evidence of parental encouragement of sociability is associated with less adolescent anxiety; endorsed by experts
Establish family rules and consequences	Your family rules	Raising good kids into great adults: establishing family rules	Highlights the importance of consistent and clear boundaries for adolescent behaviors, and provides specific strategies to establish these	Emerging evidence of the association between inconsistent discipline and depression; endorsed by experts
Minimize conflict in the home	Your home environment	Calm versus conflict	Addresses the need for adaptive conflict management between parents and between parent and adolescent, and provides specific strategies to do these	Sound evidence that interparental conflict and aversiveness (including parent-adolescent conflict) are risk factors for both depression and anxiety; endorsed by experts
Encourage good health habits	Health habits	Good health habits for good mental health	Provides strategies to help parents encourage good health habits in their adolescent, including a healthy diet, physical activity, good sleep habits, and abstinence from alcohol and drugs	Endorsed by experts; evidence that these health habits are associated with risk for depression and anxiety
Help your teenager to deal with problems	Dealing with problems in your teenager's life	Partners in problem solving	Provides strategies for parents to help their adolescent develop good problem solving and stress management skills	Endorsed by experts
Help your teenager to deal with anxiety	Coping with anxiety	From surviving to thriving: helping your teenager deal with anxiety	Provides strategies for parents to help their adolescent manage their everyday anxiety	Sound evidence that overprotective, anxious parenting is associated with both anxiety and depression in adolescents; endorsed by experts
Encourage professional help seeking when needed	Getting help when needed	When things aren't okay: getting professional help	Helps parents understand what depression and anxiety problems can look like in adolescents, and what they can do if their adolescent is or becomes unwell	Endorsed by experts; evidence that parents are important conduits to young people seeking professional help for mental health problems
Don't blame yourself	Don't blame yourself (not included in parenting scale, included in feedback report for all parents)	N/A; No module on this topic	Aims to dispel guilt or self-blame in parents	Endorsed by experts

^aN/A: not applicable.

Stakeholder Consultations—Adolescents

Finally, to ensure that the suggested strategies recommended to parents in the intervention were acceptable and relevant to adolescents, we consulted with two focus groups of adolescents in the age range of 12 to 15 years. Adolescents were recruited through two local schools that differed on ethnic and sociodemographic characteristics, and focus group consultations were conducted in school classrooms. Consulting with adolescents of different ages and in different schools enabled us to capture some developmental, ethnic, and sociodemographic variations in adolescent views. Adolescents were presented with some of the parenting strategies recommended for parents in PIP (eg, show interest in your adolescent's life and spend regular one-on-one time together) and provided feedback about some ways in which the strategies could be implemented in an acceptable way with contemporary adolescents. Adolescents provided specific ideas and suggestions that were incorporated into the content of various modules, including activities they enjoy doing with their parents and ways their parents could show them affection. These consultations also informed the scripts for adolescent audio clips included in some modules, where adolescents talked about topical issues such as how they feel when their parents argue, and how parents could help when they (the adolescents) get "stressed out."

The PIP intervention development was completed in May 2015. We are evaluating the effects of the intervention via two randomized controlled trials (RCTs) that have been registered with the Australian New Zealand Clinical Trials Registry (Trial IDs ACTRN12615000247572 and ACTRN12615000328572).

Proposed Uses of the PIP Intervention: A Multi-Level Public Health Approach

Overview

The PIP intervention was designed for implementation as a multi-level public health intervention to empower parents to support their child's mental health across all levels of the mental health intervention continuum [2]. Figure 1 depicts a model of the proposed that involves different PIP components in varying degrees of intensity (or levels). We propose that the level of PIP required will be related to the level of risk and extent of current difficulties in the child [2], as well as the parent's self-efficacy (confidence about their ability to parent successfully) and parenting competencies or skills [67,68].

Level 1: General Guidelines

Level 1 is the minimal intervention and constitutes a general parent-education initiative across the community. Parents can choose to consider and apply any of the Guidelines' recommendations as and when they deem fit. Given the evidence base [23] and expert endorsement [63] supporting these recommendations, we postulate that when parents apply these strategies, they are taking preventive actions that are likely to benefit their child's mental health. Given preliminary evidence that accessing these guidelines was sufficient to prompt some behavior change in parents [51], these guidelines represent a promising minimal-cost universal prevention strategy for parents

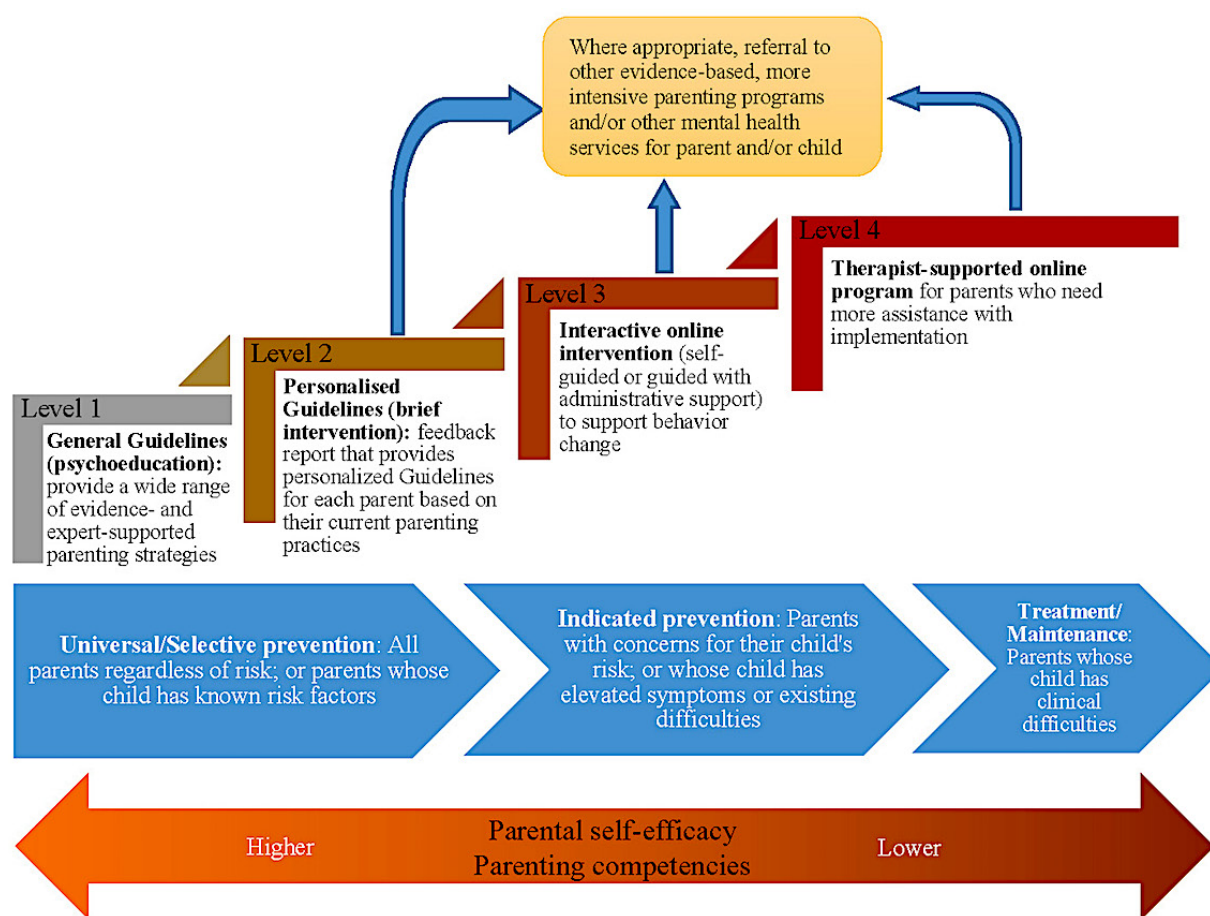
of adolescents. This minimal intervention is likely to be sufficient for parents who are highly motivated, educated, and have higher parental self-efficacy and parenting competence and whose child is generally functioning well (ie, no known risk or current concern). The Guidelines can serve as a benchmark for parents, providing reminders of strategies to maintain, increase, or reduce, a toolkit to draw from as required, as well as an assurance that they are "on the right track" [51].

Level 2: Personalized Guidelines (Brief Intervention)

Each subsequent level in the model represents increasing intensity of support and intervention for parents. Level 2 requires parents to first complete a self-assessment parenting scale (the PRADAS) to receive their personalized feedback report. This level is likely to suit a similar group of parents as level 1 but who prefer a tailored approach. Level 2 can also serve as a prompt for some parents to take further action, if required, to seek further support to improve their parenting practices. Parents with lower parental self-efficacy may find the level of support provided by a once-off brief intervention such as the feedback report insufficient and thus, be prompted to complete the interactive Web-based program (next level up) and/or seek other resources or services including mental health services for themselves and/or their child. To facilitate this, the feedback report includes links to other online resources, including an online screening tool (the Strengths and Difficulties Questionnaire; [69]) for parents who are concerned about their child's mental health.

Level 3: Interactive Online Intervention

At level 3, parents receive both the tailored feedback report and are recommended specific modules to provide additional support to implement the strategies highlighted in their feedback report. Drawing heavily from PSD principles, the intervention is designed to maximize adherence as a self-guided program [70], with automated email reminders and prompts to guide parents through their program to completion. We expect that parents who are motivated to improve their parenting and have moderate levels of parental self-efficacy would successfully complete their program on their own. However, evidence to date indicates that having some form of human support, be it administrative or therapeutic, enhances adherence to Web-based interventions (ie, completing the program as designed) and in turn, improves outcomes [71]. Hence, to maximize the potential benefits and cost-effectiveness of PIP, it may need to be delivered with at least administrative support, following a specified protocol (eg, a standard script with specific prompts to encourage progress through the Web-based program). It is pertinent that personnel delivering such administrative support have comprehensive training and ongoing supervision in the requisite skills to communicate with parents in a supportive and nonjudgmental manner and are equipped with referral information to additional support services (including level 4 of PIP) as required. Given the greater intensity of intervention that parents need to commit to, level 3 is more likely to appeal to parents who have some cause for concern (*selective prevention*; eg, lower parental self-efficacy during the child's developmental transition into adolescence) or have existing concerns for their child's mood or behavior (*indicated prevention*) [2].

Figure 1. A multi-level public health approach to support parents.

However, a recent review (Finan SJ et al, 2017, unpublished data) found that although higher child mental health symptoms may be associated with initial engagement (eg, enrolment) in preventive parenting programs, this does not increase attendance or reduce the likelihood of parents dropping out of programs [72]. In a Web-based intervention such as PIP, it may be possible to partially ameliorate this challenge by providing the personal administrative-support contact [71].

Level 4: Therapist-Supported Online Intervention

At level 4, parents receive not only all components of the PIP Web-based intervention but also the support of a trained therapist to coach them in implementing the strategies recommended in the PIP program. According to the Health Belief Model [33], this form of human support can act as a “cue to action” and help to increase intervention adherence through accountability to a coach who is perceived to be trustworthy, benevolent, and having expertise [73]. This additional level of support is particularly important when the child is already experiencing clinical-level difficulties because of their association with heightened stress in the family and reduced parental self-efficacy and parenting competence [67,68]. As noted earlier, there is a dearth of evidence-based supportive resources or services for parents of adolescents in the clinical setting [74]. Due to the increasing individuation from parents that emerges during adolescence [75] and a corresponding clinical imperative to promote independence and self-reliance in adolescents, parents are commonly less involved in treatment

with their adolescent than they are with younger children. Inevitably, this can leave concerned parents feeling excluded from their child's care, disempowered and helpless about how they can best manage their child's condition outside the clinic, and frustrated when they are unable to access support for themselves from the child's clinician [51,76]. Various systemic factors may also contribute to this, including the funding structure of public mental health services being directed at individuals rather than families, the professional competencies of youth mental health clinicians being limited to working with individual clients rather than the family system, and a largely overloaded and reactive mental health system. Within this context, the PIP intervention can be adapted for use to meet the critical gap in support services for parent caregivers of young people with internalizing disorders. Parents can access PIP with a separate PIP therapist-coach, who will, with the parent's consent, communicate with the child's clinician about the support the parent is getting from PIP, with the goal of enhancing their child's treatment. Alternatively, youth mental health clinicians can be trained in PIP content as part of their professional and specialist training and development, which will enable them to provide coaching to parents who access PIP in their own time, in addition to the individual work done with the adolescent, as well as some family sessions. The PIP therapist-coach can capitalize on the automated tailoring features of PIP by using their parent client's PRADAS responses and feedback report as a basis for discussion during coaching sessions. Evidence to date suggests that such an approach is

likely to facilitate the young person's recovery [14,74], support parents in their caregiver role, and increase adherence to treatment [76] without imposing significant added burden on the already overloaded treatment services because of PIP's Web-based delivery.

Criteria for Stepping Up

Within the proposed model, stepping up is based on one or both of the following criteria: (1) automated recommendation of the tailored program based on parents' responses to a self-assessment of their current parenting (parenting competencies as assessed by the PRADAS), parental self-efficacy, or their child's current symptoms and/or (2) parents' personal preference, which can override the program's recommendation. Referral to other evidence-based, more intensive parenting programs can occur at any point throughout the model for parents who want programs with a different delivery mode, increased support (therapist or nontherapist), or a specific focus (eg, emotion coaching). Parents whose personal mental health and/or other difficulties hinder them from engaging with and benefitting from the Web-based program will be referred to other mental health services for themselves. Parents who raise significant concerns about their child's behavior and mental health will also be referred to additional services to better support their child (parents can still continue to use the PIP program if they wish).

Discussion

Summary

In this paper, we have described a new approach to developing a Web-based intervention that rigorously translates research evidence into intervention strategies and aligns with more established development models from the parenting program [61] and eHealth intervention [60,62] literature. The PIP intervention is the product of a research translation process to identify the range of potentially modifiable parenting factors for adolescent depression and anxiety [23]. The various components of the intervention were developed to tailor the intervention to each parent's strengths and areas for improvement, covering the range of factors that are relevant for each family. The intervention can be implemented with varying levels of intervention intensity to meet the level of need of different families at various points along the mental health intervention continuum [2]. PIP is the second intervention developed following this research-translation approach, modeled on the earlier intervention to prevent adolescent alcohol misuse [59]. Such an approach answers the call for better translation of research evidence into interventions [14,15] and can be adopted for other populations (eg, parents of younger children [Fernando LM et al, 2017, unpublished data] and young people [21,77]) and other health and well-being outcomes for which there are a diverse range of risk, protective, and maintenance factors. An important caveat to note about the development process concerns the parent stakeholder consultation group involved in shaping the current version of PIP. Our recruitment for this group used similar methods to those that we predict will underpin the eventual, public implementation of the program, that is, via online networks and through schools. We expect

self-selected users of the intervention to have similar characteristics to the parents who comprised our reference groups. To ensure the acceptability of the intervention to underrepresented subgroups of parents (eg, fathers, single parents, and lower income), further consultations with parents from these subgroups would be required [61].

Challenges and Opportunities for the Implementation Process

An important consideration for the proposed multi-level approach is the source of funding to sustain it. Given that the Web-based intervention is fully developed and evaluated, it is in itself relatively inexpensive to maintain, except when substantial updates and improvements are required. However, where personnel are involved, for either administrative or therapeutic or coaching support, substantial costs will be incurred if the program is implemented at scale. Possible funding models include a user-pays business model, an advertising-based revenue model, or government or third-sector funding. As an international leader in e-mental health [78], Australia is fortunate to have ongoing financial support from the Australian Government for some evidence-based e-mental health programs [79]. As evidence for its efficacy and cost-effectiveness is gathered, such a public health approach may garner the required financial support from the government for its implementation. Moreover, as the program is in a widely understood language such as English, it can potentially be used internationally pending minor cultural adaptations. If this occurs, international funding models will be required [80].

To maximize its uptake and sustainability, the program needs to be integrated into existing public health and health care systems [80]. At a community level, it is important to raise awareness about the program through schools, parenting associations, and other media (including online networks and social media) to facilitate self-referral by parents, or recommendation of the program by teachers, student welfare staff, or school psychologists or counselors to parents within the school. Youth mental health clinicians in the public and private health care systems can refer parents of their youth clients to the fourth level of the program, or deliver it themselves as part their therapeutic work with the adolescent. More broadly, targeted strategies may be required to increase parents' engagement in parenting programs for their adolescent's mental health, given that rates of engagement are less than optimal [81]. For harder-to-reach subgroups of parents (eg, parents living in poverty and recent immigrants), additional efforts may be required to improve engagement [82]. Program adaptations may also be needed to make the program more acceptable (and effective) with specific high-risk subgroups, for example, parents of adolescents with autism, disabilities, or chronic health problems.

Research on parent preferences for information on child mental health, in the context of seeking treatment services for their child, also highlights the importance of considering specific preferences of different subgroups [83,84]. For example, a Web-based program will simply not be acceptable to some parents who prefer direct face-to-face contact with a clinician and/or other parents. Similarly, some professionals are skeptical

about the ability of Web-based programs to bring about real behavior change and are less likely to recommend it to parents [85]. The parent-preference literature also suggests that parents with the greatest need (ie, higher levels of child oppositional and conduct problems, greater impact of child difficulties on family functioning, and elevated personal depressive symptoms) may be less likely to engage with parenting programs or other resources. Notably, these parents show a stronger preference for information on the Internet, which they can access on demand [83]. These findings highlight the trade-offs between different levels of intervention, which, along with the preferences of various subgroups of parents, should be considered when planning the implementation of parenting programs [86]. For example, parents with the greatest need could just be informed about the availability of the online resources (eg, the Guidelines and the website link) when they first seek mental health services for their child, which is often a time of heightened stress. Once the family settles into treatment and the crisis starts to subside, parents could then be

encouraged to consider seeking resources for themselves. Further research on parent preferences for child mental health information for prevention is required.

Conclusions

Parents have an important role in reducing the risk and impact of adolescent internalizing disorders, but there is a lack of evidence-based, cost-effective programs to equip parents for this role. This paper described the development of the PIP Web-based intervention and proposed a public health approach that utilizes this intervention at varying levels of intensity to support parents. Evaluation of each separate level of the model is ongoing. Further evaluation of the whole approach is required to assess the utility of the intervention as a public health approach, and its effects not just on parenting competencies, parental self-efficacy, and adolescent depression and anxiety outcomes, but also broader functioning (eg, school engagement, general health, quality of life, and peer relationships), and socioeconomic outcomes.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshots of the Partners in Parenting intervention.

[PDF File (Adobe PDF File), 856KB - [mental_v4i4e59_app1.pdf](#)]

Multimedia Appendix 2

Persuasive systems design (PSD) principles fulfilled in the Partners in Parenting (PIP) intervention.

[PDF File (Adobe PDF File), 507KB - [mental_v4i4e59_app2.pdf](#)]

References

1. Whiteford HA, Ferrari AJ, Degenhardt L, Feigin V, Vos T. The global burden of mental, neurological and substance use disorders: an analysis from the Global Burden of Disease Study 2010. PLoS One 2015 Feb;10(2):e0116820 [FREE Full text] [doi: [10.1371/journal.pone.0116820](#)] [Medline: [25658103](#)]
2. Mrazek P, Haggerty R. Reducing Risks for Mental Disorders: Frontiers for Preventive Intervention Research. Washington, DC: National Academies Press; 1994.
3. Kessler RC, Petukhova M, Sampson NA, Zaslavsky AM, Wittchen H. Twelve-month and lifetime prevalence and lifetime morbid risk of anxiety and mood disorders in the United States. Int J Methods Psychiatr Res 2012 Sep;21(3):169-184 [FREE Full text] [doi: [10.1002/mp.1359](#)] [Medline: [22865617](#)]
4. Woodward LJ, Fergusson DM. Life course outcomes of young people with anxiety disorders in adolescence. J Am Acad Child Adolesc Psychiatry 2001 Sep;40(9):1086-1093. [doi: [10.1097/00004583-200109000-00018](#)] [Medline: [11556633](#)]

5. Copeland WE, Shanahan L, Costello EJ, Angold A. Childhood and adolescent psychiatric disorders as predictors of young adult disorders. *Arch Gen Psychiatry* 2009 Jul;66(7):764-772 [FREE Full text] [doi: [10.1001/archgenpsychiatry.2009.85](https://doi.org/10.1001/archgenpsychiatry.2009.85)] [Medline: [19581568](#)]
6. Dekker MC, Ferdinand RF, Van Lang ND, Bongers IL, Van Der Ende J, Verhulst FC. Developmental trajectories of depressive symptoms from early childhood to late adolescence: gender differences and adult outcome. *J Child Psychol Psychiatry* 2007 Jul;48(7):657-666. [doi: [10.1111/j.1469-7610.2007.01742.x](https://doi.org/10.1111/j.1469-7610.2007.01742.x)] [Medline: [17593146](#)]
7. Lawrence D, Johnson S, Hafekost J, Boterhoven De Haan K, Sawyer M, Ainley J. The Mental Health of Children and Adolescents: Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing. Canberra: Department of Health. Canberra: Department of Health; 2015.
8. Andrews G, Issakidis C, Sanderson K, Corry J, Lapsley H. Utilising survey data to inform public policy: comparison of the cost-effectiveness of treatment of ten mental disorders. *Br J Psychiatry* 2004 Jun;184(6):526-533 [FREE Full text] [Medline: [15172947](#)]
9. Kessler RC, Angermeyer M, Anthony JC, DE Graaf R, Demyttenaere K, Gasquet I, et al. Lifetime prevalence and age-of-onset distributions of mental disorders in the World Health Organization's World Mental Health Survey Initiative. *World Psychiatry* 2007 Oct;6(3):168-176 [FREE Full text] [Medline: [18188442](#)]
10. Thapar A, Collishaw S, Pine DS, Thapar AK. Depression in adolescence. *Lancet* 2012 Mar 17;379(9820):1056-1067 [FREE Full text] [doi: [10.1016/S0140-6736\(11\)60871-4](https://doi.org/10.1016/S0140-6736(11)60871-4)] [Medline: [22305766](#)]
11. Yap MB, Reavley N, Jorm AF. Where would young people seek help for mental disorders and what stops them? Findings from an Australian national survey. *J Affect Disord* 2013 May;147(1-3):255-261. [doi: [10.1016/j.jad.2012.11.014](https://doi.org/10.1016/j.jad.2012.11.014)] [Medline: [23228570](#)]
12. Jorm AF, Wright A, Morgan AJ. Where to seek help for a mental disorder? National survey of the beliefs of Australian youth and their parents. *Med J Aust* 2007 Nov 19;187(10):556-560. [Medline: [18021042](#)]
13. Yap MB, Fowler M, Reavley N, Jorm AF. Parenting strategies for reducing the risk of childhood depression and anxiety disorders: a Delphi consensus study. *J Affect Disord* 2015 Sep 01;183:330-338. [doi: [10.1016/j.jad.2015.05.031](https://doi.org/10.1016/j.jad.2015.05.031)] [Medline: [26047961](#)]
14. Schleider JL, Weisz JR. Family process and youth internalizing problems: a triadic model of etiology and intervention. *Dev Psychopathol* 2017 Feb;29(1):273-301. [doi: [10.1017/S095457941600016X](https://doi.org/10.1017/S095457941600016X)] [Medline: [27048767](#)]
15. Restifo K, Bögels S. Family processes in the development of youth depression: translating the evidence to treatment. *Clin Psychol Rev* 2009 Jun;29(4):294-316. [doi: [10.1016/j.cpr.2009.02.005](https://doi.org/10.1016/j.cpr.2009.02.005)] [Medline: [19356833](#)]
16. Commonwealth of Australia. Fourth National Mental Health Plan: An agenda for collaborative government action in mental health 2009-2014. Canberra: Commonwealth of Australia, Department of Health; 2009:1-88.
17. National Prevention Council. Washington, DC: Department of Health and Human Services; 2011. National Prevention Strategy: America's Plan for Better Health and Wellness URL: <https://www.surgeongeneral.gov/priorities/prevention/strategy/report.pdf> [WebCite Cache ID 6vV3DFJwu]
18. World Health Organization. Geneva, Switzerland: World Health Organization Document Production Services; 2013. Mental health action plan 2013-2020 URL: http://apps.who.int/iris/bitstream/10665/89966/1/9789241506021_eng.pdf?ua=1 [accessed 2017-12-06] [WebCite Cache ID 6vV4GKXr8]
19. European Commission. 2014. Joint Action on Mental Health and Well-being: Mental Health in All Policies. Situation analysis and recommendations for action URL: <http://www.mentalhealthandwellbeing.eu/assets/docs/publications/MHiAP%20Final.pdf> [accessed 2017-12-06] [WebCite Cache ID 6vV45W21p]
20. Beesdo K, Knappe S, Pine DS. Anxiety and anxiety disorders in children and adolescents: developmental issues and implications for DSM-V. *Psychiatr Clin North Am* 2009 Sep;32(3):483-524 [FREE Full text] [doi: [10.1016/j.psc.2009.06.002](https://doi.org/10.1016/j.psc.2009.06.002)] [Medline: [19716988](#)]
21. Cairns KE, Yap MB, Pilkington PD, Jorm AF. Risk and protective factors for depression that adolescents can modify: a systematic review and meta-analysis of longitudinal studies. *J Affect Disord* 2014 Dec;169:61-75. [doi: [10.1016/j.jad.2014.08.006](https://doi.org/10.1016/j.jad.2014.08.006)] [Medline: [25154536](#)]
22. Sandler I, Schoenfelder E, Wolchik S, MacKinnon D. Long-term impact of prevention programs to promote effective parenting: lasting effects but uncertain processes. *Annu Rev Psychol* 2011;62:299-329 [FREE Full text] [doi: [10.1146/annurev.psych.121208.131619](https://doi.org/10.1146/annurev.psych.121208.131619)] [Medline: [20822438](#)]
23. Yap MB, Pilkington PD, Ryan SM, Jorm AF. Parental factors associated with depression and anxiety in young people: a systematic review and meta-analysis. *J Affect Disord* 2014 Mar;156:8-23. [doi: [10.1016/j.jad.2013.11.007](https://doi.org/10.1016/j.jad.2013.11.007)] [Medline: [24308895](#)]
24. Schwartz OS, Dudgeon P, Sheeber LB, Yap MB, Simmons JG, Allen NB. Parental behaviors during family interactions predict changes in depression and anxiety symptoms during adolescence. *J Abnorm Child Psychol* 2012 Jan;40(1):59-71. [doi: [10.1007/s10802-011-9542-2](https://doi.org/10.1007/s10802-011-9542-2)] [Medline: [21789522](#)]
25. Yap MB, Jorm AF. Parents' beliefs about actions they can take to prevent depressive disorders in young people: results from an Australian national survey. *Epidemiol Psychiatr Sci* 2012 Mar;21(1):117-123. [Medline: [22670419](#)]

26. Sheeber LB, Davis B, Leve C, Hops H, Tildesley E. Adolescents' relationships with their mothers and fathers: associations with depressive disorder and subdiagnostic symptomatology. *J Abnorm Psychol* 2007 Feb;116(1):144-154 [[FREE Full text](#)] [doi: [10.1037/0021-843X.116.1.144](https://doi.org/10.1037/0021-843X.116.1.144)] [Medline: [17324025](#)]
27. Sheeber L, Hops H, Davis B. Family processes in adolescent depression. *Clin Child Fam Psychol Rev* 2001 Mar;4(1):19-35. [Medline: [11388562](#)]
28. Rapee RM. Family factors in the development and management of anxiety disorders. *Clin Child Fam Psychol Rev* 2012 Mar;15(1):69-80. [doi: [10.1007/s10567-011-0106-3](https://doi.org/10.1007/s10567-011-0106-3)] [Medline: [22116624](#)]
29. Yap MB, Allen NB, Sheeber L. Using an emotion regulation framework to understand the role of temperament and family processes in risk for adolescent depressive disorders. *Clin Child Fam Psychol Rev* 2007 Jun;10(2):180-196. [doi: [10.1007/s10567-006-0014-0](https://doi.org/10.1007/s10567-006-0014-0)] [Medline: [17265137](#)]
30. Rose G. *The Strategy of Preventive Medicine*. Oxford: Oxford University Press; 1992.
31. Yap MB, Morgan A, Cairns K, Jorm A, Hetrick S, Merry S. Parents in prevention: a meta-analysis of randomized controlled trials of parenting interventions to prevent internalizing problems in children from birth to age 18. *Clin Psychol Rev* 2016 Oct 21;50:138-158. [doi: [10.1016/j.cpr.2016.10.003](https://doi.org/10.1016/j.cpr.2016.10.003)] [Medline: [27969003](#)]
32. Koerting J, Smith E, Knowles M, Latter S, Elsey H, McCann D, et al. Barriers to, and facilitators of, parenting programmes for childhood behaviour problems: a qualitative synthesis of studies of parents' and professionals' perceptions. *Eur Child Adolesc Psychiatry* 2013 Nov;22(11):653-670 [[FREE Full text](#)] [doi: [10.1007/s00787-013-0401-2](https://doi.org/10.1007/s00787-013-0401-2)] [Medline: [23564207](#)]
33. Janz NK, Becker MH. The Health Belief Model: a decade later. *Health Educ Behav* 1984 Jan 01;11(1):1-47. [doi: [10.1177/109019818401100101](https://doi.org/10.1177/109019818401100101)] [Medline: [6392204](#)]
34. Rickwood DJ, Deane FP, Wilson CJ. When and how do young people seek professional help for mental health problems? *Med J Aust* 2007 Oct 01;187(7 Suppl):S35-S39. [Medline: [17908023](#)]
35. Nauta MH, Scholing A, Emmelkamp PM, Minderaa RB. Cognitive-behavioral therapy for children with anxiety disorders in a clinical setting: no additional effect of a cognitive parent training. *J Am Acad Child Adolesc Psychiatry* 2003 Nov;42(11):1270-1278. [doi: [10.1097/01.chi.0000085752.71002.93](https://doi.org/10.1097/01.chi.0000085752.71002.93)] [Medline: [14566163](#)]
36. Cox GR, Callahan P, Churchill R, Hunot V, Merry SN, Parker AG, et al. Psychological therapies versus antidepressant medication, alone and in combination for depression in children and adolescents. *Cochrane Database Syst Rev* 2014 Nov 30(11):CD008324. [doi: [10.1002/14651858.CD008324.pub3](https://doi.org/10.1002/14651858.CD008324.pub3)] [Medline: [25433518](#)]
37. Fisak BD, Richard D, Mann A. The prevention of child and adolescent anxiety: a meta-analytic review. *Prev Sci* 2011 Sep;12(3):255-268. [doi: [10.1007/s11121-011-0210-0](https://doi.org/10.1007/s11121-011-0210-0)] [Medline: [21437675](#)]
38. Hetrick SE, Cox GR, Witt KG, Bir JJ, Merry SN. Cognitive behavioural therapy (CBT), third-wave CBT and interpersonal therapy (IPT) based interventions for preventing depression in children and adolescents. *Cochrane Database Syst Rev* 2016 Aug 09(8):CD003380. [doi: [10.1002/14651858.CD003380.pub4](https://doi.org/10.1002/14651858.CD003380.pub4)] [Medline: [27501438](#)]
39. Fisak BJ, Richard D, Mann A. The prevention of child and adolescent anxiety: a meta-analytic review. *Prev Sci* 2011 Sep;12(3):255-268. [doi: [10.1007/s11121-011-0210-0](https://doi.org/10.1007/s11121-011-0210-0)] [Medline: [21437675](#)]
40. Stockings EA, Degenhardt L, Dobbins T, Lee YY, Erskine HE, Whiteford HA, et al. Preventing depression and anxiety in young people: a review of the joint efficacy of universal, selective and indicated prevention. *Psychol Med* 2016 Jan;46(1):11-26. [doi: [10.1017/S0033291715001725](https://doi.org/10.1017/S0033291715001725)] [Medline: [26315536](#)]
41. Rothbaum F, Weisz J. Parental caregiving and child externalizing behavior in nonclinical samples: a meta-analysis. *Psychol Bull* 1994 Jul;116(1):55-74. [Medline: [8078975](#)]
42. Hoeve M, Dubas JS, Eichelsheim VI, van der Laan PH, Smeenk W, Gerris JR. The relationship between parenting and delinquency: a meta-analysis. *J Abnorm Child Psychol* 2009 Aug;37(6):749-775 [[FREE Full text](#)] [doi: [10.1007/s10802-009-9310-8](https://doi.org/10.1007/s10802-009-9310-8)] [Medline: [19263213](#)]
43. Yap MB, Cheong TW, Zaravinos-Tsakos F, Lubman DI, Jorm AF. Modifiable parenting factors associated with adolescent alcohol misuse: a systematic review and meta-analysis of longitudinal studies. *Addiction* 2017 Jul;112(7):1142-1162. [doi: [10.1111/add.13785](https://doi.org/10.1111/add.13785)] [Medline: [28178373](#)]
44. James AC, James G, Cowdrey FA, Soler A, Choke A. Cognitive behavioural therapy for anxiety disorders in children and adolescents. *Cochrane Database Syst Rev* 2013;6:CD004690. [doi: [10.1002/14651858.CD004690.pub3](https://doi.org/10.1002/14651858.CD004690.pub3)] [Medline: [23733328](#)]
45. Breinholst S, Esbjørn BH, Reinholdt-Dunne M, Stallard P. CBT for the treatment of child anxiety disorders: a review of why parental involvement has not enhanced outcomes. *J Anxiety Disord* 2012 Apr;26(3):416-424. [doi: [10.1016/j.janxdis.2011.12.014](https://doi.org/10.1016/j.janxdis.2011.12.014)] [Medline: [22306129](#)]
46. Heinrichs N, Bertram H, Kuschel A, Hahlweg K. Parent recruitment and retention in a universal prevention program for child behavior and emotional problems: barriers to research and program participation. *Prev Sci* 2005 Dec;6(4):275-286. [doi: [10.1007/s11121-005-0006-1](https://doi.org/10.1007/s11121-005-0006-1)] [Medline: [16075192](#)]
47. Cuijpers P, van Straten A, Warmerdam L, van Rooy M. Recruiting participants for interventions to prevent the onset of depressive disorders: possible ways to increase participation rates. *BMC Health Serv Res* 2010;10:181 [[FREE Full text](#)] [doi: [10.1186/1472-6963-10-181](https://doi.org/10.1186/1472-6963-10-181)] [Medline: [20579332](#)]
48. Australian Bureau of Statistics. Canberra, Australia: Australian Bureau of Statistics; 2016. Household Use of Information Technology, Australia 2014-2015 URL: <http://www.abs.gov.au/ausstats/abs@.nsf/PrimaryMainFeatures/8146.0?OpenDocument> [accessed 2017-05-22] [[WebCite Cache ID 6qdiS9O1z](#)]

49. Andrews G, Cuijpers P, Craske MG, McEvoy P, Titov N. Computer therapy for the anxiety and depressive disorders is effective, acceptable and practical health care: a meta-analysis. *PLoS One* 2010;5(10):e13196 [FREE Full text] [doi: [10.1371/journal.pone.0013196](https://doi.org/10.1371/journal.pone.0013196)] [Medline: [20967242](https://pubmed.ncbi.nlm.nih.gov/20967242/)]
50. Metzler CW, Sanders MR, Rusby JC, Crowley RN. Using consumer preference information to increase the reach and impact of media-based parenting interventions in a public health approach to parenting support. *Behav Ther* 2012 Jun;43(2):257-270 [FREE Full text] [doi: [10.1016/j.beth.2011.05.004](https://doi.org/10.1016/j.beth.2011.05.004)] [Medline: [22440064](https://pubmed.ncbi.nlm.nih.gov/22440064/)]
51. Yap MB, Martin P, Jorm AF. Online parenting guidelines to prevent adolescent depression and anxiety: evaluating user characteristics and usefulness. *Early Interv Psychiatry* 2017 Oct 27 Epub ahead of print(forthcoming). [doi: [10.1111/eip.12503](https://doi.org/10.1111/eip.12503)] [Medline: [29076246](https://pubmed.ncbi.nlm.nih.gov/29076246/)]
52. Donker T, Blankers M, Hedman E, Ljótsson B, Petrie K, Christensen H. Economic evaluations of Internet interventions for mental health: a systematic review. *Psychol Med* 2015 Dec;45(16):3357-3376. [doi: [10.1017/S0033291715001427](https://doi.org/10.1017/S0033291715001427)] [Medline: [26235445](https://pubmed.ncbi.nlm.nih.gov/26235445/)]
53. Cascar A, Christensen H. Review of internet-based prevention and treatment programs for anxiety and depression in children and adolescents. *Med J Aust* 2010 Jun 07;192(11 Suppl):S12-S14. [Medline: [20528700](https://pubmed.ncbi.nlm.nih.gov/20528700/)]
54. Love SM, Sanders MR, Turner KM, Maurange M, Knott T, Prinz R, et al. Social media and gamification: engaging vulnerable parents in an online evidence-based parenting program. *Child Abuse Negl* 2016 Mar;53:95-107. [doi: [10.1016/j.chiabu.2015.10.031](https://doi.org/10.1016/j.chiabu.2015.10.031)] [Medline: [26880281](https://pubmed.ncbi.nlm.nih.gov/26880281/)]
55. Morgan AJ, Rapee RM, Salim A, Goharpey N, Tamir E, McLellan LF, et al. Internet-delivered parenting program for prevention and early intervention of anxiety problems in young children: randomized controlled trial. *J Am Acad Child Adolesc Psychiatry* 2017 May;56(5):417-425.e1. [doi: [10.1016/j.jaac.2017.02.010](https://doi.org/10.1016/j.jaac.2017.02.010)] [Medline: [28433091](https://pubmed.ncbi.nlm.nih.gov/28433091/)]
56. Lee YY, Barendregt JJ, Stockings EA, Ferrari AJ, Whiteford HA, Patton GA, et al. The population cost-effectiveness of delivering universal and indicated school-based interventions to prevent the onset of major depression among youth in Australia. *Epidemiol Psychiatr Sci* 2016 Aug 11;26(5):545-564. [doi: [10.1017/S2045796016000469](https://doi.org/10.1017/S2045796016000469)] [Medline: [27509769](https://pubmed.ncbi.nlm.nih.gov/27509769/)]
57. Kreuter M, Farrell D, Olevitch L, Brennan L. *Tailoring Health Messages: Customizing Communication With Computer Technology*. Mahwah, NJ: Lawrence Erlbaum Associates; 2000.
58. Wildeboer G, Kelders SM, van Gemert-Pijnen JE. The relationship between persuasive technology principles, adherence and effect of web-based interventions for mental health: a meta-analysis. *Int J Med Inform* 2016 Apr 14;96:71-85. [doi: [10.1016/j.ijmedinf.2016.04.005](https://doi.org/10.1016/j.ijmedinf.2016.04.005)] [Medline: [27117057](https://pubmed.ncbi.nlm.nih.gov/27117057/)]
59. Yap MB, Jorm AF, Bazley R, Kelly CM, Ryan SM, Lubman D. Web-based parenting program to prevent adolescent alcohol misuse: rationale and development. *Australas Psychiatry* 2011 Aug;19(4):339-344. [doi: [10.3109/10398562.2011.603334](https://doi.org/10.3109/10398562.2011.603334)] [Medline: [21861634](https://pubmed.ncbi.nlm.nih.gov/21861634/)]
60. van Gemert-Pijnen JE, Nijland N, van Limburg MA, Ossebaard HC, Kelders SM, Eysenbach G, et al. A holistic framework to improve the uptake and impact of eHealth technologies. *J Med Internet Res* 2011 Dec;13(4):e111 [FREE Full text] [doi: [10.2196/jmir.1672](https://doi.org/10.2196/jmir.1672)] [Medline: [22155738](https://pubmed.ncbi.nlm.nih.gov/22155738/)]
61. Sanders MR, Kirby JN. Consumer engagement and the development, evaluation, and dissemination of evidence-based parenting programs. *Behav Ther* 2012 Jun;43(2):236-250 [FREE Full text] [doi: [10.1016/j.beth.2011.01.005](https://doi.org/10.1016/j.beth.2011.01.005)] [Medline: [22440062](https://pubmed.ncbi.nlm.nih.gov/22440062/)]
62. Oinas-Kukkonen H, Harjuma M. Persuasive systems design: key issues, process model, and system features. *CAIS* 2009;24:485-500 [FREE Full text]
63. Yap MB, Pilkington PD, Ryan SM, Kelly C, Jorm AF. Parenting strategies for reducing the risk of adolescent depression and anxiety disorders: a Delphi consensus study. *J Affect Disord* 2014 Mar;156:67-75. [doi: [10.1016/j.jad.2013.11.017](https://doi.org/10.1016/j.jad.2013.11.017)] [Medline: [24359862](https://pubmed.ncbi.nlm.nih.gov/24359862/)]
64. Jorm AF. Using the Delphi expert consensus method in mental health research. *Aust N Z J Psychiatry* 2015 Oct;49(10):887-897. [doi: [10.1177/0004867415600891](https://doi.org/10.1177/0004867415600891)] [Medline: [26296368](https://pubmed.ncbi.nlm.nih.gov/26296368/)]
65. Parenting Strategies Program. How to prevent depression and clinical anxiety in your teenager: Strategies for parents. Melbourne: Beyondblue; 2013.
66. Cardamone-Breen MC, Jorm AF, Lawrence KA, Mackinnon AJ, Yap MB. The Parenting to Reduce Adolescent Depression and Anxiety Scale: assessing parental concordance with parenting guidelines for the prevention of adolescent depression and anxiety disorders. *PeerJ* 2017;5:e3825 [FREE Full text] [doi: [10.7717/peerj.3825](https://doi.org/10.7717/peerj.3825)] [Medline: [28951815](https://pubmed.ncbi.nlm.nih.gov/28951815/)]
67. Jones T, Prinz R. Potential roles of parental self-efficacy in parent and child adjustment: a review. *Clin Psychol Rev* 2005 May;25(3):341-363. [doi: [10.1016/j.cpr.2004.12.004](https://doi.org/10.1016/j.cpr.2004.12.004)] [Medline: [15792853](https://pubmed.ncbi.nlm.nih.gov/15792853/)]
68. Wittkowski A, Dowling H, Smith DM. Does engaging in a group-based intervention increase parental self-efficacy in parents of preschool children? A systematic review of the current literature. *J Child Fam Stud* 2016;25(11):3173-3191 [FREE Full text] [doi: [10.1007/s10826-016-0464-z](https://doi.org/10.1007/s10826-016-0464-z)] [Medline: [27795657](https://pubmed.ncbi.nlm.nih.gov/27795657/)]
69. youthinmind. 2017. Youth in Mind: For stressed children and teenagers - and those who care for them URL: <http://youthinmind.info/> [WebCite Cache ID 6u9RWu8fR]
70. Kelders SM, Kok RN, Ossebaard HC, Van Gemert-Pijnen JE. Persuasive system design does matter: a systematic review of adherence to web-based interventions. *J Med Internet Res* 2012 Nov 14;14(6):e152 [FREE Full text] [doi: [10.2196/jmir.2104](https://doi.org/10.2196/jmir.2104)] [Medline: [23151820](https://pubmed.ncbi.nlm.nih.gov/23151820/)]

71. Richards D, Richardson T. Computer-based psychological treatments for depression: a systematic review and meta-analysis. *Clin Psychol Rev* 2012 Jun;32(4):329-342. [doi: [10.1016/j.cpr.2012.02.004](https://doi.org/10.1016/j.cpr.2012.02.004)] [Medline: [22466510](#)]
72. Dadds MR, Roth JH. Prevention of anxiety disorders: results of a universal trial with young children. *J Child Fam Stud* 2007 Aug 15;17(3):320-335. [doi: [10.1007/s10826-007-9144-3](https://doi.org/10.1007/s10826-007-9144-3)]
73. Mohr DC, Cuijpers P, Lehman K. Supportive accountability: a model for providing human support to enhance adherence to eHealth interventions. *J Med Internet Res* 2011 Mar;13(1):e30 [FREE Full text] [doi: [10.2196/jmir.1602](https://doi.org/10.2196/jmir.1602)] [Medline: [21393123](#)]
74. Restifo K, Bögels S. Family processes in the development of youth depression: translating the evidence to treatment. *Clin Psychol Rev* 2009 Jun;29(4):294-316. [doi: [10.1016/j.cpr.2009.02.005](https://doi.org/10.1016/j.cpr.2009.02.005)] [Medline: [19356833](#)]
75. Steinberg L, Morris AS. Adolescent development. *Annu Rev Psychol* 2001;52:83-110. [doi: [10.1146/annurev.psych.52.1.83](https://doi.org/10.1146/annurev.psych.52.1.83)] [Medline: [11148300](#)]
76. Gopalan G, Goldstein L, Klingenstein K, Sicher C, Blake C, McKay MM. Engaging families into child mental health treatment: updates and special considerations. *J Can Acad Child Adolesc Psychiatry* 2010 Aug;19(3):182-196 [FREE Full text] [Medline: [20842273](#)]
77. Cairns KE, Yap MB, Reavley NJ, Jorm AF. Identifying prevention strategies for adolescents to reduce their risk of depression: a Delphi consensus study. *J Affect Disord* 2015 Sep 01;183:229-238. [doi: [10.1016/j.jad.2015.05.019](https://doi.org/10.1016/j.jad.2015.05.019)] [Medline: [26025369](#)]
78. Christensen H, Petrie K. State of the e-mental health field in Australia: where are we now? *Aust N Z J Psychiatry* 2013 Feb;47(2):117-120. [doi: [10.1177/0004867412471439](https://doi.org/10.1177/0004867412471439)] [Medline: [23297367](#)]
79. Australian Government. Health. Canberra: Department of Health and Ageing; 2012. E-Mental Health Strategy for Australia URL: [http://www.health.gov.au/internet/main/publishing.nsf/content/7C7B0BFEB985D0EBCA257BF0001BB0A6/\\$File/emstrat.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/7C7B0BFEB985D0EBCA257BF0001BB0A6/$File/emstrat.pdf) [accessed 2017-12-06] [WebCite Cache ID 6vV7rWfIK]
80. Jorm AF, Morgan AJ, Malhi GS. The future of e-mental health. *Aust N Z J Psychiatry* 2013 Feb;47(2):104-106. [doi: [10.1177/0004867412474076](https://doi.org/10.1177/0004867412474076)] [Medline: [23382504](#)]
81. Ingoldsby EM. Review of interventions to improve family engagement and retention in parent and child mental health programs. *J Child Fam Stud* 2010 Oct 01;19(5):629-645 [FREE Full text] [doi: [10.1007/s10826-009-9350-2](https://doi.org/10.1007/s10826-009-9350-2)] [Medline: [20823946](#)]
82. Sanders MR. Triple P-Positive Parenting Program as a public health approach to strengthening parenting. *J Fam Psychol* 2008 Aug;22(4):506-517. [doi: [10.1037/0893-3200.22.3.506](https://doi.org/10.1037/0893-3200.22.3.506)] [Medline: [18729665](#)]
83. Cunningham CE, Deal K, Rimas H, Buchanan DH, Gold M, Sdao-Jarvie K, et al. Modeling the information preferences of parents of children with mental health problems: a discrete choice conjoint experiment. *J Abnorm Child Psychol* 2008 Oct;36(7):1123-1138. [doi: [10.1007/s10802-008-9238-4](https://doi.org/10.1007/s10802-008-9238-4)] [Medline: [18481167](#)]
84. Cunningham CE, Rimas H, Chen Y, Deal K, McGrath P, Lingley-Pottie P, et al. Modeling parenting programs as an interim service for families waiting for children's mental health treatment. *J Clin Child Adolesc Psychol* 2015 Apr;44(4):616-629. [doi: [10.1080/15374416.2014.888666](https://doi.org/10.1080/15374416.2014.888666)] [Medline: [24702236](#)]
85. Cunningham CE, Deal K, Rimas H, Chen Y, Buchanan DH, Sdao-Jarvie K. Providing information to parents of children with mental health problems: a discrete choice conjoint analysis of professional preferences. *J Abnorm Child Psychol* 2009 Nov;37(8):1089-1102. [doi: [10.1007/s10802-009-9338-9](https://doi.org/10.1007/s10802-009-9338-9)] [Medline: [19629676](#)]
86. Offord DR, Kraemer HC, Kazdin AE, Jensen PS, Harrington R. Lowering the burden of suffering from child psychiatric disorder: trade-offs among clinical, targeted, and universal interventions. *J Am Acad Child Adolesc Psychiatry* 1998 Jul;37(7):686-694. [doi: [10.1097/00004583-199807000-00007](https://doi.org/10.1097/00004583-199807000-00007)] [Medline: [9666623](#)]

Abbreviations

CBT: cognitive behavioral therapy

CeHRes: Center for eHealth Research

eHealth: electronic health

PIP: Partners in Parenting

PSD: Persuasive Systems Design

PRADAS: Parenting to Reduce Adolescent Depression and Anxiety Scale

RCT: randomized controlled trial

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Original Paper

Can Facebook Reduce Perceived Anxiety Among College Students? Randomized Controlled Exercise Trial Using the Transtheoretical Model of Behavior Change

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Abstract

Background: Recent studies suggest social media may be an attractive strategy to promote mental health and wellness. There remains a need to examine the utility for individually tailored wellness messages posted to social media sites such as Facebook to facilitate positive psychological outcomes.

Objective: Our aim was to extend the growing body of evidence supporting the potential for social media to enhance mental health. We evaluated the influence of an 8-week social media intervention on anxiety in college students and examined the impact of dynamic (active) versus static (passive) Facebook content on physical activity behaviors.

Methods: Participants in the static group (n=21) accessed a Facebook page featuring 96 statuses. Statuses were intended to engage cognitive processes followed by behavioral processes of change per the transtheoretical model of behavior change. Content posted on the static Facebook page was identical to the dynamic page; however, the static group viewed all 96 statuses on the first day of the study, while the dynamic group received only 1 to 2 of these status updates per day throughout the intervention. Anxiety was measured using the Overall Anxiety Severity and Impairment Scale (OASIS). Time spent engaging in physical activity was assessed using the International Physical Activity Questionnaire (IPAQ).

Results: The OASIS change score for the dynamic Facebook group was statistically significant ($P=.003$), whereas the change score for the static group was not ($P=.48$). A statistically significant group-by-time interaction was observed ($P=.03$). The total IPAQ group-by-time interaction was not statistically significant ($P=.06$).

Conclusions: We observed a decrease in anxiety and increase in total physical activity for the dynamic group only. Dynamic social networking sites, featuring regularly updated content, may be more advantageous than websites that retain static content over time.

Trial Registration: ClinicalTrials.gov NCT03363737; <https://clinicaltrials.gov/ct2/show/NCT03363737> (Archived by WebCite at <http://www.webcitation.org/6vXzNbOWJ>)

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KEYWORDS

mental health; physical activity behavior change; social media

Introduction

Verduyn and colleagues [1] suggest a passive online presence on social networking sites is detrimental to mental health. A passive presence involves 1-sided consumption of digital media, devoid of attempts to connect with fellow users [2]. Passive

social networking site behaviors may encourage unhealthy comparisons and jealousy, which may exert profoundly negative effects on psychological health. Conversely, an active social presence may predict perceived well-being via intentional connectivity, which serves to expand and strengthen social capital among social networking site members [1,2]. Kreps and Neuhauser [3] support the progressive social relevancy of online

communication technologies to promote health, where viewable content is interactive and user-centered. To this end, target audiences are given the power to embark upon a meaningful health journey capable of addressing their unique goals and concerns [3]. The digital age has influenced widespread transmission of relational information. Tailored wellness messages posted to social media sites such as Facebook access specific populations who receive instantaneous virtual feedback, which may help to facilitate social support, physical health, and psychological well-being [1,4,5]. However, despite recent strides in mobile health (mHealth) research, there remains a need to further parse the significance of active versus passive mHealth interventions on mediating psychological outcomes among social networking site users. This pilot study evaluates the relationship between a Facebook-based exercise intervention and level of anxiety among college students, as anxiety is both a widespread and underdiagnosed public health concern within this population [6].

Although mHealth is less investigated than traditional, face-to-face therapeutic interventions, emerging work has begun to evaluate the effectiveness of online-based mHealth interventions [7]. The growing body of existing social media research lacks adherence to validated theoretical models and evidence-based practice [8,9]. Additionally, many websites contain content which fails to elicit sustained health behavior change [10]. Social media offers researchers the opportunity to assume an active and dynamic online presence, posting relevant wellness content, which, ideally, could increase user interaction and dissemination of promoted health topics. Recent interventions have illuminated the potential for social networking sites to function not only as popular communication platforms but also provide reliable hubs for accessing health information [11,12]. Social networking site and mobile phone apps are inexpensive, private, collaborative, and offer opportunities for rapid communication between users within an expansive social context, making virtual content attractive to young men and women around the globe [13,14].

Collectively, recent studies have demonstrated social media may be an attractive strategy to promote mental health and wellness. Social media champions a robust individual social presence, as well as mass interactivity, which may contribute to user satisfaction and subjective well-being [1]. These constituents enable users within social networking site communities to cultivate relationships and disseminate loadable content, which may begin as individually generated information but propagate virally as active users share media relevant to the generation of popular culture. Facebook use among college students is influenced most heavily by opportunities for members to develop a collaborative social presence [15]. Social support has been shown to facilitate enhanced perceptions of personal well-being and fulfillment [1,16,17]. Social media has the power to evoke feelings of belonging and, perhaps, raise self-esteem within users [18]. Such interactive content mobilization offers unique educational opportunities and may

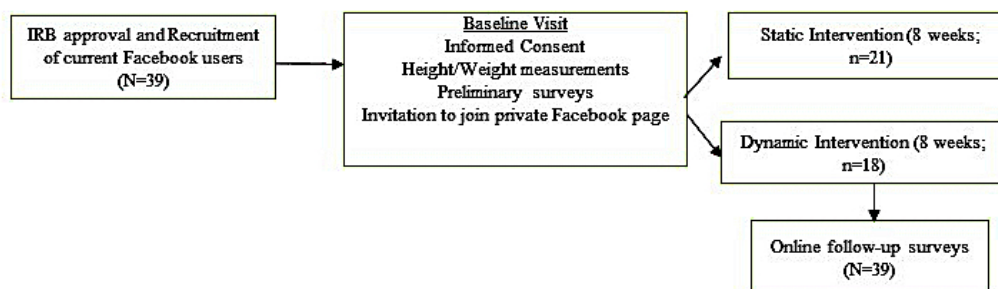
be a springboard to link public engagement with the wellness domain.

Firth et al [7] conducted a meta-analysis of 9 randomized controlled trials that evaluated the utility for mHealth interventions to favorably influence anxiety symptoms. The authors suggest the potential for effective digital technology strategies to significantly reduce anxiety. Among 4 reviewed interventions that specifically targeted anxiety outcomes, 2 demonstrated no reductions in anxiety beyond those observed in waitlist control groups [19,20]. Notably, 2 interventions reduced anxiety significantly more than waitlist conditions but were not superior to active controls [21,22]. Therefore, the magnitude of efficacy for mobile phone research remains unclear [23], and thus, requires additional research. In comparison to the research in Firth's meta-analysis, we used the transtheoretical model of health behavior change rather than employing strategies specifically designed to treat mental disorders because this model has been shown to be associated with reduced anxiety symptoms [23]. Further, the transtheoretical model is widely used in physical activity research, and exercise is known to exert beneficial effects on mood profile, particularly within the college-aged population [23-25]. Additionally, unlike the studies included in the aforementioned meta-analysis, we did not use indication of mental health issues as inclusionary criteria and recruited from the general student body in an attempt to comprehensively address the health needs of the average college adult, who may be reluctant to expose their mental health concerns upon recruitment [26,27]. To this end, our pilot study aims to extend the growing body of evidence supporting the use of mobile phones as tools to promote mental health, address important gaps in the literature, and provide direction for future interventions evaluating the link between mobile phones and mental health. The specific purpose of this brief report was to examine the utility of an 8-week Facebook-based wellness intervention to serve as a platform for researchers to promote reliable and accurate wellness information. The primary objectives of the study were 2-fold: we aimed to examine the potential for dynamic (active) versus static (passive) Facebook content to influence physical activity behavior and evaluate the influence of a social media intervention on anxiety within a sample of undergraduate and graduate college students. Such a side-by-side comparison between an active versus static media-based intervention on physical activity is, to our knowledge, the first to be conducted.

Methods

Setting and Participants

Undergraduate and graduate students (N=39; n=21 for static arm and n=18 for dynamic arm; see Figure 1) were recruited via convenience-based sampling at the University of Mississippi. Participants attended a baseline laboratory visit during which they provided consent, had their height and weight measured, completed preliminary surveys, and were given instructions to accept a researcher invitation to join a private Facebook page.

Figure 1. Study design schematic.

Pilot Intervention

This pilot study was approved by the institutional review board at the University of Mississippi. Participants randomly allocated to join the static Facebook page ($n=21$) were exposed to a page that already contained 96 status updates targeting the precontemplation, contemplation, preparation, action, and maintenance phases of the transtheoretical model. The statuses progressed through general information tailored to participants' community and university resources for healthy eating, stress and time management, physical activity benefits, and tips to implement positive lifestyle changes. Statuses were intended to offer participants awareness and specific tools necessary to engage cognitive processes of change (ie, consciousness raising, dramatic relief, self-evaluation, environmental evaluation, and social liberation) followed by behavioral processes of change (helping relationships, self-liberation, reinforcement, stimulus control, and counterconditioning) throughout the 8-week intervention period. Posts on the static Facebook page consisted of identical content as the dynamic group. The only distinction was that the static group received access to all 96 statuses on the first day of the study, while the dynamic group was exposed to 1 to 2 of these status updates per day across the 8-week intervention period.

Participants randomly allocated to join the dynamic Facebook page ($n=18$) were exposed to 2 status updates per weekday and 1 status update per weekend day for 7 weeks (96 status updates). During the final week, participants did not receive daily notifications to read status updates but were encouraged to complete online follow-up surveys. No incentives were provided to participants upon completion of this study.

Main Outcome Measures

The primary outcomes assessed were changes in physical activity behavior and anxiety, measured via self-report. After meeting inclusionary criteria, which included having an active Facebook account, daily access to a mobile phone, and a current University of Mississippi email account, eligible participants were sent a Facebook invitation to join either the static or dynamic Facebook group. Time spent engaging in vigorous,

moderate, and walking physical activity habits was assessed using the International Physical Activity Questionnaire (IPAQ), which has demonstrated adequate reliability and validity [28]. We created a total physical activity variable by summing the minutes per week of walking, moderate-intensity, and vigorous-intensity physical activity.

Anxiety was measured using the Overall Anxiety Severity and Impairment Scale (OASIS), a 5-item psychometric instrument completed via self-reported response on a 5-point Likert scale. A sample question from the OASIS is "How much does anxiety or fear interfere with your social life and relationships?" Higher ratings indicate greater anxiety inference. This scale has been used as a valid and reliable assessment of degree of anxiety impairment in various clinical and subclinical populations [29,30]. Internal consistency was calculated using Cronbach alpha for both the static (pre: .86 and post: .76) and dynamic group (pre: .72 and post: .84).

Statistical Analyses

Stata SE version 12 (StataCorp LLC) was used to conduct paired sample t tests to examine change scores between pre- and post-OASIS scores for each group. An independent samples t test was then used to compare the change scores between the 2 intervention arms. For all analyses, statistical significance was established as a nominal alpha of .05.

Results

Demographic information is displayed in Table 1. The OASIS change score for the static Facebook group was nonsignificant ($P=.48$). The static group exhibited a baseline mean score of 4.14 and a follow-up mean score of 3.57 on the OASIS. Conversely, the OASIS change score for the dynamic Facebook group was statistically significant ($P=.003$). The dynamic group exhibited a baseline mean score of 4.91 and a follow-up mean score of 1.36 on the OASIS. Change scores were then compared across both groups using an independent samples t test. A statistically significant group-by-time interaction was observed ($P=.03$).

Table 1. Demographic information.

Variable	Entire sample mean (SD)	Dynamic group mean (95% CI)	Static group mean (95% CI)
GPA ^a , baseline	3.26 (0.63)	3.31 (3.01 to 3.62)	3.05 (2.79 to 3.31)
GPA, postintervention	3.55 (0.46)	3.52 (3.17 to 3.87)	3.47 (3.14 to 3.81)
Age, years	22.65 (3.16)	21.9 (20.42 to 23.46)	22.2 (21.22 to 23.18)
Gender (% female)	68	75	81
Race (% white)	66	75	57
Years active on Facebook	7.97 (2.99)	7.56 (6.55 to 8.58)	8.62 (6.98 to 10.25)
Number of Facebook friends	1256 (949.92)	939.93 (558.47 to 1321.4)	1390.57 (1050.1 to 1731.04)
Number of logins per day, baseline	7.72 (6.2)	6.31 (4.92 to 7.71)	6.57 (4.32 to 8.82)
Number of logins per day, postintervention	4.35 (3.98)	3.73 (2.36 to 5.09)	4 (1.7 to 6.3)
Number of intervention-page logins per day	1.38 (0.58)	1.45 (1.12 to 1.79)	1.43 (0.8 to 2.06)
Total ambulatory physical activity, minutes per week	762.8 (1375.54)	(mean change score) 1378.25 (–25.61 to 2782.11)	(mean change score) 59.44 (–132.34 to 251.22)

^aGPA: grade point average.

We used *t* tests to compare IPAQ pre- and postintervention change scores for physical activity behaviors between groups. The total IPAQ group-by-time interaction was not statistically significant ($P=.06$). We also computed the Mann-Whitney U analysis, which was not statistically significant ($P=.13$). Average reported total ambulatory movement (ie, light to vigorous physical activity) across groups was 762.8 minutes per week with a standard deviation of 1375.54. Mean ambulatory physical activity for the static group was 453.3 minutes per week at baseline and 540.72 minutes per week at follow-up. The average total physical activity change for this group was 59.44 minutes per week. Mean physical activity for the dynamic group was 366.62 minutes per week at baseline and 1393.1 minutes per week at follow-up. The average total physical activity change for the dynamic group was 1378.25 minutes per week. There was an inverse statistical correlation between changes in physical activity and anxiety. The zero-order correlation coefficient between mean physical activity change on mean anxiety change is $r=-0.51$ ($P=.01$).

Discussion

Principal Findings

The dearth of research examining the link between modern media consumption and anxiety is equivocal [31]. The relationship between mobile phone use and anxiety has been demonstrated among college students exhibiting compulsive or addictive mobile phone behaviors [32,33]. Lepp et al [31] suggest that investigations should attempt to further examine whether this correlation manifests for those not engaging in problematic usage of digital technology. We did not explicitly measure Internet addiction in this pilot intervention. However, our results indicate that for those allocated to the dynamic Facebook page, self-reported anxiety levels diminished significantly. Further, average general Facebook logins per day were marginally decreased for both groups following the

intervention (see Table 1), suggesting our investigation did not contribute to addictive social networking behaviors.

Regarding the main outcomes, we observed a statistically significant decrease in anxiety for the dynamic group only. This finding may be influenced by our adherence to the transtheoretical model of behavior change. All status updates followed a theoretically driven sequence of messages in alignment with the cognitive and behavioral processes of change. Participants in the dynamic group received daily status updates containing accurate and credible health information. A total of 96 wellness messages were posted over 7 weeks with content first focusing on cognitive processes of change (ie, consciousness raising, dramatic relief, self-evaluation, environmental evaluation, and social liberation) followed by behavioral processes of change (helping relationships, self-liberation, reinforcement, stimulus control, and counterconditioning). Participants randomized into the static, or passive, Facebook page received access to all 96 messages on the first day of the intervention with no daily updates occurring thereafter. We hypothesize the potency of the cognitive and behavioral messages was diluted in the static group, providing rationale for the observed reduction in anxiety in the dynamic group alone. We also found a statistically significant inverse correlation between mean total physical activity change and mean change in anxiety. We feel this finding underscores the importance of daily, dynamic exposure to Facebook wellness messages. Physical activity behavior changes are difficult to sustain over time, so perhaps consistent social media notifications were advantageous reminders for participants in the dynamic group to increase total ambulatory movement throughout the 8-week intervention period. Thus, our findings suggest that dynamic social networking sites featuring regularly updated content may be more advantageous than websites that retain static content over time.

Strengths and Limitations

Despite the plausibility for social media to be used effectively in physical and mental health research, there are numerous concerns that must be addressed when implementing social networking site interventions. Social media is user-centered, meaning individuals consume and produce content relevant to their unique goals and interests. Thus, efficacious social networking site research must be individually tailored. Lack of tailored content is a possible limitation of this pilot study. Although we observed increased changes in physical activity in the dynamic group, the majority of our recruited participants were exercise science or health promotion students already engaging in physical activity. Such extensive exposure to information specifically targeting initiation of positive health behaviors may have been less impactful in this sample. Cognitive and behavioral processes of change may be more appropriately tailored to individuals contemplating behavior change. Further, the risk of psychological disorders such as depression and anxiety is highest among young adults [34]. Importantly, this population is also unlikely to seek treatment, partially due to the stigmatization of mental health [26,27]. We were also unable to control for participant exposure to university courses, exercise programs, or access to wellness information outside of the pilot intervention, which may have affected physical activity or level of anxiety across the 8-week intervention period. A strength of this pilot study, as well as previous social networking site interventions, is the ability to directly target young adults, as social media use among millennials is unrivaled in today's society [35]. However, social media inherently limits privacy, as it exists as a global platform designed to proliferate opportunities for social inclusion.

Therefore, special consideration should be given to the social networking site outlet selected and precautionary measures taken to protect participant safety and anonymity. Our protocol addressed this issue appropriately by using a private, invitation-only Facebook page, although study participants were aware of fellow participants who had access to the page. The inability to completely blind participants may have limited participant interaction and comfortability in this study. Future research should design empirically based methodology that controls for participant privacy while retaining the social aspect integral to social media research.

Conclusion

The results of this pilot study suggest reduced anxiety among college students may be associated with exposure to dynamic, or active, Facebook wellness interventions. We propose mHealth interventions be used as self-monitoring aids rather than for mental health diagnoses. That is, mobile phone technologies should not replace face-to-face therapeutic interventions but may be complementary to clinical services. Awareness and management of psychological health status may be improved through social media, which has been suggested to enhance self-efficacy and decrease the functional impairment associated with anxiety, depression, stress, and psychological disturbances [36]. Social media research is an emerging field deserving special investigation in university settings. Communication hubs including Facebook, Twitter, Instagram, Snapchat, and YouTube are powerful modern research tools. These sites offer the novel potential for rapid dissemination of tailored messages, which may revolutionize the field of psychological and behavioral health promotion.

Conflicts of Interest

None declared.

Notice of editorial concern: This randomized study was only retrospectively registered, in violation of ICMJE rules for prospective registration of randomized trials, explained by authors with the fact that they "did not consider the study a clinical trial because the content (which is not unusual for most people to observe via the Internet) was not necessarily designed to examine a causal effect on a health outcome." The editor granted an exception because the risk of bias appears low and the study was considered explorative. However, readers are warned to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

References

1. Verduyn P, Ybarra O, Résibois M, Jonides J, Kross E. Do social network sites enhance or undermine subjective well-being? A critical review. *Soc Iss Policy Rev* 2017 Jan 13;11(1):274-302. [doi: [10.1111/sipr.12033](https://doi.org/10.1111/sipr.12033)]
2. Verduyn P, Lee DS, Park J, Shablack H, Orvell A, Bayer J, et al. Passive Facebook usage undermines affective well-being: experimental and longitudinal evidence. *J Exp Psychol Gen* 2015 Apr;144(2):480-488. [doi: [10.1037/xge0000057](https://doi.org/10.1037/xge0000057)] [Medline: [25706656](https://pubmed.ncbi.nlm.nih.gov/25706656/)]
3. Kreps GL, Neuhauser L. New directions in eHealth communication: opportunities and challenges. *Patient Educ Couns* 2010 Mar;78(3):329-336. [doi: [10.1016/j.pec.2010.01.013](https://doi.org/10.1016/j.pec.2010.01.013)] [Medline: [20202779](https://pubmed.ncbi.nlm.nih.gov/20202779/)]
4. Cavallo DN, Tate DF, Ries AV, Brown JD, DeVellis RF, Ammerman AS. A social media-based physical activity intervention: a randomized controlled trial. *Am J Prev Med* 2012 Nov;43(5):527-532 [FREE Full text] [doi: [10.1016/j.amepre.2012.07.019](https://doi.org/10.1016/j.amepre.2012.07.019)] [Medline: [23079176](https://pubmed.ncbi.nlm.nih.gov/23079176/)]
5. Napolitano MA, Hayes S, Bennett GG, Ives AK, Foster GD. Using Facebook and text messaging to deliver a weight loss program to college students. *Obesity (Silver Spring)* 2013 Jan;21(1):25-31. [doi: [10.1002/oby.20232](https://doi.org/10.1002/oby.20232)] [Medline: [23505165](https://pubmed.ncbi.nlm.nih.gov/23505165/)]

6. Beiter R, Nash R, McCrady M, Rhoades D, Linscomb M, Clarahan M, et al. The prevalence and correlates of depression, anxiety, and stress in a sample of college students. *J Affect Disord* 2015 Mar 01;173:90-96. [doi: [10.1016/j.jad.2014.10.054](https://doi.org/10.1016/j.jad.2014.10.054)] [Medline: [25462401](https://pubmed.ncbi.nlm.nih.gov/25462401/)]
7. Firth J, Torous J, Nicholas J, Carney R, Rosenbaum S, Sarris J. Can smartphone mental health interventions reduce symptoms of anxiety? A meta-analysis of randomized controlled trials. *J Affect Disord* 2017 Aug 15;218:15-22 [FREE Full text] [doi: [10.1016/j.jad.2017.04.046](https://doi.org/10.1016/j.jad.2017.04.046)] [Medline: [28456072](https://pubmed.ncbi.nlm.nih.gov/28456072/)]
8. Mani M, Kavanagh DJ, Hides L, Stoyanov SR. Review and evaluation of mindfulness-based iPhone apps. *JMIR Mhealth Uhealth* 2015;3(3):e82 [FREE Full text] [doi: [10.2196/mhealth.4328](https://doi.org/10.2196/mhealth.4328)] [Medline: [26290327](https://pubmed.ncbi.nlm.nih.gov/26290327/)]
9. Meng J, Martinez L, Holmstrom A, Chung M, Cox J. Research on social networking sites and social support from 2004 to 2015: a narrative review and directions for future research. *Cyberpsychol Behav Soc Netw* 2016 Dec 21;20(1):44-51. [doi: [10.1089/cyber.2016.0325](https://doi.org/10.1089/cyber.2016.0325)] [Medline: [28002686](https://pubmed.ncbi.nlm.nih.gov/28002686/)]
10. Doshi A, Patrick K, Sallis JF, Calfas K. Evaluation of physical activity web sites for use of behavior change theories. *Ann Behav Med* 2003;25(2):105-111. [Medline: [12704012](https://pubmed.ncbi.nlm.nih.gov/12704012/)]
11. Baptist AP, Thompson M, Grossman KS, Mohammed L, Sy A, Sanders GM. Social media, text messaging, and email-preferences of asthma patients between 12 and 40 years old. *J Asthma* 2011 Oct;48(8):824-830. [doi: [10.3109/02770903.2011.608460](https://doi.org/10.3109/02770903.2011.608460)] [Medline: [21864099](https://pubmed.ncbi.nlm.nih.gov/21864099/)]
12. Hedge KC, Donald CP. Evaluation of the use of a social networking site in sexual health care. *Int J STD AIDS* 2011 Mar;22(3):171-172. [doi: [10.1258/ijsa.2010.010355](https://doi.org/10.1258/ijsa.2010.010355)] [Medline: [21464456](https://pubmed.ncbi.nlm.nih.gov/21464456/)]
13. Ellison N, Steinfield C, Lampe C. The benefits of Facebook "friends": social capital and college students' use of online social network sites. *J Comput-Mediat Comm* 2007;12(4):1143-1168. [doi: [10.1111/j.1083-6101.2007.00367.x](https://doi.org/10.1111/j.1083-6101.2007.00367.x)]
14. Kaplan AM, Haenlein M. Users of the world, unite! The challenges and opportunities of social media. *Bus Horizons* 2010;53(1):59-68. [doi: [10.1016/j.bushor.2009.09.003](https://doi.org/10.1016/j.bushor.2009.09.003)]
15. Cheung C, Chiu P, Mee MK. Online social networks: why do students use facebook? *Comput Hum Behav* 2011;27:1337-1343. [doi: [10.1016/j.chb.2010.07.028](https://doi.org/10.1016/j.chb.2010.07.028)]
16. Argyle M, Crossland J. The dimensions of positive emotions. *Br J Soc Psychol* 1987 Jun;26 (Pt 2):127-137. [Medline: [3607389](https://pubmed.ncbi.nlm.nih.gov/3607389/)]
17. DeNeve K. Happy as an extraverted clam? The role of personality for subjective well-being. *Curr Dir Psychol Sci* 1999;8(5):141-144.
18. Best P, Taylor B. Online communication, social media and adolescent wellbeing: a systematic narrative review. *Child Youth Serv Rev* 2014;41:27-36. [doi: [10.1016/j.childyouth.2014.03.001](https://doi.org/10.1016/j.childyouth.2014.03.001)]
19. Pham Q, Khatib Y, Stansfeld S, Fox S, Green T. Feasibility and efficacy of an mHealth game for managing anxiety: "flowy" randomized controlled pilot trial and design evaluation. *Games Health J* 2016 Feb;5(1):50-67. [doi: [10.1089/g4h.2015.0033](https://doi.org/10.1089/g4h.2015.0033)] [Medline: [26536488](https://pubmed.ncbi.nlm.nih.gov/26536488/)]
20. Villani D, Grassi A, Cognetta C, Toniolo D, Cipresso P, Riva G. Self-help stress management training through mobile phones: an experience with oncology nurses. *Psychol Serv* 2013 Aug;10(3):315-322. [doi: [10.1037/a0026459](https://doi.org/10.1037/a0026459)] [Medline: [23937091](https://pubmed.ncbi.nlm.nih.gov/23937091/)]
21. Enock P, Hofmann S, McNally R. Attention bias modification training via smartphone to reduce social anxiety: a randomized, controlled multi-session experiment. *Cognitive Ther Res* 2014;38(2):200-216. [doi: [10.1007/s10608-014-9606-z](https://doi.org/10.1007/s10608-014-9606-z)]
22. Ivanova E, Lindner P, Ly KH, Dahlin M, Vernmark K, Andersson G, et al. Guided and unguided Acceptance and Commitment Therapy for social anxiety disorder and/or panic disorder provided via the Internet and a smartphone application: a randomized controlled trial. *J Anxiety Disord* 2016 Dec;44:27-35. [doi: [10.1016/j.janxdis.2016.09.012](https://doi.org/10.1016/j.janxdis.2016.09.012)] [Medline: [27721123](https://pubmed.ncbi.nlm.nih.gov/27721123/)]
23. Joyner C, Loprinzi P. Examining the association of transtheoretical model constructs on physical activity: considerations of anxiety symptomology as a potential moderator. *J Molecular Pathophysiol* 2017;6(1):12-16. [doi: [10.5455/jmp.20170413124004](https://doi.org/10.5455/jmp.20170413124004)]
24. Edwards MK, Loprinzi PD. Experimentally increasing sedentary behavior results in increased anxiety in an active young adult population. *J Affect Disord* 2016 Nov 01;204:166-173. [doi: [10.1016/j.jad.2016.06.045](https://doi.org/10.1016/j.jad.2016.06.045)] [Medline: [27351099](https://pubmed.ncbi.nlm.nih.gov/27351099/)]
25. Stubbs B, Koyanagi A, Hallgren M, Firth J, Richards J, Schuch F, et al. Physical activity and anxiety: a perspective from the World Health Survey. *J Affect Disord* 2017 Jan 15;208:545-552. [doi: [10.1016/j.jad.2016.10.028](https://doi.org/10.1016/j.jad.2016.10.028)] [Medline: [27802893](https://pubmed.ncbi.nlm.nih.gov/27802893/)]
26. Gulliver A, Griffiths KM, Christensen H. Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry* 2010;10:113 [FREE Full text] [doi: [10.1186/1471-244X-10-113](https://doi.org/10.1186/1471-244X-10-113)] [Medline: [21192795](https://pubmed.ncbi.nlm.nih.gov/21192795/)]
27. Rickwood DJ, Deane FP, Wilson CJ. When and how do young people seek professional help for mental health problems? *Med J Aust* 2007 Oct 1;187(7 Suppl):S35-S39. [Medline: [17908023](https://pubmed.ncbi.nlm.nih.gov/17908023/)]
28. Curi HP, Gomes V. Reliability and validity of the international physical activity questionnaire (IPAQ). *Med Sci Sport Exer* 2004;36(3):556. [doi: [10.2188/jea.JE20110003](https://doi.org/10.2188/jea.JE20110003)]
29. Norman SB, Cissell SH, Means-Christensen AJ, Stein MB. Development and validation of an Overall Anxiety Severity And Impairment Scale (OASIS). *Depress Anxiety* 2006;23(4):245-249. [doi: [10.1002/da.20182](https://doi.org/10.1002/da.20182)] [Medline: [16688739](https://pubmed.ncbi.nlm.nih.gov/16688739/)]
30. Campbell-Sills L, Norman SB, Craske MG, Sullivan G, Lang AJ, Chavira DA, et al. Validation of a brief measure of anxiety-related severity and impairment: the Overall Anxiety Severity and Impairment Scale (OASIS). *J Affect Disord* 2009 Jan;112(1-3):92-101 [FREE Full text] [doi: [10.1016/j.jad.2008.03.014](https://doi.org/10.1016/j.jad.2008.03.014)] [Medline: [18486238](https://pubmed.ncbi.nlm.nih.gov/18486238/)]

31. Lepp A, Barkley J, Karpinski A. The relationship between cell phone use, academic performance, anxiety, and satisfaction with life in college students. *Comput Hum Behav* 2014;31:343-350. [doi: [10.1016/j.chb.2013.10.049](https://doi.org/10.1016/j.chb.2013.10.049)]
32. Jenaro C, Flores N, Gómez-Vela M, González-Gil F, Caballo C. Problematic internet and cell-phone use: psychological, behavioral, and health correlates. *Addict Res Theory* 2007;15(3):309-320. [doi: [10.1080/16066350701350247](https://doi.org/10.1080/16066350701350247)]
33. Takao M, Takahashi S, Kitamura M. Addictive personality and problematic mobile phone use. *Cyberpsychol Behav* 2009 Oct;12(5):501-507. [doi: [10.1089/cpb.2009.0022](https://doi.org/10.1089/cpb.2009.0022)] [Medline: [19817562](https://pubmed.ncbi.nlm.nih.gov/19817562/)]
34. National survey of mental health and wellbeing: summary of results. 2007. URL: http://www.abs.gov.au/ausstats/subscriber.nsf/log?openagent&43260_2007.pdf&4326_0&Publication&6AE6DA447F985FC2CA2574EA00122BD6&&2007&23.10.2008&Latest [accessed 2017-10-18]
35. Lenhart A, Purcell K, Smith A, Zickuhr K. Social media and mobile Internet use among teens and young adults. Washington: Pew Internet and American Life Project URL: http://www.pewinternet.org/~media/Files/Reports/2010/PIP_Social_Media_and_Young_Adults_Report_Final_with_toplevels.pdf [accessed 2017-10-18] [WebCite Cache ID 6uIsp2aFy]
36. Harrison V, Proudfoot J, Wee PP, Parker G, Pavlovic DH, Manicavasagar V. Mobile mental health: review of the emerging field and proof of concept study. *J Ment Health* 2011 Dec;20(6):509-524. [doi: [10.3109/09638237.2011.608746](https://doi.org/10.3109/09638237.2011.608746)] [Medline: [21988230](https://pubmed.ncbi.nlm.nih.gov/21988230/)]

Abbreviations

IPAQ: International Physical Activity Questionnaire

OASIS: Overall Anxiety Severity and Impairment Scale

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Original Paper

Development of a Questionnaire to Measure the Attitudes of Laypeople, Physicians, and Psychotherapists Toward Telemedicine in Mental Health

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Abstract

Background: In the field of psychiatry and psychotherapy, there are now a growing number of Web-based interventions, mobile phone apps, or treatments that are available via remote transmission screen worldwide. Many of these interventions have been shown to be effective in studies but still find little use in everyday therapeutic work. However, it is important that attitude and expectation toward this treatment are generally examined, because these factors have an important effect on the efficacy of the treatment. To measure the general attitude of the users and prescribers toward telemedicine, which may include, for instance, Web-based interventions or interventions through mobile phone apps, there are a small number of extensive tests. The results of studies based on small groups of patients have been published too, but there is no useful short screening tool to give an insight into the general population's attitude. We have developed a screening instrument that examines such attitude through a few graded questions.

Objective: This study aimed to explore the Attitude toward Telemedicine in Psychiatry and Psychotherapy (ATiPP) and to evaluate the results of general population and some subgroups.

Methods: In a three-step process, the questionnaire, which is available in three versions (laypeople, physicians, and psychologists), was developed. Afterwards, it was evaluated by four groups: population-representative laypeople, outpatients in different faculties, physicians, and psychotherapists.

Results: The results were evaluated from a total of 1554 questionnaires. The sample population included 1000 laypeople, 455 outpatients, 62 physicians, and 37 psychotherapists. The reliability of all three versions of the questionnaire seemed good, as indicated by the Cronbach alpha values of .849 (the laypeople group), .80 (the outpatients' group), .827 (the physicians' group), and .855 (the psychotherapists' group).

Conclusions: The ATiPP was found to be useful and reliable for measuring the attitudes toward the Web-based interventions in psychiatry and psychotherapy and should be used in different studies in this field in the future to evaluate and reflect the attitude of the participants.

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KEYWORDS

screening; questionnaire; e-mental health; remote consultation; attitude to computers; physician expectations; telemedicine; online-intervention

Introduction

There are many options currently available for telemedical contact or communication between the patients and the professionals. These include Web-based interventions, mobile phone apps, and remote screen calls. In psychiatry and psychotherapy, in addition to the conventional long-distance contact via phone calls or mail, the Web-based interventions (e-mental health) and mobile apps (m-mental health) are increasingly becoming important areas of care for the patients. Mental health, as a special part of the so-called telemedicine, covers two important areas. The first involves the information and education about the psychiatric disorders and psychosocial distress, and the second pertains to diagnostic and treatment tools. Many different Web-based services, in the form of email, social media, and other avenues, are accessible over the Internet almost worldwide. Also, a number of telemedical apps are available, especially via the Internet, for the somatic illnesses [1]. The everyday use (outside clinical trials) of Web-based tools for the diagnosis and treatment of mental illness, however, is not very popular yet [2,3]. For example, in the United Kingdom, there are only two computerized interventions recommended for the clinical treatment of psychiatric diseases (one against depression and another against panic and phobia) [4-6]. Phone calls or emails are regularly, though not frequently, used as the media of communication between the therapists and the patients in psychiatry or psychotherapy. Web-based interventions, however, are seldom used. Hence, it seems that there are barriers to the implementation of effective Web-based interventions that can help identify and overcome the issues related to mental health. The potential users recognize the rational advantages of the Web-based interventions such as anonymity, convenience regarding time, location, and the ability to do without a structured setting [7,8]. At the same time, the dropout rate among the users of computerized interventions of cognitive behavior therapy (CBT) is almost twice as high as compared with the dropout rate of face-to-face CBT [9]. The willingness to participate in a study on a *new* therapeutic concept seems to be good, but its application and use in the daily practice of therapy is very limited [10]. In a paper on the question of the meaningfulness of computerized interventions, only 22% of the participants indicated that the symptoms can be effectively improved [8]. Other studies show a negative attitude of the patients toward Web-based interventions, too. They have shown a low expectation of patients regarding whether their psychological complaints can be improved by computerized interventions, even to the conclusion that the patients do not want to use Web-based interventions in the future [11]. The current surveys on the attitudes toward and expectations from Web-based interventions are, in part, too comprehensive for a screening tool. Also, they do not reflect the attitude of the general population, focusing instead on selected populations (certain patient groups, Internet users with high affinity to the medium, etc). Another aspect is their outdated status, which renders them unable to represent the current possibilities that the Internet offers today.

Nevertheless, a considerable number of interventions via the Internet are actually already available, for example, to support

the detection and treatment of posttraumatic stress disorder [4,12,13], anxiety disorders [14], or depression. In e-mental health, the currently available Web-based tools differ, among other things, regarding their depth of information—some only provide information about the disorder (psychoeducative), whereas others give different instructions for self-help (self-guided) or give some guidance from a psychotherapist about helpful activity (guided help) [1,15-17]. A few Web-based interventions allow additional contact with a psychotherapist via video call (Web-based counseling) or face-to-face care (blended) [18]. It is foreseeable that the Web-based interventions will play a growing role in all areas of medicine, even in psychiatry and psychotherapy, in the future [19]. However, the everyday use of the Web-based interventions does not correspond to the optimum use of the available resources. Also, the efficacy of the Web-based interventions does not lead to their use on a larger scale [10]. Therefore, it is necessary to find out the background of the probable users (both patients and the physicians or psychotherapists) to integrate this information into the development and distribution of new apps [20-27]. Furthermore, it also appears necessary, especially in the studies on efficacy and effectiveness, to examine the expectations of the users from such tools as a positive complement to the existing therapeutic spectrum. This is also important because, since the 1970s, it has been possible to show repeatedly that the patients' expectations from and belief in the credibility of a therapeutic medium or process can significantly influence its effectiveness and efficacy [28]. Therefore, in the studies on the effectiveness of the Web-based interventions, especially when the participants are recruited from a website or other Web-based media, the sample may have been biased. This can be quantified at least by using a simple screening tool, which can show the data of the general population as comparative values.

To our knowledge, there is no short questionnaire that measures the concept of a favorable attitude toward telemedicine in psychiatry and psychotherapy, especially, but not exclusively, e-mental health. Only some difficult and complex measurements are published yet [7]. Therefore, we developed a questionnaire that can be used to evaluate the expectations and the attitudes of the users of such interventions, and we seek to publish the data of a large sample of the general population and some special groups (patients of different faculties, physicians, and psychotherapists) to present the comparative values.

Methods

To develop the questionnaire, Attitudes toward Telemedicine in Psychiatry and Psychotherapy (ATiPP), we undertook a three-step process. We started by generating a set of items reflecting the attitude toward and the expectations from telemedicine in general and particularly, the use of telemedicine in mental health. We used the experience of a psychotherapeutic team and psychiatric consultants to find as many statements as possible, as well as depending on the available literature. For example, one statement was, "In general, telemedicine is a good addition to medical services." The initial 15-item questionnaire was then used in a discussion process with the experts not otherwise involved in the development of the scale. The notes and comments that arose independently were included in the

further development of the questionnaire. This was done in a modified Delphi process, which means that the experts discussed and developed the questions over several sessions [29]. In the modified Delphi technique, the panelists begin with a set of items to rate according to importance, rather than with an open-ended questionnaire. Here, these items were selected by the study team, drawing from various sources, including a literature review and interviews with content experts, patients, and the technical and medical specialists for Web-based interventions. The primary advantage of using this modification is that it typically improves the initial response rate [30]. The questions are posed in a series of rounds until a consensus is achieved or until it is obvious that the future rounds will not provide additional information. At each round after the first, the experts are provided with a feedback of anonymous comments from the panelists in the round before. The questions evaluated as substantive duplicates or evaluated as not relevant were excluded after the discussion when we developed the questionnaire. Then in a second step, we condensed the items to an 8-item questionnaire (from the initial 15-item questionnaire). A 5-point Likert scale was used with anchors ranging from 1="I strongly agree" to 5="I strongly disagree." At this point, we developed three versions of the questionnaire so that the exact wording was matched to the individual function of the respondents. Consequently, the laypeople were asked what they prefer for themselves, whereas the practitioners were asked what they want to offer their patients.

We explain the questionnaire with the following sentences (ie, questionnaire for the laypeople):

The use of telemedicine as an online service, by phone call or, as a smartphone application, is lately being discussed more and more intensively. This is one of the consequences of improved technical opportunities on the one hand and scarcer resources on the other hand.

While radiology or dermatology are already using telemedicine for the purpose of image transmission for X-rays, CT scan, or skin photos, the use of telemedicine in the area of psychiatry and psychotherapy—despite some pilot projects worldwide—is still, largely, an uncharted territory.

In the context of a scientific study on psychiatric care research, we are investigating the attitudes of the users, the patients, and the referring physicians toward the telemedical services.

With the following questions, we would like to determine how you assess psychiatric or psychotherapeutic care via a telemedical offer, ie, via the Internet, email, telephone, or via a smartphone application.

We are also interested in whether you would use such an offer yourself.

Table 1 shows the 8 items of the three different versions of the questionnaire. The differences of the question texts are essentially explained by the functions of the respondents. Thus,

the psychotherapists are specifically asked whether they consider telemedicine to be helpful in somatic medicine because the Delphi process in developing the questionnaire showed that the psychotherapists did not reflect the somatic applications of telemedicine in the vast majority. Also in Question 6, the differences arise from the fact that the psychotherapists are in contact with the patients who are or have already been in a face-to-face therapy, that is, only those who have already been treated or who are waiting for treatment are affected, whereas in the case of the physicians, the patients were treated with many diagnoses but usually not in a psychotherapeutic setting there. In Question 3, we asked the patients for a successful treatment in colloquial speech, while we asked the same from the physicians and psychotherapists in professional wording.

The resulting questionnaire was then used in a study with four groups of participants—the physicians, the psychotherapists, the outpatients in the waiting areas of various medical disciplines, and a representative population sample in a telephone interview.

The population sample was based on the telephone number ranges provided by the German Federal Network Agency. This number range includes all telephone numbers in the Federal Republic of Germany, including mobile telephone numbers. We used the nationwide sample of telephone numbers. A nationwide list of the German Market Research Association (ADM) was used for the telephone survey. The connection data are presorted here according to various aspects (eg, regions) and can be appropriately used in a representative sample. As the share of households that do not publish their telephone numbers is increasing steadily, the ADM telephone sample contains both registered and generated numbers. The generation of numbers was done with a process similar to Brick [31]. In this study, we collected 50.00% (500/1000) of the general population with the generated numbers and 50.00% (500/1000) with the published numbers. This procedure ensured that both the regional distribution of the calls as well as the allocation to age groups, etc, corresponded to the population distribution in Germany; thus, a representative study sample could be collected.

The group of patients was selected from four outpatient clinics—two general practitioners' practices, a gynecology practice, and a center for neurology. The physicians and the psychotherapists were selected through a Germany-wide mailing action. We randomized 200 physicians from different disciplines and 200 psychotherapists from the nationwide database of the physicians and therapists by the means of a computer-generated randomization. We distributed the questionnaire as a printed version. The return was free and anonymous, and no reward was given.

We analyzed the data from the measurement by testing the reliability. We had expected the items to be presented in a graduated form as one dimension—acceptance or attitude. In particular, we assumed that the questions are in a relationship with each other, and we examined whether the individual questions are replaceable or dispensable.

Table 1. The 8 items of the Attitude toward Telemedicine in Psychiatry and Psychotherapy (ATiPP) questionnaire.

Number	Laypeople	Physicians	Psychotherapists
1	Generally, telemedicine is a good addition to the medical services.	Generally, telemedicine is a good addition to the medical services.	Telemedicine in somatic medicine is a good addition to the medical services.
2	For psychiatric or psychotherapeutic issues or mental illness, patient information via Internet or telemedicine is very helpful.	For psychiatric or psychotherapeutic issues or mental illness, patient information via Internet or telemedicine is very helpful.	For psychiatric or psychotherapeutic issues or mental illness, patient information via Internet or telemedicine is very helpful.
3	A successful treatment of the patients with mental illness via Internet or telemedicine is possible.	An effective treatment of the patients with mental illness via Internet or telemedicine is possible.	An effective treatment of the patients with mental illness via Internet or telemedicine is possible.
4	The bridging of the waiting time for an appointment with a psychiatrist/psychotherapist by using the Internet services or telemedicine is a sensible option.	The bridging of the waiting time for an appointment in psychiatry/psychotherapy by using the Internet services or telemedicine is a sensible option.	The bridging of the waiting time for an appointment in psychiatry/psychotherapy by using the Internet services or telemedicine is a sensible option.
5	Aftercare and counseling after a presence therapy by a psychiatrist or psychotherapist through contact via the Internet or email or telephone are realizable.	Aftercare and stabilization after a presence therapy by a psychiatrist or psychotherapist through contact via the Internet or or email or telephone are realizable.	Aftercare and stabilization after a presence therapy by a psychiatrist or psychotherapist through contact via the Internet or email or telephone are realizable.
6	I would make use of Web-based interventions or telemedicine without an accompanying face-to-face therapy in the case of a mental illness.	I would absolutely recommend my patients with psychiatric or psychotherapeutic treatment needs a Web-based intervention or telemedical support, if such were to be offered for the clinical picture.	For my own patients, I would offer support and intervention via the Internet or telephone.
7	An online therapy via the Internet services or telemedicine is only sensible as an addition to face-to-face therapy.	In addition to a face-to-face therapy, an accompanying psychoeducational or psychosocial or additional intervention via the Internet is sensible.	In addition to a face-to-face therapy, an accompanying psychoeducational or psychosocial or additional intervention via the Internet is sensible.
8	An online therapy through the Internet services or telemedicine can only work effectively with live contact with a therapist through video calling and email or chat.	An online therapy through the Internet services or telemedicine for mental illness can only work effectively with live contact with a therapist through video calling and email or chat.	An online therapy through the Internet services or telemedicine for mental illness can only work effectively with live contacts to a therapist through video calling and email or chat.

All statistical data were analyzed with the open source program R, version 2.2.4 (R-Core-Team).

The chair of the Ethical Commission of the Board of Physicians (Institutional Review Board) in Hamburg, Germany, did not consider ethical approval to be necessary because of the anonymous type of survey of the participants.

Results

The participants of the first survey answering the questionnaire as a population-representative random sample were 51.40% (514/1000) female. The age was distributed according to the proportion in the population and divided into 10-year clusters. The smallest age group with 12.60% ranged from 16 to 25 years, followed by 14.30% (143/1000) from 26 to 35 years, 15.00% (150/1000) from 36 to 45 years, 17.70% (177/1000) from 46 to 55 years, 16.00% (160/1000) from 56 to 65 years, and 24.40% (244/1000) for the age group of 65 years and older.

The Cronbach alpha value for the 8 items reached the conventional standards for scale reliability ($\alpha=.849$), and

no item reduction seemed meaningful. We used the questionnaire version for the laypeople in this particular study.

In the next part of the study, we included a sample of outpatients in the waiting rooms of different physicians—the general practitioners, the gynecologists, and the neurologists. Here, 324 participants (of 624 asked) completed the questionnaire; 65.7% (213/324) of them were female. The age showed a distribution of 13.7% (48/324) in the age group of 16 to 25 years, 26.9% (94/324) for 26 to 35 years, 17.4% (61/324) for 36 to 45 years, 17.4% (61/324) for 46 to 55 years, 11.1% (39/324) for 56 to 65 years, and 13.4% (47/324) for those aged 65 years and older.

The Cronbach alpha value for the 8 items reached the conventional standards for scale reliability ($\alpha=.80$), and no item reduction seemed meaningful. We also used the questionnaire version for laypeople. Table 2 shows the results of the study with the mean (M) and standard deviations (SD). Due to the low sample size of the psychotherapists, we added the physicians and the psychotherapists here to the category of professionals.

Table 2. The mean and the SD of the items and the overall measures. The questions are coded from “1=strongly agree” to “5=strongly disagree,” and so, the lower values are in better agreement with the question whereas the higher values indicate more disagreement. The total scale is the mean of the 8 single-item values.

Item	General population, mean (SD ^a)	Professionals, mean (SD)
1	3.06 (1.27)	2.26 (1.09)
2	3.04 (1.23)	2.54 (1.14)
3	3.59 (1.26)	3.45 (1.20)
4	2.94 (1.29)	2.64 (1.26)
5	2.95 (1.28)	2.89 (1.14)
6	3.97 (1.28)	2.89 (1.33)
7	2.84 (1.37)	2.39 (1.13)
8	2.96 (1.26)	2.67 (1.24)
Total scale	3.17 (0.89)	2.64 (0.88)

^aSD: standard deviation.

Table 3. The scale reliability with single-item deficient (Cronbach alpha deleted for one item) and selectivity coefficient (corrected part-whole-correlation).

No.	Laypeople		Physicians		Psychotherapists	
	Cronbach alpha	Selectivity	Cronbach alpha	Selectivity	Cronbach alpha	Selectivity
1	.829	.603	.887	.663	.842	.565
2	.826	.627	.883	.716	.814	.791
3	.837	.532	.876	.784	.828	.687
4	.816	.706	.879	.752	.829	.669
5	.817	.701	.879	.755	.825	.729
6	.843	.484	.873	.811	.818	.745
7	.838	.533	.886	.683	.833	.644
8	.840	.511	.917	.325	.897	.083

The third part of our study was directed toward the physicians. The group size was 92, with 47% (43/92) of the physicians being female (and the distribution of age showing 1% for those under 36 years (1/92), 11% (10/92) for those in the age range of 36 to 45 years, 43% (39/92) for 46 to 55 years, and 44% (41/92) for those aged above 55 years. We used the questionnaire version for the physicians in this part of the study. The Cronbach alpha value was .827, and so, no correction of the questionnaire was necessary at this point.

In the last part of the study, we surveyed the psychotherapists. This group consisted of 36 participants, with 67% female and the distribution of age revealing 5% (2/36) to be less than 36 years, 5% between 36 and 45 years (2/36), 36% (13/36) in the 46 to 55 years age range, and 53% (19/36) being older than 55 years. Reliability was good; we found a Cronbach alpha value of .855. Here, we used the questionnaire version for the psychotherapists.

The comparison of the 3 versions of the questionnaire shows no relevant differences; the reliability is nearly similar. Only in the questionnaire for the psychotherapists, item 8 (*Therapy through the Internet services/telemedicine for mental illness*

can only work effectively with live contacts with a therapist through video calling and email/chat.) shows a selectivity under 0.1 and must, therefore, be questioned.

The analysis of the Cronbach alpha values by deleting the singular items and selectivity are shown in Table 3.

Question 4 shows the clearest significance ($P=0.001$) among the laity in the positive assessment; also in the Cronbach alpha a good consistency is confirmed here.

A presentation and comparison of the results of all aspects of the study will be done and published.

Discussion

We developed an 8-item questionnaire with three versions that cover the important aspects of the attitudes and expectations of the laypeople, the physicians, and the psychotherapists toward the telemedical interventions in psychiatry and psychotherapy (eg, e-mental health, Web-based interventions, and phone interventions). This is the first time that a really short and clear questionnaire has been constructed to look at the attitudes toward Web-based interventions and telemedicine in mental health.

This was important because of the influence that the patients' expectations and attitudes toward a diagnostic and therapeutic process or tool have on the efficacy and the results of these processes or tools.

Earlier studies have shown that a variety of telemedical interventions, especially Web-based interventions, are available in many countries. And it seems that the number, especially of Web-based interventions or mobile phone apps, is growing daily. However, despite the high demand for psychological support, these resources are only used to a limited extent in the everyday therapeutic work. It is unclear whether this is related to the attitude toward Web-based interventions and other telemedical services. However, previous work has already shown, for example, with the help of the credibility and expectancy questionnaire, that therapeutic success is closely related to the attitude toward therapy. So far, such investigations with regard to the Internet-based interventions have been carried out with some limitations. Schröder et al [32] had examined the patients and the psychotherapists in the context of telemedical care, but there has not been any recruitment of a sample of the general population. Gun et al [33] have also interrogated the disorder-specific groups, even in a large sample. Musiat et al [7] and Wangberg et al [34] have attempted to investigate a non-disorder-specific group, but as a population is only accessible by social media, those people questioned can be estimated as being open-minded toward the Internet. There is no doubt that a similar bias is to be feared in the evaluation of the therapeutic approaches on the Internet—especially if those who are positively opposed to this medium will take part in these studies. To achieve a broad effect and to use the Web-based interventions not only as niche products, the patients who are not “early adopters” must also be reached. Also, the (particularly) positive expectation of the participants in the studies—which may differ significantly from the general population—must be considered. Checking this possible bias will be helpful for examining the attitudes of the participants and the patients in a study and for a comparison with the general population. This can be done with a questionnaire such as the ATiPP—because it is short and quick, and there are growing numbers of different participants and groups we had checked (and will publish the data in the near future).

Actually, we had a sufficient number of participants among the general population and the patients, but the physicians and the

psychotherapists were also included in the first evaluation. The comparison of the three versions indicates that the same contents are measured, reflecting the positions of the participants. The collection and analysis of more data from the participants using the ATiPP is currently underway; we are testing the results in other groups and with other subjects. In addition, the questionnaires published so far, such as Credibility/Expectancy Questionnaire (CEQ) [28], will be checked against the ATiPP in smaller groups. In principle, we assume that the attitudes toward the use of Web-based interventions and other telemedical services can be adequately examined and recorded with the ATiPP.

However, we are conducting a study to create pre- and postdata using the questionnaire in a sample of laypeople and professionals before and after participating in a three-lesson e-learning session with a focus on e-mental health interventions. We expect a further confirmation that the questionnaire may also reflect the developments in the attitudes toward and expectations regarding e-mental health. There are currently some limitations. Thus, there is a lack of a factor analysis, which we have prepared but have not yet concluded with regard to the evaluation of the subgroups. It is, thus, not clear whether the questionnaire actually measures a dimension, as the reliability values suggest, or whether the two dimensions (credibility and expectancy) are also collectively taken as an attitude in ATiPP, which the CEQ as somewhat a comparable instrument might at least suggest.

In conclusion, we recommend the use of the questionnaire to measure the attitude toward and expectations regarding e-mental health. The growing number of Web-based interventions needs a growing knowledge of the potential users—the laypeople as well as the physicians and the psychotherapists. They must be informed about the bugs and hints as also the positive effects in order for them to accept the Web-based interventions and to understand the strengths and limitations of e-mental health. Only if the attitudes toward the Web-based interventions become more positive and the expectations of the users correspond to the actual good results of the interventions, a therapeutic use of telemedicine, especially e-mental health and m-mental health, will occupy a wider space in everyday work and life. This could be achieved through training programs, and the effect of such programs can be evaluated by the use of our questionnaire.

Conflicts of Interest

None declared.

References

1. Eysenbach G, Wyatt J. Using the internet for surveys and health research. *J Med Internet Res* 2002 Nov;4(2):E13 [FREE Full text] [doi: [10.2196/jmir.4.2.e13](https://doi.org/10.2196/jmir.4.2.e13)] [Medline: [12554560](https://pubmed.ncbi.nlm.nih.gov/12554560/)]
2. Kurki M, Koivunen M, Anttila M, Hätönen H, Välimäki M. Usefulness of internet in adolescent mental health outpatient care. *J Psychiatr Ment Health Nurs* 2011 Apr;18(3):265-273. [doi: [10.1111/j.1365-2850.2010.01661.x](https://doi.org/10.1111/j.1365-2850.2010.01661.x)] [Medline: [21395918](https://pubmed.ncbi.nlm.nih.gov/21395918/)]
3. Moritz S, Van QN, Lincoln TM, Köther U, Andreou C. Can we trust the internet to measure psychotic symptoms? *Schizophr Res Treatment* 2013;2013:457010 [FREE Full text] [doi: [10.1155/2013/457010](https://doi.org/10.1155/2013/457010)] [Medline: [23936652](https://pubmed.ncbi.nlm.nih.gov/23936652/)]

4. Lange A, Rietdijk D, Hudcovicova M, van de Ven J, Schrieken B, Emmelkamp PMG. Interapy: a controlled randomized trial of the standardized treatment of posttraumatic stress through the internet. *J Consult Clin Psychol* 2003 Oct;71(5):901-909. [doi: [10.1037/0022-006X.71.5.901](https://doi.org/10.1037/0022-006X.71.5.901)] [Medline: [14516238](#)]
5. Depression: the treatment and management of depression in adults. In: *Depression: The NICE Guideline on the Treatment and Management of Depression in Adults (Updated Edition)*. London: RCPsych Publications; 2010.
6. General anxiety disorder and panic disorder in adults - NICE GC 113. London: The British Psychological Society and The Royal College of Psychiatrists; Oct 11, 2011.
7. Musiat P, Goldstone P, Tarrier N. Understanding the acceptability of e-mental health - attitudes and expectations towards computerized self-help treatments for mental health problems. *BMC Psychiatry* 2014 Apr 11:109. [doi: [10.1186/1471-244X-14-109](https://doi.org/10.1186/1471-244X-14-109)]
8. Wootton BM, Titov N, Dear BF, Spence J, Kemp A. The acceptability of internet-based treatment and characteristics of an adult sample with obsessive compulsive disorder: an Internet survey. *PLoS One* 2011;6(6):e20548 [FREE Full text] [doi: [10.1371/journal.pone.0020548](https://doi.org/10.1371/journal.pone.0020548)] [Medline: [21673987](#)]
9. Melville KM, Casey LM, Kavanagh DJ. Dropout from internet-based treatment for psychological disorders. *Br J Clin Psychol* 2010 Nov;49(Pt 4):455-471. [doi: [10.1348/014466509X472138](https://doi.org/10.1348/014466509X472138)] [Medline: [19799804](#)]
10. Waller R, Gilbody S. Barriers to the uptake of computerized cognitive behavioural therapy: a systematic review of the quantitative and qualitative evidence. *Psychol Med* 2009 May;39(5):705-712. [doi: [10.1017/S0033291708004224](https://doi.org/10.1017/S0033291708004224)] [Medline: [18812006](#)]
11. Carper MM, McHugh RK, Barlow DH. The dissemination of computer-based psychological treatment: a preliminary analysis of patient and clinician perceptions. *Adm Policy Ment Health* 2013 Mar;40(2):87-95. [doi: [10.1007/s10488-011-0377-5](https://doi.org/10.1007/s10488-011-0377-5)] [Medline: [22001968](#)]
12. Ruwaard J, Lange A, Schrieken B, Dolan CV, Emmelkamp P. The effectiveness of online cognitive behavioral treatment in routine clinical practice. *PLoS One* 2012;7(7):e40089 [FREE Full text] [doi: [10.1371/journal.pone.0040089](https://doi.org/10.1371/journal.pone.0040089)] [Medline: [22792217](#)]
13. Van Voorhees BW, Gollan J, Fogel J. Pilot study of Internet-based early intervention for combat-related mental distress. *J Rehabil Res Dev* 2012;49(8):1175-1190 [FREE Full text] [Medline: [23341310](#)]
14. Craske MG, Rose RD, Lang A, Welch SS, Campbell-Sills L, Sullivan G, et al. Computer-assisted delivery of cognitive behavioral therapy for anxiety disorders in primary-care settings. *Depress Anxiety* 2009 Mar;26(3):235-242 [FREE Full text] [doi: [10.1002/da.20542](https://doi.org/10.1002/da.20542)] [Medline: [19212970](#)]
15. Brijnath B, Protheroe J, Mahtani KR, Antoniadou J. Do web-based mental health literacy interventions improve the mental health literacy of adult consumers? results from a systematic review. *J Med Internet Res* 2016 Jun 20;18(6):e165 [FREE Full text] [doi: [10.2196/jmir.5463](https://doi.org/10.2196/jmir.5463)] [Medline: [27323907](#)]
16. Morrison L, Moss-Morris R, Michie S, Yardley L. Optimizing engagement with internet-based health behaviour change interventions: comparison of self-assessment with and without tailored feedback using a mixed methods approach. *Br J Health Psychol* 2014 Nov;19(4):839-855 [FREE Full text] [doi: [10.1111/bjhp.12083](https://doi.org/10.1111/bjhp.12083)] [Medline: [24308806](#)]
17. Zabinski MF, Wilfley DE, Calfas KJ, Winzelberg AJ, Taylor CB. An interactive psychoeducational intervention for women at risk of developing an eating disorder. *J Consult Clin Psychol* 2004 Oct;72(5):914-919. [doi: [10.1037/0022-006X.72.5.914](https://doi.org/10.1037/0022-006X.72.5.914)] [Medline: [15482051](#)]
18. Månsson KN, Skagius RE, Gervind E, Dahlin M, Andersson G. Development and initial evaluation of an internet-based support system for face-to-face cognitive behavior therapy: a proof of concept study. *J Med Internet Res* 2013;15(12):e280 [FREE Full text] [doi: [10.2196/jmir.3031](https://doi.org/10.2196/jmir.3031)] [Medline: [24326065](#)]
19. Ben-Zeev D, Scherer EA, Wang R, Xie H, Campbell AT. Next-generation psychiatric assessment: using smartphone sensors to monitor behavior and mental health. *Psychiatr Rehabil J* 2015 Sep;38(3):218-226 [FREE Full text] [doi: [10.1037/prj0000130](https://doi.org/10.1037/prj0000130)] [Medline: [25844912](#)]
20. Andersson G. The promise and pitfalls of the internet for cognitive behavioral therapy. *BMC Med* 2010;8:82 [FREE Full text] [doi: [10.1186/1741-7015-8-82](https://doi.org/10.1186/1741-7015-8-82)] [Medline: [21138574](#)]
21. Ebert DD, Berking M, Cuijpers P, Lehr D, Pörtner M, Baumeister H. Increasing the acceptance of internet-based mental health interventions in primary care patients with depressive symptoms. A randomized controlled trial. *J Affect Disord* 2015 May 1;176:9-17. [doi: [10.1016/j.jad.2015.01.056](https://doi.org/10.1016/j.jad.2015.01.056)] [Medline: [25682378](#)]
22. Edwards L, Thomas C, Gregory A, Yardley L, O'Cathain A, Montgomery AA, et al. Are people with chronic diseases interested in using telehealth? a cross-sectional postal survey. *J Med Internet Res* 2014;16(5):e123 [FREE Full text] [doi: [10.2196/jmir.3257](https://doi.org/10.2196/jmir.3257)] [Medline: [24811914](#)]
23. Handley T, Perkins D, Kay-Lambkin F, Lewin T, Kelly B. Familiarity with and intentions to use internet-delivered mental health treatments among older rural adults. *Aging Ment Health* 2015;19(11):989-996. [doi: [10.1080/13607863.2014.981744](https://doi.org/10.1080/13607863.2014.981744)] [Medline: [25420968](#)]
24. Johnston L, Dear BF, Gandy M, Fogliati VJ, Kayrouz R, Sheehan J, et al. Exploring the efficacy and acceptability of internet-delivered cognitive behavioural therapy for young adults with anxiety and depression: an open trial. *Aust N Z J Psychiatry* 2014 Sep;48(9):819-827. [doi: [10.1177/0004867414527524](https://doi.org/10.1177/0004867414527524)] [Medline: [24622977](#)]

25. Mewton L, Sachdev PS, Andrews G. A naturalistic study of the acceptability and effectiveness of internet-delivered cognitive behavioural therapy for psychiatric disorders in older australians. PLoS One 2013 Aug;8(8):e71825 [FREE Full text] [doi: [10.1371/journal.pone.0071825](https://doi.org/10.1371/journal.pone.0071825)] [Medline: [23951253](#)]
26. Oh E, Jorm AF, Wright A. Perceived helpfulness of websites for mental health information: a national survey of young Australians. Soc Psychiatry Psychiatr Epidemiol 2009 Apr;44(4):293-299. [doi: [10.1007/s00127-008-0443-9](https://doi.org/10.1007/s00127-008-0443-9)] [Medline: [18830552](#)]
27. Schneider J, Sarraimi FP, Grime P, Thornicroft G. Acceptability of online self-help to people with depression: users' views of MoodGYM versus informational websites. J Med Internet Res 2014 Mar;16(3):e90 [FREE Full text] [doi: [10.2196/jmir.2871](https://doi.org/10.2196/jmir.2871)] [Medline: [24681717](#)]
28. Devilly GJ, Borkovec TD. Psychometric properties of the credibility/expectancy questionnaire. J Behav Ther Exp Psychiatry 2000 Jun;31(2):73-86. [Medline: [11132119](#)]
29. Murphy MK, Black NA, Lamping DL, McKee CM, Sanderson CF, Askham J, et al. Consensus development methods, and their use in clinical guideline development. Health Technol Assessment 1998 Mar 01;2(3):1-88. [doi: [10.3310/hta2030](https://doi.org/10.3310/hta2030)] [Medline: [9561895](#)]
30. Custer R, Scarcella J, Stewart B. The modified delphi technique - a rotational modification. JCTE 1999 May 01;15(2):8. [doi: [10.21061/jcte.v15i2.702](https://doi.org/10.21061/jcte.v15i2.702)]
31. Brick JM. Random digit-dialing. In: Lavrakas P, editor. Encyclopedia of Survey Research Methods. Thousand Oaks, CA: Sage Publications, Inc; 2008.
32. Schröder J, Sautier L, Kriston L, Berger T, Meyer B, Späth C, et al. Development of a questionnaire measuring attitudes towards psychological online interventions-the APOI. J Affect Disord 2015 Nov 15;187:136-141. [doi: [10.1016/j.jad.2015.08.044](https://doi.org/10.1016/j.jad.2015.08.044)] [Medline: [26331687](#)]
33. Gun SY, Titov N, Andrews G. Acceptability of Internet treatment of anxiety and depression. Australas Psychiatry 2011 Jun;19(3):259-264. [doi: [10.3109/10398562.2011.562295](https://doi.org/10.3109/10398562.2011.562295)] [Medline: [21682626](#)]
34. Wangberg SC, Gammon D, Spitznogle K. In the eyes of the beholder: exploring psychologists' attitudes towards and use of e-therapy in Norway. Cyberpsychol Behav 2007 Jun;10(3):418-423. [doi: [10.1089/cpb.2006.9937](https://doi.org/10.1089/cpb.2006.9937)] [Medline: [17594266](#)]

Abbreviations

ATiPP: Attitude toward Telemedicine in Psychiatry and Psychotherapy

CBT: cognitive behavior therapy

CEQ: Credibility/Expectancy Questionnaire

SD: standard deviation

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Original Paper

Sharing Family Life Information Through Video Calls and Other Information and Communication Technologies and the Association With Family Well-Being: Population-Based Survey

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Abstract

Background: The use of information and communication technologies (ICTs) for information sharing among family members is increasing dramatically. However, little is known about the associated factors and the influence on family well-being.

Objective: The authors investigated the pattern and social determinants of family life information sharing with family and the associations of different methods of sharing with perceived family health, happiness, and harmony (3Hs) in Hong Kong, where mobile phone ownership and Internet access are among the most prevalent, easiest, and fastest in the world.

Methods: A territory-wide population-based telephone survey was conducted from January to August 2016 on different methods of family life information (ie, information related to family communication, relationships with family members, emotion and stress management) sharing with family members, including face-to-face, phone, instant messaging (IM), social media sites, video calls, and email. Family well-being was assessed by three single items on perceived family health, happiness, and harmony, with higher scores indicating better family well-being. Adjusted prevalence ratios were used to assess the associations of sociodemographic factors with family life information sharing, and adjusted beta coefficients for family well-being.

Results: Of 2017 respondents, face-to-face was the most common method to share family life information (74.45%, 1502/2017), followed by IM (40.86%, 824/2017), phone (28.10%, 567/2017), social media sites (11.91%, 240/2017), video calls (5.89%, 119/2017), and email (5.48%, 111/2017). Younger age and higher education were associated with the use of any (at least one) method, face-to-face, IM, and social media sites for sharing family life information (all *P* for trend <.01). Higher education was most strongly associated with the use of video calls (adjusted prevalence ratio=5.61, 95% CI 2.29-13.74). Higher household income was significantly associated with the use of any method, face-to-face, and IM (all *P* for trend <.05). Sharing family life information was associated with a higher level of perceived family well-being (beta=0.56, 95% CI 0.37-0.75), especially by face-to-face (beta=0.62, 95% CI 0.45-0.80) and video calls (beta=0.34, 95% CI 0.04-0.65). The combination of face-to-face and video calls was most strongly associated with a higher level of perceived family well-being (beta=0.81, 95% CI 0.45-1.16).

Conclusions: The differential use of ICTs to share family life information was observed. The prevalence of video calls was low, but associated with much better family well-being. The results need to be confirmed by prospective and intervention studies to promote the use of video calls to communicate and share information with family, particularly in disadvantaged groups.

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KEYWORDS

mobile phone, video call, Chinese

Introduction

Family life information refers to information that strengthens family functioning through improving communication skills, knowledge about developmental tasks, decision-making skills, self-esteem, and interpersonal relationships [1]. Previous studies on family life information have focused on specific topics such as parenting, childcare, and partner relationships [2,3]. The authors adopted a broad, simple, and practical definition of family life information related to family communication, relationships with family members such as children and partner, family activities, work-life balance, and emotion and stress management because these components are reported as main factors affecting family well-being [4,5]. Sharing family life information is a reflection of obtaining information (intentional seeking and unintentional exposure), trust, and perceived usefulness. The authors have reported that these factors were associated with better family well-being [6]. Sharing information can prompt conversation and may facilitate positive family communication, which is crucial for family well-being [7]. Family well-being, often conceptualized as “family life satisfaction,” “sense of well-being,” and “family function” [8], is an important embodiment of collectivism culture, where cohesion and harmony among family members, dependence on the family, and strict obedience of parents are favored [9,10]. Family health, happiness, and harmony (3Hs) were perceived to be significant for families in Hong Kong [11,12].

With advances in technology and high prevalence of mobile phone ownership and Internet penetration, the use of information and communication technologies (ICTs), including instant messaging (IM), social media sites, video calls, and email, to share information is increasing dramatically. These newly emerging ICTs enable people to communicate and share information more conveniently, interactively, and at lower cost. For instance, IM enables users to send information by text, photograph, audio clips, and video at any time, and can reach many individuals simultaneously. Social media sites allow for interconnectivity and provide a platform for information sharing. Video calls provide visual cues along with immediate interaction and feedback for geographically separated individuals [13].

Hong Kong is the most modernized and westernized city in China. There is also widespread penetration of mobile phones and the Internet (in 2015, approximately 83.3% and 84.3% of adults had used a mobile phone and the Internet in the past 12 months, respectively) owing to the advanced cyber-infrastructure and low cost of access to the Internet [14]. Mobile phone ownership and Internet connection in Hong Kong are among the most prevalent in the world [15,16]. Hong Kong has a wide coverage of free public Wi-Fi services (>44,000 hotspots in 2017) [17]. The Internet connection speed in Hong Kong is also among the highest in the world (second in 2015) [18]. Hong Kong has the highest number of young people reporting daily or greater Internet use (68%) compared to other Asian countries [19]. The prevalence of Internet addiction and problematic Internet use were 3% and 31.6%, respectively [19].

However, people with low socioeconomic position (SEP) (lower education or income) often have low access and usage of ICTs [20,21], which may be attributed to the differences among social groups in their ability to access, process, and act on information (communication inequality theory) [22]. For instance, the prevalence of personal computers at home with Internet connection for people with a monthly household income less than HK \$10,000 (US \$1=HK \$7.80) is much lower than those with more than HK \$50,000 (35.6% vs 97.9%) [14]. The authors previously proposed the “Inverse ICT Law” [23] based on the Inverse Information Law, which states that the access to appropriate information is particularly difficult for those who are most in need [24,25]. Based on the Inverse ICT Law, those who are most in need may have less access to family-related information, services, and care communicated by ICTs. Online family life information seeking is socially patterned, with lower SEP associated with lower frequency of seeking and paying attention to such information [6,26]. However, people with low SEP also have greater needs to improve their family relationship and family well-being [27].

Despite the high prevalence of ICT use, traditional communication methods (face-to-face and phone) are most used in a family context in Hong Kong, along with a higher level of family well-being [28]. Face-to-face communication includes verbal, nonverbal, and social context cues with real-time feedback and interaction, which can provide greater communication satisfaction [29,30]. Phone calls enable people separated by a long distance to communicate with immediate feedback and real-time interaction. The use of ICTs, including IM, social media, and email, for family communication is not associated with a higher level of family well-being because of the disconnection between verbal and nonverbal signals, impacting the quality of communication [28]. However, the use of video calls may act as a good alternative when face-to-face communication is not possible. Some studies have found that ICTs can strengthen family bonds and improve family cohesion through sharing online activities among family members, such as watching movies and co-playing video games [31-33]. Nevertheless, excessive use of ICTs may reduce time with family and create intergenerational conflicts [34,35], and is associated with poor family relationships [36,37].

To the best of the authors’ knowledge, no studies have investigated the use of different methods to share family life information or its association with family well-being. The authors used a large population-based telephone survey to investigate the pattern and social determinants of family life information sharing with family and the associations of different methods of family life information sharing, especially video calls, with perceived family well-being in Chinese adults living in Hong Kong. The authors examined whether the findings support the Inverse ICT Law on family information sharing.

Methods

Study Design

The Hong Kong Family and Health Information Trends Survey (FHInTs) was part of a project entitled “FAMILY: A Jockey Club Initiative for a Harmonious Society.” FHInTs was a regular periodic population-based telephone survey of the general Hong Kong public’s opinions and behaviors on family health, information use, and health communication. Since 2009, five waves of FHInTs have been conducted and details are reported elsewhere [6,26]. The most recent wave was conducted from January to August 2016 to collect data on ICT use on family and health information, family communication, and family well-being.

All interviews were conducted by trained interviewers of the Public Opinion Program at The University of Hong Kong using a Web-based computer-assisted telephone interview system. The survey targeted the Cantonese-speaking adult population aged 18 years and older. Hong Kong residents aged 18 or older were eligible to participate in the telephone survey. Respondents who were psychologically or physically unable to communicate or were unable to communicate using Cantonese over the phone were excluded. Landline telephone numbers were randomly generated using known prefixes assigned to telecommunication services providers under the Numbering Plan provided by the government Office of the Communications Authority. When contact was successfully established with a target household, one qualified person was selected from all those present using the “next birthday” rule [38]. The person from the household who had the nearest next birthday among all household members who were aged 18 years and older was interviewed. Verbal informed consent was obtained from the respondents. Ethical approval was granted by the Institutional Review Board of the University of Hong Kong / Hospital Authority Hong Kong West Cluster.

The most recent wave consisted of four subsets: health, health information, family information, and family communication. Each subset had core questions (questions in all subsets) and subset-specific questions. The authors set the sampling error at 3.1% with 5% type I error. Based on the population size in mid-2009 (N=6,143,300) [39], the authors expected to obtain 1000 successful respondents in each subset. Eligible respondents were randomly assigned into these four subsets. Subsets with questions on family life information sharing (family information and family communication) are included in this analysis (N=2017).

Measurements

Definitions of family (family members who are related through biological, marital, cohabitation, and/or emotional bonding) and family life information (as mentioned previously) were explained to the respondents before asking questions about family life information sharing and family 3Hs. Methods of family life information sharing were assessed by asking

respondents the usual methods of sharing family life information with their family, including face-to-face, phone, IM, social media sites, video calls, and email. Family 3Hs were measured by using three separate questions with a score from 0 to 10. Family well-being was calculated based on the composite score of the 3Hs with higher scores indicating better family well-being. In this sample, the Cronbach alpha coefficient of family well-being was .89, indicating good internal consistency [40].

Socioeconomic position was measured using educational attainment, employment status, and monthly household income. Educational attainment was categorized as primary or below, secondary, and tertiary or above. Employment status was categorized as full time, part time, self-employed, and unemployed. Monthly household income was categorized as <HK \$10,000, HK \$10,000-\$19,999, HK \$20,000-\$29,999, HK \$30,000-\$39,999, and >HK \$40,000.

Statistical Analysis

To improve the representativeness of the findings, the raw data were weighted using the random iterative method [41,42] according to provisional figures obtained from the Census and Statistics Department on the gender-age distribution of the Hong Kong population at the end of 2015 and the educational attainment (highest level attended) distribution in the 2011 census. Poisson regression models with robust variance estimators [43] yielded adjusted prevalence ratios (aPR) of different methods of family life information sharing related to age, gender, marital status, and SEP. Multivariable linear regression was used to assess the adjusted associations of different methods of family life information sharing with perceived family 3Hs and well-being scores (continuous variables), adjusting for potential confounders including age, gender, educational attainment, employment status, monthly household income, and marital status. All analyses were conducted using STATA version 13.0. A *P* value <.05 was considered statistically significant.

Results

Of 2017 respondents after weighting, most were women, aged 25 to 64 years, and married or cohabitating (Table 1). Most respondents had secondary or higher education and had monthly household income of HK \$30,000 or greater (median monthly income in Hong Kong was HK \$25,000 in 2016). Most respondents (79.41%, 1602/2017) had ever shared family life information with their family.

In the total sample after weighting, the most common method of family life information sharing was face-to-face (74.45%, 1502/2017), followed by IM, phone, and social media sites (Table 2). Only a small percentage of respondents shared family life information by video calls (5.89%, 119/2017) and email (5.48%, 111/2017). The use of the face-to-face method was positively related to the use of each of the other methods (all *P*<.001).

Table 1. Sociodemographic characteristics of sample (N=2017).

Demographics	Unweighted, n (%)	Weighted, n (%)
Gender		
Men	751 (37.23)	910 (45.11)
Women	1266 (62.77)	1107 (54.89)
Age		
18-24	245 (12.15)	191 (9.47)
25-44	371 (18.39)	715 (35.44)
45-64	773 (38.32)	743 (36.86)
≥65	628 (31.14)	368 (18.23)
Marital status		
Single	497 (24.64)	584 (28.93)
Married or cohabitated	1237 (61.33)	1227 (60.86)
Widowed or divorced	283 (14.03)	206 (10.21)
Education attainment		
Primary or below	468 (23.20)	477 (23.66)
Secondary	858 (42.54)	970 (48.09)
Tertiary or above	691 (34.26)	570 (28.25)
Employment status		
Full time	563 (27.91)	763 (37.81)
Part time	165 (8.18)	190 (9.42)
Self-employed	68 (3.37)	90 (4.47)
Unemployed	1221 (60.54)	974 (48.31)
Monthly household income (HK\$) ^a		
<10,000	472 (26.27)	368 (20.47)
10,000-19,999	303 (16.86)	345 (19.17)
20,000-29,999	292 (16.25)	326 (18.15)
30,000-39,999	222 (12.35)	236 (13.15)
≥40,000	508 (28.27)	522 (29.06)
Family life information sharing		
Yes	1563 (77.49)	1602 (79.41)
No	454 (22.51)	415 (20.59)

^aUS \$1=HK \$7.80.**Table 2.** Prevalence (weighted) of different methods of sharing family life information for total sample (N=2017).

Means	Prevalence, n (%)
No sharing	415 (20.59)
One or more methods	
Face-to-face	1502 (74.45)
Instant messaging	824 (40.86)
Phone	567 (28.10)
Social media sites	240 (11.91)
Video calls	119 (5.89)
Email	111 (5.48)

Table 3. Association of sociodemographic characteristics with the use of different methods to share family life information with family (N=2017).^a

Sociodemographic characteristic	Method of sharing family life information, aPR (95% CI) ^b						
	Any (at least one) (n=1602)	Face-to-face (n=1502)	Instant messaging (n=824)	Phone (n=567)	Social media (n=240)	Video calls (n=119)	Email (n=111)
Gender							
Men	1	1	1	1	1	1	1
Women	1.07 (1.02, 1.13)	1.05 (0.99, 1.12)	1.34 (1.19, 1.51)	1.31 (1.11, 1.55)	1.66 (1.19, 2.30)	1.58 (1.04, 2.39)	1.51 (1.03, 2.21)
Age							
18-24	1	1	1	1	1	1	1
25-44	0.95 (0.88, 1.04)	0.95 (0.86, 1.05)	0.99 (0.80, 1.24)	1.16 (0.80, 1.68)	1.54 (0.81, 2.94)	1.12 (0.50, 2.50)	1.80 (0.40, 8.08)
45-64	0.88 (0.80, 0.97)	0.89 (0.80, 1.00)	0.87 (0.68, 1.10)	1.06 (0.72, 1.56)	0.96 (0.49, 1.87)	1.17 (0.54, 2.53)	4.13 (0.89, 19.1)
≥65	0.75 (0.66, 0.84)	0.77 (0.67, 0.88)	0.48 (0.35, 0.64)	0.96 (0.64, 1.44)	0.48 (0.22, 1.06)	0.98 (0.39, 2.45)	3.34 (0.67, 16.6)
P for trend	<.001	<.001	<.001	.42	.002	.89	.06
Educational attainment							
Primary or below	1	1	1	1	1	1	1
Secondary	1.22 (1.11, 1.34)	1.20 (1.09, 1.34)	2.14 (1.66, 2.76)	1.32 (1.07, 1.63)	2.45 (1.34, 4.49)	4.04 (1.73, 9.47)	2.54 (1.36, 4.75)
Tertiary or above	1.25 (1.13, 1.38)	1.22 (1.09, 1.36)	2.55 (1.94, 3.34)	1.24 (0.95, 1.60)	3.32 (1.69, 6.51)	5.61 (2.29, 13.74)	4.67 (2.43, 9.01)
P for trend	<.001	.001	<.001	.13	<.001	<.001	<.001
Employment status							
Full time	1	1	1	1	1	1	1
Part time	0.99 (0.91, 1.07)	1.02 (0.93, 1.12)	1.12 (0.94, 1.33)	1.01 (0.75, 1.34)	1.17 (0.74, 1.86)	1.33 (0.65, 2.69)	1.91 (1.05, 3.49)
Self-employed	1.03 (0.94, 1.14)	0.97 (0.85, 1.11)	1.01 (0.77, 1.32)	1.10 (0.74, 1.65)	0.92 (0.45, 1.88)	1.87 (0.82, 4.29)	2.58 (1.28, 5.22)
Unemployed	1.00 (0.94, 1.06)	1.00 (0.94, 1.07)	0.99 (0.87, 1.13)	0.97 (0.79, 1.19)	0.97 (0.68, 1.39)	1.52 (0.94, 2.46)	1.39 (0.87, 2.23)
Monthly household income (HK\$)^c							
<10,000	1	1	1	1	1	1	1
10,000-19,999	0.99 (0.89, 1.10)	1.02 (0.90, 1.14)	1.15 (0.90, 1.46)	0.84 (0.66, 1.06)	0.75 (0.44, 1.29)	0.80 (0.40, 1.61)	1.01 (0.51, 2.00)
20,000-29,999	1.07 (0.97, 1.18)	1.10 (0.98, 1.23)	1.39 (1.10, 1.75)	0.82 (0.64, 1.06)	1.12 (0.66, 1.92)	1.06 (0.55, 2.05)	1.15 (0.58, 2.29)
30,000-39,999	1.16 (1.06, 1.27)	1.23 (1.11, 1.37)	1.54 (1.21, 1.95)	0.85 (0.65, 1.12)	1.11 (0.63, 1.95)	1.50 (0.79, 2.86)	2.38 (1.25, 4.54)
≥40,000	1.13 (1.03, 1.23)	1.22 (1.10, 1.35)	1.29 (1.02, 1.62)	0.78 (0.61, 0.99)	0.89 (0.52, 1.52)	0.86 (0.44, 1.67)	1.10 (0.57, 2.13)
P for trend	<.001	<.001	.02	.11	.98	.92	.29
Marital status							
Single	1	1		1	1	1	1
Married/cohabitated	1.11 (1.03, 1.20)	1.08 (0.99, 1.17)	1.46 (1.23, 1.74)	1.39 (1.06, 1.82)	2.07 (1.34, 3.19)	1.49 (0.84, 2.64)	2.79 (1.14, 6.85)
Others	1.03 (0.91, 1.17)	0.94 (0.81, 1.09)	1.50 (1.13, 1.99)	1.49 (1.07, 2.08)	1.75 (0.86, 3.56)	0.90 (0.36, 2.26)	2.40 (0.84, 6.85)

^aAll variables were mutually adjusted.

^baPR: adjusted prevalence ratio.

^cUS \$1=HK \$7.80.

More women shared family life information than men by all methods except face-to-face (all $P < .05$) (Table 3). Younger age was associated with the use of any method, face-to-face, IM, and social media sites (all P for trend $< .01$). Higher education level was associated with the use of any method, face-to-face, IM, social media sites, video calls, and email (all P for trend $< .01$), with the strongest association observed for video calls (aPR=5.61, 95% CI 2.29-13.74). Higher monthly household income was associated with the use of any method, face-to-face, and IM to share family life information (all P for trend $< .05$). However, household income was inversely associated with the

use of phone, particularly for respondents with household income higher than HK \$40,000 (aPR=0.78, 95% CI 0.61-0.99).

Family life information sharing by any method and face-to-face were strongly associated with higher levels of perceived family health, happiness, harmony, and overall family well-being (all beta > 0.50) (Table 4). The use of video calls was associated with higher levels of perceived family health (beta=0.36, 95% CI 0.01-0.70), happiness (beta=0.37, 95% CI 0.03-0.70), and overall family well-being (beta=0.34, 95% CI 0.04-0.65). The associations of using IM, social media sites, and email with perceived family 3Hs and well-being were positive but nonsignificant.

Table 4. The use of different methods to share family life information with family and perceived family 3Hs and well-being (N=2007).^a

Method of sharing	Family health		Family happiness		Family harmony		Family well-being	
	Mean (SD)	Beta (95% CI) ^b	Mean (SD)	Beta (95% CI) ^b	Mean (SD)	Beta (95% CI) ^b	Mean (SD)	Beta (95% CI) ^b
Any								
No	6.9 (2.2)	0	7.2 (2.3)	0	7.3 (2.2)	0	7.1 (2.0)	0
Yes	7.5 (1.7)	0.54 (0.33, 0.76)	7.7 (1.6)	0.53 (0.32, 0.74)	7.8 (1.6)	0.59 (0.39, 0.79)	7.7 (1.5)	0.56 (0.37, 0.75)
Face-to-face								
No	6.9 (2.2)	0	7.2 (2.2)	0	7.3 (2.1)	0	7.1 (1.8)	0
Yes	7.6 (1.6)	0.59 (0.39, 0.79)	7.7 (1.6)	0.63 (0.44, 0.82)	7.8 (1.6)	0.63 (0.45, 0.82)	7.7 (1.4)	0.62 (0.45, 0.80)
Instant messaging								
No	7.3 (2.0)	0	7.5 (1.9)	0	7.6 (1.9)	0	7.5 (1.7)	0
Yes	7.6 (1.6)	0.12 (−0.06, 0.30)	7.7 (1.6)	0.11 (−0.07, 0.29)	7.8 (1.6)	0.07 (−0.10, 0.25)	7.7 (1.4)	0.10 (−0.06, 0.27)
Phone								
No	7.3 (1.9)	0	7.5 (1.9)	0	7.6 (1.8)	0	7.5 (1.7)	0
Yes	7.6 (1.8)	0.22 (0.03, 0.40)	7.7 (1.7)	0.14 (−0.04, 0.32)	7.8 (1.7)	0.18 (0.01, 0.36)	7.7 (1.5)	0.18 (0.02, 0.34)
Social media								
No	7.4 (1.8)	0	7.6 (1.8)	0	7.7 (1.8)	0	7.5 (1.7)	0
Yes	7.6 (1.7)	0.05 (−0.23, 0.33)	7.8 (1.6)	0.15 (−0.12, 0.42)	7.9 (1.5)	0.18 (−0.08, 0.45)	7.7 (1.5)	0.13 (−0.11, 0.37)
Video calls								
No	7.4 (1.8)	0	7.6 (1.8)	0	7.7 (1.8)	0	7.5 (1.6)	0
Yes	7.9 (1.5)	0.36 (0.01, 0.70)	8.0 (1.5)	0.37 (0.03, 0.70)	8.0 (1.5)	0.30 (−0.03, 0.63)	8.0 (1.3)	0.34 (0.04, 0.65)
Email								
No	7.4 (1.9)	0	7.6 (1.8)	0	7.7 (1.8)	0	7.5 (1.6)	0
Yes	7.9 (1.5)	0.32 (−0.02, 0.66)	7.9 (1.6)	0.26 (−0.07, 0.60)	8.0 (1.4)	0.28 (−0.04, 0.61)	7.9 (1.4)	0.29 (−0.01, 0.59)

^aFamily 3Hs and well-being ranged from 0 to 10, with a higher score indicating better outcome.

^bAdjusted for gender, age, educational attainment, employment status, monthly household income, and marital status.

Table 5. The combination of face-to-face and video calls to share family life information with family and perceived family 3Hs and well-being (N=2007).^a

Method of sharing	Family health		Family happiness		Family harmony		Family well-being	
	Mean (SD)	Beta (95% CI) ^b	Mean (SD)	Beta (95% CI) ^b	Mean (SD)	Beta (95% CI) ^b	Mean (SD)	Beta (95% CI) ^b
Never (n=408)	6.9 (2.2)	0	7.2 (2.3)	0	7.3 (2.2)	0	7.1 (2.0)	0
Face-to-face only (n=1392)	7.6 (1.7)	0.57 (0.36, 0.79)	7.7 (1.6)	0.57 (0.36, 0.79)	7.8 (1.6)	0.63 (0.42, 0.84)	7.7 (1.5)	0.60 (0.41, 0.79)
Video calls only (n=12)	8.1 (1.6)	0.80 (0.23, 1.82)	8.0 (1.7)	0.59 (, 0.42, 1.60)	8.4 (1.5)	0.85 (–0.13, 1.83)	8.2 (1.5)	0.75 (–0.15, 1.66)
Both (n=107)	7.9 (1.5)	0.80 (0.40, 1.20)	8.0 (1.5)	0.82 (0.43, 1.22)	8.0 (1.5)	0.78 (0.40, 1.16)	8.0 (1.3)	0.81 (0.45, 1.16)
Others ^c (n=88)	6.8 (1.9)	–0.13 (–0.56, 0.30)	6.8 (1.9)	–0.30 (–0.72, 0.12)	7.1 (2.0)	–0.10 (–0.51, 0.31)	6.9 (1.8)	–0.17 (–0.54, 0.21)

^aFamily 3Hs and well-being ranged from 0 to 10, with a higher score indicating better outcomes.

^bAdjusted for gender, age, educational attainment, employment status, monthly household income, and marital status.

^cOther methods included any method except face-to-face and video calls.

Compared with the respondents who had never shared family life information, the use of both face-to-face and video calls appeared to be most strongly associated with higher levels of perceived family health (beta=0.80, 95% CI 0.40-1.20), happiness (beta=0.82, 95% CI 0.43-1.22), harmony (beta=0.78, 95% CI 0.40-1.16), and overall family well-being (beta=0.81, 95% CI 0.45-1.16), although the 95% CIs overlapped with the use of face-to-face only (Table 5).

Discussion

This study provides the first evidence of family life information sharing in one of the most developed non-Western urban settings with high penetration of mobile phones and Internet, and widespread and fast Internet connection. Although the 95% CIs overlapped, it is noteworthy that respondents with higher education were much more likely to share family life information with family by video calls (aPR=5.61, 95% CI 2.29-13.74). This study also found that family life information sharing by the combination of face-to-face and video calls appeared to be most strongly associated with higher levels of perceived family 3Hs and overall well-being.

This study shows that women in Hong Kong are more likely to share family life information than men are, especially by ICTs. However, researchers showed an emerging trend that both genders have equal access to the Internet in developing Asian countries such as Vietnam [44]. Given that mobile phone ownership and Internet access are more prevalent in men than women in Hong Kong [14], such reverse gender difference in family life information sharing by ICTs may be explained by the gender-specific family orientation in Chinese context. Most men are breadwinners and women take care of the family and are therefore more likely to share family life information.

A previous survey showed that people with low SEP were less likely to seek family life information online and use ICTs to communicate with family members [6,28]. This study adds to the literature by showing that people with low SEP are also less likely to share family life information, particularly by ICTs. Lack of cognitive skills, social support, information literacy,

and Internet access are documented barriers [14,45]. Household income was inversely associated with the use of the telephone, indicating that more high-income individuals use ICTs to replace the conventional telephone. Compared with income, education was more strongly associated with the use of ICTs to share family life information, indicating that cognitive skills are more important than physical access to the Internet. Sufficient cognitive skills are necessary to understand the content, evaluate the usefulness, and share with others. The wide coverage of free public Wi-Fi services may reduce the access gap between rich and poor. The strongest association of education with the use of video calls still had a low prevalence of use (<10%), and could add new evidence of the emergence of the Inverse ICT Law. However, it also suggests a great potential to improve family life information sharing by video calls in disadvantaged groups, such as increasing the accessibility of video calls (ie, free of charge), ensuring it is user-friendly, and making people aware of the potential family benefits with increased communication. As the costs for subscription to high-speed data packages for home Wi-Fi are decreasing, it leads to more people abandoning the conventional telephone communication method (and saving money), thus video calls could become more popular and could be a greater benefit to underprivileged families.

Moreover, the authors found that family life information sharing was associated with all three dimensions of family well-being (health, happiness, and harmony). Intervention studies have found that family life education programs have benefits of forming and sustaining healthy relationships and improving family functions because family life information can help manage family activities, cope with family problems effectively, and deliver care of the children and the elderly [46,47]. In addition, sharing such information with family can promote positive communication among family members, which is a characteristic of well-functioning family [48].

Notably, the authors found that the use of face-to-face sharing of family life information was most strongly associated with all three dimensions of family well-being. Previous studies in Hong Kong and elsewhere [30,49,50] have reported that face-to-

face communication is most commonly endorsed compared to recently emerging ICTs and that using face-to-face communication with family, rather than new ICTs, is associated with better family well-being [28]. This study on family communication focusing on family life information showed similar results. Although frequent use of ICTs is observed particularly in young people, face-to-face remains the main mode of communication and information sharing in a family context [32,33,51,52]. A possible explanation is that face-to-face information sharing delivers verbal, nonverbal, and social context cues simultaneously and receives immediate and synchronized feedback of the information, indicating greater communication satisfaction and better information interpretation [30]. Moreover, the authors found that video calls were associated with a higher level of family well-being. Video calls can act as a good alternative when face-to-face is not possible because they provide visual cues with synchronized interaction and feedback. On the contrary, the use of other ICTs, such as IM, social media, or email, to share information may disconnect verbal and nonverbal signals and constrain the number of cues [35,53], and information is easily missing or misinterpreted.

Limitations

This study has some limitations. First, the cross-sectional study could have residual confounding or the temporal sequence of family life information sharing and family well-being was uncertain. Second, the methods of family life information sharing were determined only by a simple yes/no question; more detailed information such as the frequency of using face-to-face or ICTs to share should be collected in future research. Nevertheless, the authors have shown that a simple question could yield preliminary data to show the presence of the Inverse ICT Law and guide more in-depth studies. Third, the sampling method only covered adults. However, adolescents are more active digital users and more likely to embrace ICTs in various forms. Exploration of ICT use in young people may enable a better understanding of how it affects family well-being. In addition, online interpersonal influences may affect health-related quality of life in adolescents [44]. Finally, because of the small numbers for some uncommonly used methods, such as video calls, the 95% CIs of the aPRs and beta coefficients overlapped, meaning that differences could be due to chance. A much larger sample size is needed for more detailed subgroup analyses.

Future Work

This study suggests several avenues for future research. First, qualitative research on family life information sharing should be conducted in this setting for a deeper understanding of information sharing behaviors in a family context. Prospective cohort studies and intervention studies are also needed to assess the impact of family life information sharing by video calls on family well-being. Second, information on specific groups of families is important to further address the impact of ICT use on those with special needs. For instance, in families with members living in geographically separated areas, ICTs such as video calls can be increasingly used to maintain family relationships and bonds [54]. ICTs such as social media can be used to provide support for family members who provide care for other members who suffer from chronic diseases and improve family well-being [55]. However, in families with adolescents living in the same house where face-to-face encounters occur frequently, high frequency of ICTs can lead to negative impact, such as a lower level of family cohesion [34,35] and Internet addiction [19,56]. Third, because previous studies found that mobile phone ownership [19], time management problems (ie, the average time spent on the Internet per day) [56], and psychological well-being [57] might affect ICT use, further research is also warranted to investigate how these factors affect the relationship between ICT use and family well-being.

Conclusions

Although the impact of ICT usage on family has been extensively studied, this study has provided the first evidence of different methods of information sharing with family, especially video calls, and their associations with family well-being. The differential use of ICTs to share family life information supports the emergence of the Inverse ICT Law. Face-to-face communication remained the main mode for family life information sharing and was associated with better family well-being. The prevalence of video calls was low but associated with better perceived family well-being, denoting a feasible way by better use of ICTs to improve family well-being. Further prospective and intervention studies are warranted to confirm the results and to promote the use of video calls to communicate and share information with family, particularly in disadvantaged groups.

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Conflicts of Interest

None declared.

References

1. National Council on Family Relations. 2013. What is family life education? URL: <https://www.ncfr.org/cfile-certification/what-family-life-education> [accessed 2017-06-02] [WebCite Cache ID 6quvxixZQ]

2. Neill S, Roland D, Jones CH, Thompson M, Lakhanpaul M, ASK SNIFF Study Group. Information resources to aid parental decision-making on when to seek medical care for their acutely sick child: a narrative systematic review. *BMJ Open* 2015 Dec 16;5(12):e008280 [FREE Full text] [doi: [10.1136/bmjopen-2015-008280](https://doi.org/10.1136/bmjopen-2015-008280)] [Medline: [26674495](https://pubmed.ncbi.nlm.nih.gov/26674495/)]
3. Plantin L, Daneback K. Parenthood, information and support on the internet. A literature review of research on parents and professionals online. *BMC Fam Pract* 2009;10:34 [FREE Full text] [doi: [10.1186/1471-2296-10-34](https://doi.org/10.1186/1471-2296-10-34)] [Medline: [19450251](https://pubmed.ncbi.nlm.nih.gov/19450251/)]
4. Armstrong M, Birnie-Lefcovitch S, Ungar M. Pathways between social support, family well being, quality of parenting, and child resilience: what we know. *J Child Fam Stud* 2005 Jun;14(2):269-281. [doi: [10.1007/s10826-005-5054-4](https://doi.org/10.1007/s10826-005-5054-4)]
5. Kinnunen * U, Geurts S, Mauno S. Work-to-family conflict and its relationship with satisfaction and well-being: a one-year longitudinal study on gender differences. *Work Stress* 2004 Jan;18(1):1-22. [doi: [10.1080/02678370410001682005](https://doi.org/10.1080/02678370410001682005)]
6. Wang MP, Wang X, Viswanath K, Wan A, Lam TH, Chan SS. Digital inequalities of family life information seeking and family well-being among Chinese adults in Hong Kong: a population survey. *J Med Internet Res* 2014 Oct 03;16(10):e227 [FREE Full text] [doi: [10.2196/jmir.3386](https://doi.org/10.2196/jmir.3386)] [Medline: [25281831](https://pubmed.ncbi.nlm.nih.gov/25281831/)]
7. Olson D. Circumplex model of marital and family systems. *J Family Therapy* 2000 May;22(2):144-167. [doi: [10.1111/1467-6427.00144](https://doi.org/10.1111/1467-6427.00144)]
8. Pinquart M, Sörensen S. Influences of socioeconomic status, social network, and competence on subjective well-being in later life: a meta-analysis. *Psychol Aging* 2000 Jun;15(2):187-224. [Medline: [10879576](https://pubmed.ncbi.nlm.nih.gov/10879576/)]
9. Bond M, Hwang KK. The social psychology of Chinese people. In: *The Psychology of the Chinese People*. New York: Oxford University Press; 1986:213-266.
10. Triandis H. Individualism & collectivism. In: *New Directions in Social Psychology*. Boulder, CO: Westview Press; 1995.
11. Lam WW, Fielding R, McDowell I, Johnston J, Chan S, Leung GM, et al. Perspectives on family health, happiness and harmony (3H) among Hong Kong Chinese people: a qualitative study. *Health Educ Res* 2012 Oct;27(5):767-779. [doi: [10.1093/her/cys087](https://doi.org/10.1093/her/cys087)] [Medline: [22907531](https://pubmed.ncbi.nlm.nih.gov/22907531/)]
12. Chan SS, Viswanath K, Au DW, Ma CM, Lam WW, Fielding R, et al. Hong Kong Chinese community leaders' perspectives on family health, happiness and harmony: a qualitative study. *Health Educ Res* 2011 Aug;26(4):664-674. [doi: [10.1093/her/cyr026](https://doi.org/10.1093/her/cyr026)] [Medline: [21536713](https://pubmed.ncbi.nlm.nih.gov/21536713/)]
13. Facebook. Newsroom URL: <http://newsroom.fb.com/Key-Facts> [accessed 2017-09-28] [WebCite Cache ID 6quw8L9nl]
14. Census and Statistic Department, Hong Kong Special Administrative Region. Thematic Household Survey. Report No 59. URL: <http://www.statistics.gov.hk/pub/B11302592016XXXXB0100.pdf> [accessed 2017-06-02] [WebCite Cache ID 6quwIKR0E]
15. Pew Research Center. 2017 Jan 12. Internet/Broadband fact sheet URL: <http://www.pewinternet.org/fact-sheet/internet-broadband/> [accessed 2017-06-02] [WebCite Cache ID 6quwNg5Ef]
16. Pew Research Center. 2016 Nov 11. Social media update 2016 URL: <http://www.pewinternet.org/2016/11/11/social-media-update-2016/> [accessed 2017-09-28] [WebCite Cache ID 6quwVF0Z5]
17. Office of the Communications Authority, The Government of Hong Kong Special Administrative Region. Public Wi-Fi services URL: http://www.ofca.gov.hk/mobile/en/media_focus/data_statistics/wifi/index.html [accessed 2017-09-28] [WebCite Cache ID 6quwZctvS]
18. Akamai. 2015. State of the Internet URL: <https://www.akamai.com/us/en/our-thinking/state-of-the-internet-report/index.jsp> [accessed 2017-09-28] [WebCite Cache ID 6quwFHEmp]
19. Mak K, Lai C, Watanabe H, Kim D, Bahar N, Ramos M, et al. Epidemiology of internet behaviors and addiction among adolescents in six Asian countries. *Cyberpsychol Behav Soc Netw* 2014 Nov;17(11):720-728. [doi: [10.1089/cyber.2014.0139](https://doi.org/10.1089/cyber.2014.0139)] [Medline: [25405785](https://pubmed.ncbi.nlm.nih.gov/25405785/)]
20. Kontos E, Blake KD, Chou WS, Prestin A. Predictors of eHealth usage: insights on the digital divide from the Health Information National Trends Survey 2012. *J Med Internet Res* 2014;16(7):e172 [FREE Full text] [doi: [10.2196/jmir.3117](https://doi.org/10.2196/jmir.3117)] [Medline: [25048379](https://pubmed.ncbi.nlm.nih.gov/25048379/)]
21. van Deursen AJ, van Dijk JA, ten Klooster PM. Increasing inequalities in what we do online: a longitudinal cross sectional analysis of Internet activities among the Dutch population (2010 to 2013) over gender, age, education, and income. *Telemat Inform* 2015;32(2):259-272.
22. Viswanath K. Public communications and its role in reducing and eliminating health disparities. In: *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business*. Washington, DC: Institute of Medicine; 2006:215-253.
23. Shen C, Wang MP, Chu JT, Wan A, Viswanath K, Chan SS, et al. Health app possession among smartphone or tablet owners in Hong Kong: population-based survey. *JMIR Mhealth Uhealth* 2017 Jun 05;5(6):e77 [FREE Full text] [doi: [10.2196/mhealth.7628](https://doi.org/10.2196/mhealth.7628)] [Medline: [28583905](https://pubmed.ncbi.nlm.nih.gov/28583905/)]
24. Eysenbach G. Consumer health informatics. *BMJ* 2000 Jun 24;320(7251):1713-1716 [FREE Full text] [Medline: [10864552](https://pubmed.ncbi.nlm.nih.gov/10864552/)]
25. Eysenbach G. Poverty, human development, and the role of eHealth. *J Med Internet Res* 2007 Oct 22;9(4):e34 [FREE Full text] [doi: [10.2196/jmir.9.4.e34](https://doi.org/10.2196/jmir.9.4.e34)] [Medline: [17951217](https://pubmed.ncbi.nlm.nih.gov/17951217/)]
26. Wang MP, Viswanath K, Lam TH, Wang X, Chan SS. Social determinants of health information seeking among Chinese adults in Hong Kong. *PLoS One* 2013 Aug;8(8):e73049 [FREE Full text] [doi: [10.1371/journal.pone.0073049](https://doi.org/10.1371/journal.pone.0073049)] [Medline: [24009729](https://pubmed.ncbi.nlm.nih.gov/24009729/)]

27. Social Welfare Department, The Government of the Hong Kong Special Administrative Region. Statistics on child abuse, spouse/cohabitant battering and sex violence cases URL: <http://www.swd.gov.hk/vs/english/stat.html> [accessed 2017-09-28] [WebCite Cache ID 6txOtb1bA]
28. Wang MP, Chu JT, Viswanath K, Wan A, Lam TH, Chan SS. Using information and communication technologies for family communication and its association with family well-being in Hong Kong: FAMILY project. *J Med Internet Res* 2015 Aug 24;17(8):e207 [FREE Full text] [doi: [10.2196/jmir.4722](https://doi.org/10.2196/jmir.4722)] [Medline: [26303434](https://pubmed.ncbi.nlm.nih.gov/26303434/)]
29. Walther J. Computer-Mediated Communication. *Commun Res* 2016 Jun 29;23(1):3-43. [doi: [10.1177/009365096023001001](https://doi.org/10.1177/009365096023001001)]
30. Baym N, Zhang Y, Lin M. Social Interactions Across Media. *New Media Soc* 2016 Jun 30;6(3):299-318. [doi: [10.1177/1461444804041438](https://doi.org/10.1177/1461444804041438)]
31. Padilla-Walker L, Coyne S, Fraser A. Getting a high - speed family connection: associations between family media use and family connection. *Fam Relat* 2012;61(3):426-440. [doi: [10.1111/j.1741-3729.2012.00710.x](https://doi.org/10.1111/j.1741-3729.2012.00710.x)]
32. Williams AL, Merten MJ. iFamily: Internet and social media technology in the family context. *Family Consum Sci Res J* 2011;40(2):150-170. [doi: [10.1111/j.1552-3934.2011.02101.x](https://doi.org/10.1111/j.1552-3934.2011.02101.x)]
33. Hertlein K. Digital dwelling: technology in couple and family relationships. *Fam Relat* 2012;61(3):374-387. [doi: [10.1111/j.1741-3729.2012.00702.x](https://doi.org/10.1111/j.1741-3729.2012.00702.x)]
34. Mesch G. The family and the Internet: the Israeli case*. *Social Science Q* 2003 Dec;84(4):1038-1050. [doi: [10.1046/j.0038-4941.2003.08404016.x](https://doi.org/10.1046/j.0038-4941.2003.08404016.x)]
35. Mesch G. Family relations and the Internet: exploring a family boundaries approach. *J Fam Commun* 2006 Apr;6(2):119-138. [doi: [10.1207/s15327698jfc0602_2](https://doi.org/10.1207/s15327698jfc0602_2)]
36. Muñoz-Mirallès R, Ortega-González R, López-Morón MR, Batalla-Martínez C, Manresa JM, Montellà-Jordana N, et al. The problematic use of Information and Communication Technologies (ICT) in adolescents by the cross sectional JOITIC study. *BMC Pediatr* 2016 Aug 22;16(1):140 [FREE Full text] [doi: [10.1186/s12887-016-0674-y](https://doi.org/10.1186/s12887-016-0674-y)] [Medline: [27550020](https://pubmed.ncbi.nlm.nih.gov/27550020/)]
37. Romero-Ruiz K, Echeverri-Sánchez L, Peña-Plata J, Vásquez-Giraldo S, Aguilera-Cardona M, Herazo-Avendaño C, et al. Information and communication technologies impact on family relationship. *Procd Soc Behav* 2017 Feb;237:30-37. [doi: [10.1016/j.sbspro.2017.02.007](https://doi.org/10.1016/j.sbspro.2017.02.007)]
38. Ziersch AM, Baum FE. Involvement in civil society groups: is it good for your health? *J Epidemiol Community Health* 2004 Jun;58(6):493-500 [FREE Full text] [Medline: [15143118](https://pubmed.ncbi.nlm.nih.gov/15143118/)]
39. Census and Statistic Department, Hong Kong Government. The Profile of Hong Kong Population Analysed by District, 2009 URL: <http://www.statistics.gov.hk/pub/B71006FB2010XXXXB0100.pdf> [accessed 2017-10-04] [WebCite Cache ID 6txN5PmJO]
40. Cronbach L. Coefficient alpha and the internal structure of tests. *Psychometrika* 1951;16(3):297-334.
41. Izrael D, Hoaglin D, Battaglia M. A SAS macro for balancing a weighted sample. 2000 Presented at: Twenty-Fifth Annual SAS Users Group International Conference; Apr 9-12, 2000; Indianapolis, IN.
42. Izrael D, Hoaglin D, Battaglia M. To rake or not to rake is not the question anymore with the enhanced raking macro. 2004 Presented at: Twenty-Ninth Annual SAS Users Group International Conference; May 9-12, 2004; Montreal, QC.
43. Barros AJ, Hirakata VN. Alternatives for logistic regression in cross-sectional studies: an empirical comparison of models that directly estimate the prevalence ratio. *BMC Med Res Methodol* 2003 Oct 20;3:21 [FREE Full text] [doi: [10.1186/1471-2288-3-21](https://doi.org/10.1186/1471-2288-3-21)] [Medline: [14567763](https://pubmed.ncbi.nlm.nih.gov/14567763/)]
44. Tran BX, Huong LT, Hinh ND, Nguyen LH, Le BN, Nong VM, et al. A study on the influence of internet addiction and online interpersonal influences on health-related quality of life in young Vietnamese. *BMC Public Health* 2017 Jan 31;17(1):138 [FREE Full text] [doi: [10.1186/s12889-016-3983-z](https://doi.org/10.1186/s12889-016-3983-z)] [Medline: [28143462](https://pubmed.ncbi.nlm.nih.gov/28143462/)]
45. Viswanath K, Ackerson LK. Race, ethnicity, language, social class, and health communication inequalities: a nationally-representative cross-sectional study. *PLoS One* 2011 Jan 18;6(1):e14550 [FREE Full text] [doi: [10.1371/journal.pone.0014550](https://doi.org/10.1371/journal.pone.0014550)] [Medline: [21267450](https://pubmed.ncbi.nlm.nih.gov/21267450/)]
46. Hawkins AJ, Blanchard VL, Baldwin SA, Fawcett EB. Does marriage and relationship education work? A meta-analytic study. *J Consult Clin Psychol* 2008 Oct;76(5):723-734. [doi: [10.1037/a0012584](https://doi.org/10.1037/a0012584)] [Medline: [18837590](https://pubmed.ncbi.nlm.nih.gov/18837590/)]
47. Darling C, Cassidy D. Family Life Education: Working With Families Across the Lifespan. Long Grove, IL: Waveland Press; 2014.
48. Epstein N, Bishop D, Levin S. The McMaster model of family functioning. *J Marital Fam Ther* 1978;4(4):19-31. [doi: [10.1111/j.1752-0606.1978.tb00537.x](https://doi.org/10.1111/j.1752-0606.1978.tb00537.x)]
49. Stern M, Messer C. How family members stay in touch: a quantitative investigation of core family networks. *Marriage Fam Rev* 2009;45(6-8):654-676. [doi: [10.1080/01494920903224236](https://doi.org/10.1080/01494920903224236)]
50. Kim H, Kim G, Park H, Rice R. Configurations of relationships in different media: FtF, email, instant messenger, mobile phone, and SMS. *J Comput - Mediat Comm* 2007;12(4):1183-1207. [doi: [10.1111/j.1083-6101.2007.00369.x](https://doi.org/10.1111/j.1083-6101.2007.00369.x)]
51. Carvalho J, Francisco R, Relvas AP. Family functioning and information and communication technologies: how do they relate? A literature review. *Comput Hum Behav* 2015 Apr;45:99-108. [doi: [10.1016/j.chb.2014.11.037](https://doi.org/10.1016/j.chb.2014.11.037)]
52. Zhong B. From smartphones to iPad: power users' disposition toward mobile media devices. *Comput Hum Behav* 2013 Jul;29(4):1742-1748. [doi: [10.1016/j.chb.2013.02.016](https://doi.org/10.1016/j.chb.2013.02.016)]
53. Huisman S, Edwards A, Catapano S. The impact of technology on families. *Int J Edu Psychol Commun* 2012(II-1):44-62.

54. Mickus MA, Luz CC. Televisits: sustaining long distance family relationships among institutionalized elders through technology. *Aging Ment Health* 2002 Nov;6(4):387-396. [doi: [10.1080/1360786021000007009](https://doi.org/10.1080/1360786021000007009)] [Medline: [12425772](https://pubmed.ncbi.nlm.nih.gov/12425772/)]
55. Zhang MW, Chan S, Wynne O, Jeong S, Hunter S, Wilson A, et al. Conceptualization of an evidence-based smartphone innovation for caregivers and persons living with dementia. *Technol Health Care* 2016 Sep 14;24(5):769-773. [doi: [10.3233/THC-161165](https://doi.org/10.3233/THC-161165)] [Medline: [27129032](https://pubmed.ncbi.nlm.nih.gov/27129032/)]
56. Mak K, Lai C, Ko C, Chou C, Kim D, Watanabe H, et al. Psychometric properties of the Revised Chen Internet Addiction Scale (CIAS-R) in Chinese adolescents. *J Abnorm Child Psychol* 2014 Oct;42(7):1237-1245. [doi: [10.1007/s10802-014-9851-3](https://doi.org/10.1007/s10802-014-9851-3)] [Medline: [24585392](https://pubmed.ncbi.nlm.nih.gov/24585392/)]
57. Ho RC, Zhang MW, Tsang TY, Toh AH, Pan F, Lu Y, et al. The association between internet addiction and psychiatric co-morbidity: a meta-analysis. *BMC Psychiatry* 2014 Jun 20;14(1):14. [doi: [10.1186/1471-244x-14-183](https://doi.org/10.1186/1471-244x-14-183)]

Abbreviations

aPR: adjusted prevalence ratio

FHInTS: Family and Health Information Trends Survey

ICT: information and communication technology

IM: instant messaging

SEP: socioeconomic position

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Original Paper

Mental and Emotional Self-Help Technology Apps: Cross-Sectional Study of Theory, Technology, and Mental Health Behaviors

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Abstract

Background: Mental and emotional self-help apps have emerged as potential mental illness prevention and treatment tools. The health behavior theory mechanisms by which these apps influence mental health-related behavior change have not been thoroughly examined.

Objective: The objective of this study was to examine the association between theoretical behavior change mechanisms and use of mental and emotional self-help apps and whether the use of such apps is associated with mental health behaviors.

Methods: This study utilized a cross-sectional survey of 150 users of mental or emotional health apps in the past 6 months. Survey questions included theory-based items, app engagement and likeability items, and behavior change items. Stata version 14 was used to calculate all statistics. Descriptive statistics were calculated for each of the demographic, theory, engagement, and behavior variables. Multiple regression analysis was used to identify factors associated with reported changes in theory and separately for reported changes in actual behavior after controlling for potentially confounding variables.

Results: Participants reported that app use increased their motivation, desire to set goals, confidence, control, and intentions to be mentally and emotionally healthy. Engagement ($P<.001$) was positively associated with the reported changes in theory items, whereas perceived behavior change was positively associated with theory ($P<.001$), engagement ($P=.004$), frequency of use of apps ($P=.01$), and income ($P=.049$).

Conclusions: Participants reported that app use increased their motivation, desire to set goals, confidence, control, and intentions to be mentally and emotionally healthy. This increase in perceptions, beliefs, and attitudes surrounding their mental and emotional health was considerably associated with perceived change in behavior. There was a positive association between the level of engagement with the app and the impact on theory items. Future efforts should consider the value of impacting key theoretical constructs when designing mental and emotional health apps. As apps are evaluated and additional theory-based apps are created, cost-effective self-help apps may become common preventative and treatment tools in the mental health field.

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KEYWORDS

mental health; decision theory; mobile applications

Introduction

Mental health is a state of well-being in which every individual realizes their own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make

a contribution to the community [1]. Many Americans struggle with diagnosable mental illness such as anxiety and depression [2]. According to the National Institute of Mental Health, the prevalence of anxiety disorders among US adults is 18.1%, with 22.8% of these cases classified as *severe* mental illness [2].

Major depressive disorder affects more than 15 million American adults or approximately 6.7% of the US adult population [3]. A number of other mental illnesses, including panic disorder, phobias, bipolar disorder, schizophrenia, obsessive compulsive disorder, posttraumatic stress disorder, eating disorders, sleep disorders, substance abuse disorders, and attention deficit or hyperactive disorders also affect millions of Americans [4]. Unfortunately, many individuals with mental illnesses do not seek help. Among those that do, there are often pervasive delays in receiving care [5]. Some have turned to self-help approaches to address and manage mental health and wellness concerns.

Self-help products constitute a multibillion dollar industry [6]. Books, podcasts, and mobile phone apps are among the most popular tools. In 2014, there were 4.55 billion mobile phone users worldwide [7]. By 2016, there were 198.5 million people in the United States who owned mobile phones with functioning apps [8]. Mental and emotional self-help apps have been developed recently to meet the demands resulting from growing interest and acceptability [9]. In a survey examining the potential of mobile phone apps, 76% of respondents expressed that they were interested in using free mobile phone apps to maintain their own mental health [10]. Such apps may promote changes in care-seeking behavior [11], reduce barriers to accessing mental health treatment [12], and increase the perceived value in mental health care services [13]. For example, Mobilyze is an app designed to manage depressive symptoms. One study concluded that Mobilyze users were satisfied with the app and improved considerably on self-reported depressive symptoms and interview-reported measures of depressive symptoms. Users had decreased comorbid anxiety symptoms and were less likely to meet criteria for major depressive disorder diagnosis [14].

Mental and emotional self-help apps have the potential to play an important role in the future of mental health prevention and treatment; however, intervention evaluations suggest that such apps should integrate theory-based principles of health behavior to effectively accomplish the goal of improving mental and emotional health [15].

Health behavior theory informs the development and execution of interventions to achieve program objectives [16]. This is accomplished by addressing the mechanisms by which individuals make changes to their behavior. For example, the Health Belief Model (HBM) is used to explain and predict health behaviors by focusing on individuals' perceptions of what is likely to happen to them if they choose not to change their behavior [4]. The emphasis of social cognitive theory (SCT) is to promote change through improvements in self-efficacy and a combination of environmental- and individual-level characteristics [17,18]. According to the theory of planned behavior (TPB), human behavior is guided by behavioral, normative, and control beliefs [19]. Behavioral beliefs are the beliefs that an individual has about the probable outcomes of a behavior and the appraisals of the results. Normative beliefs are the expectancies of others and incentive to conform with these expectancies. Control beliefs are the attitudes about the presence of facilitating or impeding factors that may affect the functioning of the behavior and the influence of these aspects [20].

Although mental and emotional health self-help apps are widely used, the health behavior theory mechanisms by which these apps influence mental health-related behavior change have not been thoroughly examined [21]. Although a limited number of studies have explored the extent to which apps are founded on the principles of health behavior theory, these studies have not measured whether theoretical constructs are associated both with the use of apps and with health behavior change. The purpose of this study was to examine the association between theory-based behavior change mechanisms and use of mental and emotional self-help apps and whether the frequent use of and engagement with such apps were positively associated with perceived behavior change. We hypothesized that theoretical behavior change constructs, including knowledge, attitudes, beliefs, perceptions, self-efficacy, and intentions to behave, are related to app use and to perceived behavior change.

Methods

Design

This study utilized a cross-sectional survey directed to users of mental or emotional health apps in the past 6 months. The survey included questions about demographics, theory-informed items, as well as likeability and respondents' engagement with the apps.

Sample

A total of 207 individuals initiated the survey, with 171 meeting the inclusion criteria. Potential respondents were informed that the purpose of the study was to understand more about individuals' use of technology to improve their health, and in particular, to learn more about the use of self-help apps that can be used to track mental and emotional health status. Some popular examples of these types of apps include Happify and MindShift. To qualify for the study, participants were required to live in the United States, be at least 18 years of age or older, and have used a mental or emotional self-help app in the previous 6 months. Surveys were only provided in English. Of the 171 participants who met the inclusion criteria, 150 participants answered all survey questions and were included in the final study sample.

Procedure

An electronic Qualtrics survey was distributed through Amazon Mechanical Turk (MTurk). A pilot test involving 15 individuals was conducted before distribution of the survey to the main sample. Following the pilot test, changes were made to the survey questions and flow using feedback provided by pilot participants. The final survey link was uploaded to MTurk and participants were initially paid US \$1 for completing the survey. A total of 52 surveys had been completed after 1 week of data collection. The survey was relaunched with a compensation of US \$2, and additional 119 respondents participated in the survey. The participants' MTurk IDs were required to initiate the survey and were used to verify each survey to ensure the authenticity of the participant and to prevent duplications. Duplicates were not allowed to initiate the survey.

Measurement

Theory-based behavior change and likeability items were adapted from the previous studies of health apps. The adaptation made for this study included changes to make the items more applicable for app users' own personal experience with apps [22,23]. Demographic items in the survey included age, gender, race, ethnicity, level of education, state of residence, and combined annual household income. Using health behavior theories, Likert-type survey questions were developed to examine theory-based mechanisms of change, engagement with and likeability of the use of apps in the past 6 months, and changes in their actual behavior. Theory-based items included the following: "belief that poor mental and emotional health leads to bad health," "belief that being mentally and emotionally healthy can prevent bad health," "belief that diseases related to poor mental and emotional health are harmful," "belief that mental and emotional health is important in preventing bad health," "motivation to be mentally and emotionally healthy," "ability to be mentally and emotionally healthy," "confidence that I can be mentally and emotionally healthy," "control over my mental/emotional health," "intentions to be mentally and emotionally healthy," "attitudes about the importance of being mentally and emotionally healthy," "belief that people important to me want me to be mentally and emotionally healthy," "perception that many other people are mentally and emotionally healthy," "knowledge of the diseases/disorders that are caused by poor mental and emotional health," "knowledge of ways in which I can be mentally and emotionally healthy," "awareness of the benefits of being mentally and emotionally healthy," "desire to be mentally and emotionally healthy," "social support I have received for being mentally/emotionally healthy," "positive feedback I have received for being mentally/emotionally healthy," "desire to set goals to be mentally/emotionally healthy," and "ability to achieve my mental/emotional health goals." A composite variable was constructed summing the Likert score for all theory-related constructs to provide a broad-based theory variable. Provided the complexities relating to mental and emotional health, a practical approach to behavior change may involve a combination of distinct constructs and elements from each theory, effectively forming a polytheoretical approach. The Cronbach alpha coefficient for this composite variable was .947. This variable was not normally distributed and a square root transformation was used to normalize it.

Engagement with and likeability of the app were assessed using the following items: "the app(s) was helpful," "the app(s) was easy to use," "I enjoyed using the app(s)," "I liked the app(s)," and "I would recommend the app(s) to others." A composite engagement variable was computed to estimate the total level of engagement and likeability of the reported use of apps in the 6 months before the study period. The Cronbach alpha coefficient for this composite variable was .921.

Perceived behavior change items included the following: "actual goal setting to be mentally /emotionally healthy," "frequency

of practicing mental/emotional management techniques," "intensity to which I practice mental/emotional management techniques," and "consistency in using mental/emotional health management techniques." A composite perceived behavior change variable was computed by summing the responses to the behavior change questions. The Cronbach alpha coefficient for this composite variable was .900.

Analysis

Stata version 14 was used to calculate all statistics. Descriptive statistics were calculated for each of the demographic, theory, engagement, and behavior variables. Multiple regression analysis was used to identify factors associated with reported changes in theory and separately for reported changes in actual behavior after controlling for potentially confounding variables, including app engagement, price of each app, frequency of use, gender, age, and annual income. Assumptions of independence were tested, and tolerance levels were within acceptable ranges.

Results

Of the 150 participants, 57.3% were female, 78.7% were white, and 39.3% had a 4-year college degree (see [Table 1](#)).

Most participants agreed (44.0%) or strongly agreed (45.3%) that the mental or emotional self-help apps increased their motivation to be mentally and emotionally healthy ([Table 2](#)). Approximately half (48.7%) of the respondents agreed and 40.7% strongly agreed that the app increased their confidence that they can be mentally and emotionally healthy.

Mental and emotional self-help apps were perceived to increase the control over mental and emotional health (44.7% of respondents agreed and 38.7% strongly agreed), intentions to be mentally and emotionally healthy (38.0% agreed and 50.7% strongly agreed), attitudes about the importance of being mentally and emotionally healthy (46.0% agreed and 42.0% strongly agreed), desire to set goals to be mentally and emotionally healthy (46.0% agreed and 47.3% strongly agreed), and ability to achieve mental and emotional health goals (52.7% agreed and 36.0% strongly agreed). Participants reported varying levels of disagreement or neutrality with the following statements: the app(s) increased my belief that people important to me want me to be mentally and emotionally healthy (2.0% strongly disagree, 8.0% disagree, and 25.3% neutral); the app(s) increased my perception that many other people are mentally and emotionally healthy (1.3% strongly disagree, 15.3% disagree, and 26.0% neutral); the app(s) increased my knowledge of the diseases/disorders that are caused by poor mental health (1.3% strongly disagreed, 14.0% disagreed, and 17.3% neutral); the app(s) increased the social support I have received for being mentally/emotionally healthy (4.0% strongly disagreed, 18.0% disagreed, and 18.0% neutral); and the app(s) increased the positive feedback I have received for being mentally/emotionally healthy (3.3% strongly disagreed, 13.3% strongly disagreed, and 14.7% neutral). The behavior item response distribution is depicted in [Table 3](#).

Table 1. Summary of participant demographics.

Demographics	Frequency (N=150) n (%)
Age, years	
18-25	13 (8.7)
26-34	74 (49.3)
35-54	55 (36.7)
55-64	8 (5.3)
65 or over	0 (0.0)
Race or ethnicity	
Asian	11 (7.3)
Black/African American	21 (14.0)
White	118 (78.7)
Gender	
Male	64 (42.7)
Female	86 (57.3)
Education	
Less than high school	2 (1.3)
Diploma or GED ^a	16 (10.7)
Some college	48 (32.0)
2-year degree	17 (11.3)
4-year degree	59 (39.3)
Master's degree	6 (4.0)
Professional degree (Medical Doctor and Juris Doctor)	2 (1.3)
Household income^b	
Less than 30,000	38 (25.3)
30,000-39,999	28 (18.7)
40,000-49,999	17 (11.3)
50,000-59,999	15 (10.0)
60,000-69,999	17 (11.3)
70,000-79,999	11 (7.3)
80,000-89,999	6 (4.0)
90,000-99,999	4 (2.7)
100,000 or more	14 (9.3)

^aGED: General Educational Development.^bAll values are in 2016 US dollars.

Table 2. Summary of participant responses to theory questions.

Question ^a	Response (N=150)				
	Strongly disagree n (%)	Disagree n (%)	Neutral n (%)	Agree n (%)	Strongly agree n (%)
Increased my belief that poor mental and emotional health leads to bad health (SCT ^b and TPB ^c)	4 (2.7)	13 (8.7)	20 (13.3)	80 (53.3)	33 (22.0)
Increased my belief that being mentally and emotionally healthy can prevent bad health (SCT and TPB)	2 (1.3)	6 (4.0)	20 (13.3)	74 (49.3)	48 (32.0)
Increased my belief that diseases related to poor mental and emotional health are harmful (SCT and TPB)	2 (1.3)	10 (6.7)	25 (16.7)	69 (46.0)	44 (29.3)
Increased my belief that mental and emotional health is important in preventing bad health (SCT and TPB)	2 (1.3)	8 (5.3)	15 (10.0)	71 (47.3)	54 (36.0)
Increased my motivation to be mentally and emotionally healthy (SCT)	2 (1.3)	3 (2.0)	11 (7.3)	66 (44.0)	68 (45.3)
Increased my ability to be mentally and emotionally healthy (SCT)	3 (2.0)	5 (3.3)	16 (10.7)	71 (47.3)	55 (36.7)
Increased my confidence that I can be mentally and emotionally healthy (SCT)	0 (0.0)	3 (2.0)	13 (8.7)	73 (48.7)	61 (40.7)
Increased my control over my mental/emotional health (TPB)	1 (0.7)	6 (4.0)	18 (12.0)	67 (44.7)	58 (38.7)
Increased my intentions to be mentally and emotionally healthy (TPB)	2 (1.3)	2 (1.3)	13 (8.7)	57 (38.0)	76 (50.7)
Increased my attitudes about the importance of being mentally and emotionally healthy (TPB)	0 (0.0)	1 (0.7)	17 (11.3)	69 (46.0)	63 (42.0)
Increased my belief that people important to me want me to be mentally and emotionally healthy (TPB)	3 (2.0)	12 (8.0)	38 (25.3)	51 (34.0)	46 (30.7)
Increased my perception that many other people are mentally and emotionally healthy (TPB)	2 (1.3)	23 (15.3)	39 (26.0)	48 (32.0)	38 (25.3)
Increased my knowledge of the diseases/disorders that are caused by poor mental and emotional health (SCT)	2 (1.3)	21 (14.0)	26 (17.3)	63 (42.0)	38 (25.3)
Increased my knowledge of ways in which I can be mentally and emotionally healthy (SCT)	0 (0.0)	2 (1.3)	10 (6.7)	79 (52.7)	59 (39.3)
Increased my awareness of the benefits of being mentally and emotionally healthy (HBM ^d)	0 (0.0)	4 (2.7)	13 (8.7)	71 (47.3)	62 (41.3)
Increased my desire to be mentally and emotionally healthy (TPB)	0 (0.0)	3 (2.0)	12 (8.0)	67 (44.7)	68 (45.3)
Increased the social support I have received for being mentally/emotionally healthy (SCT)	6 (4.0)	27 (18.0)	27 (18.0)	60 (40.0)	30 (20.0)
Increased the positive feedback I have received for being mentally/emotionally healthy (SCT)	5 (3.3)	20 (13.3)	22 (14.7)	71 (47.3)	32 (21.3)
Increased my desire to set goals to be mentally/emotionally healthy (SCT)	0 (0.0)	1 (0.7)	9 (6.0)	69 (46.0)	71 (47.3)
Increased my ability to achieve my mental/emotional health goals (SCT)	0 (0.0)	4 (2.7)	13 (8.7)	79 (52.7)	54 (36.0)

^aAll theory questions in the survey were preceded by the following statement: now think about the mental and emotional health app(s) that you have used in the past 6 months. Using the app(s) has...

^bSCT: social cognitive theory.

^cTPB: theory of planned behavior.

^dHBM: health belief model.

Table 3. Summary of participant responses to behavior change questions.

Question ^a	Response (N=150)				
	Strongly disagree n (%)	Disagree n (%)	Neutral n (%)	Agree n (%)	Strongly agree n (%)
Increased my actual goal setting to be mentally/emotionally healthy	0 (0.0)	2 (1.3)	12 (8.0)	79 (52.7)	57 (38.0)
Increased my frequency of practicing mental/emotional management techniques	0 (0.0)	1 (0.7)	8 (5.3)	78 (52.0)	63 (42.0)
Increased the intensity to which I practice mental/emotional management techniques	0 (0.0)	1 (0.7)	20 (13.3)	81 (54.0)	40 (32.0)
Increased my consistency in using mental/emotional health management techniques	0 (0.0)	1 (0.7)	10 (6.7)	79 (52.7)	60 (40.0)

^aAll theory questions in the survey were preceded by the following statement: now think about the mental and emotional health app(s) that you have used in the past 6 months. Using the app(s) has...

The major proportion of participants agreed or strongly agreed that the app increased their actual goal setting to be mentally and emotionally healthy (52.7% agreed and 38.0% strongly agreed), their frequency of practicing mental and emotional management techniques (52.0% agreed and 42.0% strongly agreed), and their consistency in using mental and emotional health management techniques (52.7% agreed and 40.0% strongly agreed). Most participants reported that the app was helpful (40.0% agreed and 56.0% strongly agreed) and easy to use (40.0% agreed and 58.0% strongly agreed; [Table 4](#)).

In multivariate regression analyses, engagement with the app(s) ($P<.001$) was positively associated with the reported changes in the theory items after controlling for other variables in the model ([Table 5](#)). In the multivariate regression model with perceived behavior change as the dependent variable ([Table 6](#)), theory was positively associated ($P<.001$) as were engagement ($P=.004$), frequency of use of the app ($P=.01$), and income ($P=.049$) after controlling for other variables in the model.

Table 4. Summary of participant responses to engagement questions.

Question ^a	Response (N=150)				
	Strongly disagree n (%)	Disagree n (%)	Neutral n (%)	Agree n (%)	Strongly agree n (%)
The app was helpful.	0 (0.0)	1 (0.7)	5 (3.3)	60 (40.0)	84 (56.0)
The app was easy to use.	0 (0.0)	0 (0.0)	3 (2.0)	60 (40.0)	87 (58.0)
I enjoyed using the app.	0 (0.0)	3 (2.0)	12 (8.0)	50 (33.3)	85 (56.7)
I liked the app.	0 (0.0)	1 (0.7)	8 (5.3)	55 (36.7)	86 (57.3)
I would recommend the app to others.	0 (0.0)	2 (1.3)	15 (10.0)	53 (35.3)	80 (53.3)

^aAll engagement questions in the survey were preceded by the following statement: considering the mental and emotional health app(s) that you have used in the past 6 months...

Table 5. Regression to predict theory.

Variable	Standardized coefficient	Standard error	$P> t $	95% CI
App engagement	0.87	0.12	.001	0.63-1.11
Price of app	0.04	0.17	.81	-0.29 to 0.37
Frequency of app use	0.15	0.16	.36	-0.17 to 0.48
Female	1.00	0.15	.50	-0.19 to 0.39
Age	-0.06	0.10	.55	-0.25 to 0.13
Income	-0.03	0.03	.27	-0.08 to 0.02
_cons ^a	0.95	0.43	.03	0.11-1.80

^a_cons: constant term.

Table 6. Regression to predict behavior change.

Variable	Standardized coefficient	Standard error	$P> t $	95% CI
Theory	0.27	0.04	0.001	0.20-0.35
App engagement	0.2	0.07	0.004	0.07-0.33
Price of app	0.07	0.08	0.39	-0.09 to 0.23
Frequency of app use	0.2	0.08	0.01	0.04-0.35
Female	-0.12	0.07	0.09	-0.25 to 0.02
Age	0.05	0.05	0.25	-0.04 to 0.15
Income	0.03	0.01	0.049	0.00-0.05
_cons ^a	0.69	0.05	0.001	0.28-1.09

^a_cons: constant term.

Discussion

Principal Findings

The purpose of this study was to examine the extent to which using mental and emotional health apps may be positively associated with key theory-based constructs, which are believed to be associated with changes in behavior. Findings indicated that the mechanisms of health behavior theory were associated with both app use and perceived behavior change. These results suggest that mobile phone apps, which represent a nontraditional, low-cost approach to behavior change, may be a worthwhile tool for addressing mental health in individuals. The key theoretical constructs comprising the composite theory variables in this study were self-efficacy and behavioral intent. Participants reported increases in their motivation, desire to set goals, confidence, control, and intentions to be mentally and emotionally healthy from app use. These findings highlight the importance of increasing an individual's self-efficacy when addressing mental and emotional health. Provided the high rates of mental and emotional health challenges together with the time and resource challenges traditionally required to address these challenges, the impact of apps on self-efficacy is encouraging. Respondents were largely favorable in their assessment of the apps' impact, but some subtle differences emerged. For example, respondents almost universally said that using mental and emotional health apps increased their motivation, confidence, intentions, and attitudes. This is consistent with the findings from other studies showing theory integration into health apps, particularly for apps related to diet and physical activity [22,24]. When comparing constructs, social norms, social support, and feedback were all less impacted by the use of the app.

There are at least two paradigms that can be used to interpret these differences. As it relates to devices and behavior change, Fogg [25] introduced the idea of a functional triad. The triad is a framework that delineates the role of devices in the human-device interaction. According to the triad, devices can be tools, mediums, or social actors. The PRECEDE-PROCEED model is often used to conceptualize change determinants along three dimensions, predisposing, enabling, or reinforcing [24]. Mental and emotional health apps may involve one, two, or all three dimensions. Tools that are akin to predisposing factors

increase the user's capability (eg, knowledge and self-efficacy). Mediums that are similar to enabling factors facilitate an authentic experience for users (eg, assist in tracking). Finally, social actors, akin to reinforcing factors, assist the user in establishing and strengthening relationships (eg, social support and feedback). For example, mental and emotional health apps become tools or predisposing factors when used to diffuse information. Similarly, these apps serve as mediums or enabling factors when used by an individual to collect data regarding one's personal behavior. Apps can be considered social actors or reinforcing factors because they allow users to interact with social support networks or resources. It might be that mental and emotional health apps are currently functioning mostly as tools or predisposing factors, which is the least involved utility of these apps, and perhaps one reason for respondents agreeing that these tools or predisposing constructs were most impacted by using a mental or emotional health app. Social support and feedback are examples of social actor or reinforcing dimensions that were measured in this study. Respondents reported less agreement with respect to the use of a mental or emotional health apps having an impact on these, which relates to findings from other research showing that health and fitness apps are not equipped to address these dimensions [24]. These patterns might also relate to the level of difficulty in integrating theory into the apps of this nature. Building an app to provide users with information to influence knowledge and attitudes may simply be easier than building an app that provides feedback and facilitates social support.

As a secondary purpose of this study, there was a positive association between the level of engagement with the app and the impact on theory items. This finding is even more important, given the positive association between reporting an impact on the mechanisms of theory and reporting a change in actual behavior. This finding provides support for other studies that are focusing on theory's potential for changing diet and physical activity behaviors but for which no connection with behavior was established [22,23]. This may also provide general support for a more systematic attempt by developers to influence constructs that are believed to lead to health behavior change. Although this challenge has been noted previously [23], findings from this study may renew efforts to promote such an effort. Provided that mental and emotional health apps are anchored to theoretical constructs known to improve health behaviors

and behavioral intentions generally, this medium has great value for individuals suffering from mental and emotional distress.

Comparison With Prior Work

Recent and emerging research has helped to demonstrate that health-related apps can facilitate behavior changes. One study found that DBT Coach, a software app for a mobile phone, decreased users' depression and general distress by providing coaching against maladaptive behavior and improving adaptive coping behaviors [21]. Another study reported that users of the Mobilyze app showed considerable improvement in self-reported depressive symptoms and interview measures of depressive symptoms. Mobilyze users also had decreased comorbid anxiety symptoms and became less likely to meet criteria for major depressive disorder diagnosis [14]. Additional mental and emotional self-help apps, including Get Happy Program [26], CopeSmart [27], Mobile Type, and Mobile Stress Management [9], have also shown significant potential for improving mental and emotional health. This study helps to move this body of research forward by identifying at least some of the mechanisms by which these changes occur. Findings from this study may lead to an increase in the commitment to address health behavior theory constructs to influence mental and emotional health outcomes.

Errors and Limitations

The study findings should be interpreted in the context of its potential errors and limitations. Survey items were not divided or grouped together according to specific theories or health behaviors until the analysis phase of the study. Better planning may have resulted in more questions to evaluate additional mechanisms by which the apps impact behavior. Consequently, this study only explored mechanisms from two health behavior theories—SCT and TPB. Additionally, the study only included four questions to evaluate perceived behavior change from app use. Initially, forced responses on the survey questions were not all functional, so only 150 of the 171 participants who qualified for the survey completed all questions. This error resulted in a smaller sample size than desired. Furthermore, participants were originally compensated US \$1 on MTurk for completing the survey, but the survey had to be relaunched at US \$2 because not enough individuals completed the survey.

Several study limitations should be noted. One limitation is that the sample size was only 150 participants. A larger sample size may allow for more reliable data and greater population generalizability. Furthermore, survey method designs are inherently at risk of bias and inaccuracy as participants may not respond truthfully. Additionally, the study did not present a description of which apps may qualify as a mental or emotional self-help app. Consequently, there was a range of app classification types that participants subjectively determined as mental or emotional app. For example, participants may have used a meditation, prayer, faith-based scripture, medication adherence, mood tracker, stress management, or positive

affirmation app. One survey question asked the participants which mental or emotional self-help apps they used in the past 6 months, but we did not research each survey response to verify whether their response included a real app available for download on mobile phones. Another limitation is the inherent demographic bias from using MTurk to gather survey responses. MTurk workers are a relatively homogenous group of individuals with a majority being white, middle-aged, and socioeconomically disadvantaged. The lack of demographic variability limits the generalizability of the data to the larger American population.

Conclusions

This study examined the theoretical mechanisms by which mental and emotional self-help apps are associated with behavior. Participants reported that app use increased their motivation, desire to set goals, confidence, control, and intentions to be mentally and emotionally healthy. This increase in perceptions, beliefs, and attitudes surrounding their mental and emotional health was considerably associated with perceived change in behavior. These findings highlight the importance of increasing an individual's self-efficacy when addressing mental and emotional health. Furthermore, there was a positive association between the level of engagement with the apps and the impact on theory items. Understanding how these self-help apps promote behavior change informs app producers and health providers to more effectively change the behavior and health of their clients. Future research should study which classification types of mental and emotional self-help apps (eg, meditation, prayer, faith-based scripture, medication adherence, mood tracker, stress management, or positive affirmation) are most effective in improving health outcomes and promoting mental wellness. Further research should use other health behavior theories apart from the two theories explored in this paper (SCT and TPB) to further explore the mechanisms by which behavior change occurs. To improve the validity of this study, future research may use objective indicators instead of perceived behavior change to more directly study behavior change. Specific apps should be researched to determine the ones that are most effective in reducing mental illness and improving mental and emotional wellness. Future efforts should consider the value of impacting key theoretical constructs when designing mental and emotional health apps. As this study revealed that social support and feedback were all less impacted by the use of the apps, future apps should be designed to impact social support and feedback as additional mechanisms to change behavior. As apps are evaluated and additional theory-based apps are created, cost-effective self-help apps may become common preventative and treatment tools in the mental health field.

Understanding whether these self-help apps are associated with health behaviors will inform app producers and health providers to more effectively address health behaviors of clients.

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Conflicts of Interest

None declared.

References

1. WHO. 2014 Aug. Mental health: a state of well-being URL: http://www.who.int/features/factfiles/mental_health/en/ [accessed 2017-09-27] [WebCite Cache ID 6tnPwAnEB]
2. NIMH. 2014. Any Mental Illness (AMI) Among U.S. Adults URL: <https://www.nimh.nih.gov/health/statistics/prevalence/any-mental-illness-ami-among-us-adults.shtml> [accessed 2017-09-27] [WebCite Cache ID 6tnQ7U6Nq]
3. ADAA. ADAA. 2016. Facts and Statistics URL: <https://http://www.adaa.org/about-adaa/press-room/facts-statistics> [accessed 2017-09-27] [WebCite Cache ID 6tnQIDqCd]
4. Lennon JL. The use of the health belief model in dengue health education. *Dengue Bulletin* 2005;29:217-219.
5. Demyttenaere K, Bruffaerts R, Posada-Villa J, Gasquet I, Kovess V, Lepine JP, WHO World Mental Health Survey Consortium. Prevalence, severity, and unmet need for treatment of mental disorders in the World Health Organization World Mental Health Surveys. *JAMA* 2004 Jun 2;291(21):2581-2590. [doi: [10.1001/jama.291.21.2581](https://doi.org/10.1001/jama.291.21.2581)] [Medline: [15173149](https://pubmed.ncbi.nlm.nih.gov/15173149/)]
6. Valiunas A. The science of self-help. *The New Atlantis* 2010;28:85-100.
7. Zhang X. Exploring the patterns and determinants of the global mobile divide. *Telematics and Informatics* 2017 Feb;34(1):438-449. [doi: [10.1016/j.tele.2016.06.010](https://doi.org/10.1016/j.tele.2016.06.010)]
8. ComScore. 2016 Feb 04. comScore Reports December 2015 U.S. Smartphone Subscriber Market Share URL: http://www.comscore.com/Insights/Rankings/comScore-Reports-December-2015-US-Smartphone-Subscriber-Market-Share?cs_edgescape_cc=US [accessed 2017-09-27] [WebCite Cache ID 6tnQQG325]
9. Donker T, Petrie K, Proudfoot J, Clarke J, Birch MR, Christensen H. Smartphones for smarter delivery of mental health programs: a systematic review. *J Med Internet Res* 2013 Nov 15;15(11):e247 [FREE Full text] [doi: [10.2196/jmir.2791](https://doi.org/10.2196/jmir.2791)] [Medline: [24240579](https://pubmed.ncbi.nlm.nih.gov/24240579/)]
10. Proudfoot J, Parker G, Hadzi Pavlovic D, Manicavasagar V, Adler E, Whitton A. Community attitudes to the appropriation of mobile phones for monitoring and managing depression, anxiety, and stress. *J Med Internet Res* 2010 Dec 19;12(5):e64 [FREE Full text] [doi: [10.2196/jmir.1475](https://doi.org/10.2196/jmir.1475)] [Medline: [21169174](https://pubmed.ncbi.nlm.nih.gov/21169174/)]
11. Wendel S. Designing for Behavior Change: Applying Psychology and Behavioral Economics. Sebastopol, CA, US: O'Reilly Media; Nov 2013.
12. Watts SE, Andrews G. Internet access is NOT restricted globally to high income countries: so why are evidenced based prevention and treatment programs for mental disorders so rare? *Asian J Psychiatr* 2014 Aug;10:71-74. [doi: [10.1016/j.ajp.2014.06.007](https://doi.org/10.1016/j.ajp.2014.06.007)] [Medline: [25042956](https://pubmed.ncbi.nlm.nih.gov/25042956/)]
13. Simon GE, Ludman EJ. It's time for disruptive innovation in psychotherapy. *Lancet* 2009 Aug 22;374(9690):594-595. [doi: [10.1016/S0140-6736\(09\)61415-X](https://doi.org/10.1016/S0140-6736(09)61415-X)] [Medline: [19699995](https://pubmed.ncbi.nlm.nih.gov/19699995/)]
14. Burns MN, Begale M, Duffecy J, Gergle D, Karr CJ, Giangrande E, et al. Harnessing context sensing to develop a mobile intervention for depression. *J Med Internet Res* 2011 Aug 12;13(3):e55 [FREE Full text] [doi: [10.2196/jmir.1838](https://doi.org/10.2196/jmir.1838)] [Medline: [21840837](https://pubmed.ncbi.nlm.nih.gov/21840837/)]
15. Bakker D, Kazantzis N, Rickwood D, Rickard N. Mental health smartphone apps: review and evidence-based recommendations for future developments. *JMIR Ment Health* 2016 Mar 01;3(1):e7 [FREE Full text] [doi: [10.2196/mental.4984](https://doi.org/10.2196/mental.4984)] [Medline: [26932350](https://pubmed.ncbi.nlm.nih.gov/26932350/)]
16. Kok G, Schaalma H, Ruiter RA, van Empelen P, Brug J. Intervention mapping: protocol for applying health psychology theory to prevention programmes. *J Health Psychol* 2004 Jan;9(1):85-98. [doi: [10.1177/1359105304038379](https://doi.org/10.1177/1359105304038379)] [Medline: [14683571](https://pubmed.ncbi.nlm.nih.gov/14683571/)]
17. Bandura A. Self-efficacy: The Exercise of Control. New York, NY: Worth Publishers; 1997.
18. Bandura A. The primacy of self-regulation in health promotion. *Appl Psychol* 2005 Apr;54(2):245-254.
19. Ajzen I. From Intentions to Actions: A Theory of Planned Behavior. In: Kuhl J, Beckmann J, editors. *Action Control: From Cognition to Behavior*. Berlin Heidelberg: Springer; 1985:11-39.
20. Ajzen I. People.UMass. Behavioral Interventions Based on the Theory of Planned Behavior URL: <https://people.umass.edu/ajzen/pdf/tpb.intervention.pdf> [accessed 2017-09-27] [WebCite Cache ID 6tnQn7499]
21. Rizvi SL, Dimeff LA, Skutch J, Carroll D, Linehan MM. A pilot study of the DBT coach: an interactive mobile phone application for individuals with borderline personality disorder and substance use disorder. *Behav Ther* 2011 Dec;42(4):589-600. [doi: [10.1016/j.beth.2011.01.003](https://doi.org/10.1016/j.beth.2011.01.003)] [Medline: [22035988](https://pubmed.ncbi.nlm.nih.gov/22035988/)]
22. West JH, Cougar Hall P, Arredondo V, Berrett B, Guerra B, Farrell J. Health behavior theories in diet apps. *J Consum Health Internet* 2013;17(1):10-24.
23. Cowan LT, Van Wagenen SA, Brown BA, Hedin RJ, Seino-Stephan Y, Hall PC, et al. Apps of steel: are exercise apps providing consumers with realistic expectations?: a content analysis of exercise apps for presence of behavior change theory. *Health Educ Behav* 2013 Apr;40(2):133-139. [doi: [10.1177/1090198112452126](https://doi.org/10.1177/1090198112452126)] [Medline: [22991048](https://pubmed.ncbi.nlm.nih.gov/22991048/)]

24. West JH, Hall PC, Hanson CL, Barnes MD, Giraud-Carrier C, Barrett J. There's an app for that: content analysis of paid health and fitness apps. *J Med Internet Res* 2012 May 14;14(3):e72 [[FREE Full text](#)] [doi: [10.2196/jmir.1977](#)] [Medline: [22584372](#)]
25. Fogg BJ. *Persuasive Technology: Using Computers to Change What We Think and Do*. Waltham, MA: Morgan Kaufmann; 2002.
26. Watts S, Mackenzie A, Thomas C, Griskaitis A, Mewton L, Williams A, et al. CBT for Depression: a pilot RCT comparing mobile phone vs. computer. *BMC Psychiatry* 2013;13:49.
27. Kenny R, Dooley B, Fitzgerald A. Feasibility of "CopeSmart": a telemental health app for adolescents. *JMIR Ment Health* 2015 Aug 10;2(3):e22 [[FREE Full text](#)] [doi: [10.2196/mental.4370](#)] [Medline: [26552425](#)]

Abbreviations

GED: General Educational Development

HBM: Health Belief Model

MTurk: Mechanical Turk

SCT: social cognitive theory

TPB: theory of planned behavior

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Original Paper

Use of the Internet and Mobile Phones for Self-Management of Severe Mental Health Problems: Qualitative Study of Staff Views

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Abstract

Background: Researchers are currently investigating the feasibility, acceptability, and efficacy of digital health interventions for people who experience severe mental health problems such as psychosis and bipolar disorder. Although the acceptability of digital health interventions for severe mental health problems appears to be relatively high and some people report successfully using the Internet and mobile phones to manage their mental health, the attitudes of mental health care staff toward such approaches have yet to be considered.

Objective: The aim of this study was to explore mental health care staff experiences of clients with severe mental health problems engaging with the Internet and mobile phones to self-manage their mental health and their views toward these behaviors. The study also sought to examine the opinions expressed by mental health care staff toward digital health interventions for severe mental health problems to identify potential facilitators and barriers to implementation.

Methods: Four focus groups were conducted with 20 staff working in mental health care services in the North West of the England using a topic guide. Focus groups involved 12 staff working in secondary care psychological services (7 participants in focus group 1 and 5 participants in focus group 4), 4 staff working in a rehabilitation unit (focus group 2), and 4 staff working in a community mental health team (focus group 3). Focus groups were transcribed verbatim, and transcripts were analyzed thematically to identify key themes that emerged from the data.

Results: Four overarching themes, two with associated subthemes, were identified: (1) staff have conflicting views about the pros and cons of using Web-based resources and digital health interventions to manage mental health; (2) digital health interventions could increase access to mental health support options for severe mental health problems but may perpetuate the digital divide; (3) digital health interventions' impact on staff roles and responsibilities; and (4) digital health interventions should be used to enhance, not replace, face-to-face support.

Conclusions: This study is the first, to our knowledge, to qualitatively explore the experiences and attitudes of mental health care staff toward individuals with severe mental health problems using the Internet, mobile phones, and digital health interventions to self-manage their mental health. Understanding the positive and negative experiences and views shared by staff toward both current and potential digital health intervention use has enabled the identification of several considerations for implementation. Additionally, the findings suggest mental health care staff need clear guidance and training in relation to their responsibilities in recommending reputable and secure websites, forums, and digital health interventions and in how to manage professional

boundaries on the Internet. Overall, the study highlights that digital health interventions could be well received by staff working in mental health services but importantly, such management options must be presented to frontline staff as an avenue to enhance care and extend choice, rather than as a method to reduce costs.

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KEYWORDS

psychosis; bipolar disorder; mHealth; eHealth; clinicians; mobile phone; Internet; intervention

Introduction

Mobile phone and Web-based psychological interventions, or digital health interventions, are increasingly being developed for people who experience mental health problems. Indeed, the National Institute for Health and Care Excellence has recommended the provision of computerized cognitive behavioral therapy (cCBT) for the treatment of depression and anxiety [1]. However, the Five Year Forward View, an initiative by the UK National Health Service (NHS) aiming to reform current services and transform care, highlights the current limited use of technology within services and sets out the priority to harness technology within clinical settings [2]. To this end, the NHS has approved a number of websites and mobile phone apps for a range of mental health problems [3] and has recently launched an early version of the NHS Digital Apps Library that catalogues a number of apps aimed to help people manage their health care needs [4].

Some individuals who experience severe mental health problems such as psychosis and bipolar disorder report already using the Internet and mobile phones to self-manage their mental health. For example, some use the Internet to search for health-related information such as medication, diagnoses, and symptoms and to discuss their mental health on the Internet with others [5-10]. Additionally, staff working in mental health care services have reported largely neutral or positive attitudes toward the use of digital health interventions for the management of mental health problems [11-17] but are cautious about using digital health interventions for severe and complex cases [15-17]. Specifically, many believe that digital health interventions could improve access to psychological interventions, increase comfort in disclosing information, normalize experiences and reduce stigma, monitor clients' symptoms, evaluate therapeutic outcomes, and promote help-seeking behaviors [14-17]. However, staff also have numerous concerns about digital health interventions, including the perceived inferiority in comparison to face-to-face support, limited guidance with regard to efficacy and credibility, ethical concerns if clients report that they themselves or other people are at risk, potential breaches of data confidentiality, and limits in clients' technology access and skills [13,15-17].

An evidence base is emerging regarding current Internet and mobile phone use for self-management reported by people with severe mental health problems, but there is a paucity of research examining the experiences and views of staff toward these behaviors. Additionally, although several studies have explored service user views regarding the hypothetical acceptability of digital health interventions for severe mental health problems (ie, the acceptability before or without receiving an intervention)

[18], much of the current research investigating staff views is based on cCBT for mild-to-moderate mental health problems, rather than digital health interventions more generally for severe mental health problems. Digital health interventions based on approaches such as CBT [19], psychoeducation [20-22], and mindfulness [23] are being offered in a research context for people with severe mental health problems. However, to successfully implement digital health interventions, it is important to understand the views and concerns of staff who will be required to promote and support their use [24,25]. Therefore, this study aimed to (1) investigate the experiences and views of mental health care staff toward clients with severe mental health problems using the Internet and mobile phones to manage their mental health and (2) explore opinions expressed by mental health care staff (hypothetical acceptability) toward digital health interventions for severe mental health problems to identify the potential facilitators and barriers to the implementation of digital health interventions in mental health care services.

Methods

Design

Focus groups were used as a convenient way to explore a range of staff views while minimizing the burden of participation. Through the process of group discussion, they also facilitated the development and elaboration of ideas that may not have been previously articulated [26].

Sampling and Recruitment

Participants comprised mental health care staff working in the NHS based in the North West of England and recruited via convenience sampling. Service leads working in mental health services were approached via email by the researchers enquiring as to whether they would be open to presenting their staff with the opportunity of participating in a focus group. The researcher then liaised with the service leads to arrange the focus groups with staff who had expressed an interest in participating. The lead researcher had no established relationship with any of the participants before the start of the study.

Procedure

Four focus groups were held across three mental health trusts in the North West of England from April 2016 to September 2016. Focus groups involved staff working in psychological services, a community mental health team, and a rehabilitation unit and lasted between 30 and 60 min. Before the audio-recording of the focus groups, participants were presented with consent forms and a brief demographics and technology ownership questionnaire to complete. NB conducted all focus

groups using a topic guide ([Multimedia Appendix 1](#)) in a private room in participants' workplaces. Questioning focused on two key areas: (1) staffs' experiences of clients' use of the Internet and mobile phones and (2) views about the acceptability of implementing digital health interventions for severe mental health problems in mental health care services. NB kept field notes throughout focus groups, completed a reflective journal, and reviewed the topic guide and transcripts after each focus group to identify any additional areas of discussion that naturally arose.

Data Analysis

Data were analyzed thematically to understand common themes arising in response to the research questions [27]. After the focus groups were completed and transcribed, NB (PhD student, psychology) read each transcript repeatedly for data familiarization and initially coded the transcripts in a cyclical process, returning to previous transcripts when new codes emerged. The other members of the research team (academic clinical psychologists SB and FL) also independently read and assigned codes to the first group transcript, and the team met to discuss and compare codes and develop an initial coding scheme. NB continued to develop this coding framework by analyzing the remaining transcripts and started to draw out preliminary subthemes emerging from these codes. Further team discussion was used to refine and create a final set of themes that reflected participants' views and experiences across all focus groups. These themes were presented to some of the group participants, which helped to refine the way in which the themes were presented.

Reflexivity

NB is a PhD student investigating how digital health interventions could be used to support people with severe mental health problems. SB and FL are academic clinical psychologists who are principal investigators on clinical trials implementing digital health interventions for this population and have extensive experience in conducting and supervising qualitative studies. It is important to acknowledge that these experiences may affect the analysis and interpretation of the data, so several steps were taken to minimize the likelihood of this occurring. First, NB was careful to present the research questions in an open and neutral way with no indication of the views of the research team and encouraging people to explore the full range of views. Additionally, questions surrounding the potential benefits and drawbacks of digital health interventions were initially phrased broadly to ask staff about their *thoughts* surrounding digital health interventions, and the terms *benefits* and *drawbacks* were only used later for further probing. Finally, NB kept a reflective journal to consider how staff responses in each focus group affected her own views about digital health interventions throughout data collection, analysis, and reporting and tried to take this into consideration when analyzing the data.

Ethical Considerations

The study received ethical approval from NHS Cambridge South Research Ethics Committee (ref: 16/EE/0059). All participants provided verbal and written consent for participation, audio-recording of focus groups, and the use of direct quotations in publications resulting from the research. Participants did not receive any financial or professional incentives for participation.

Results

Participant Characteristics

A total of 20 mental health care professionals were recruited across four focus groups. A summary of participant characteristics is presented in [Table 1](#).

Thematic Analysis

Thematic analysis of focus group data generated four key themes and five subthemes: (1) staff have conflicting views about the pros and cons of using Web-based resources and digital health interventions to manage mental health; (2) digital health interventions could increase access to mental health support options for severe mental health problems but may perpetuate the digital divide; (3) digital health interventions impact on staff roles and responsibilities; and (4) digital health interventions should be used to enhance, not replace, face-to-face support. A diagram of the themes and associated subthemes is presented in [Figure 1](#).

Theme 1: Staff Have Conflicting Views About the Pros and Cons of Using Web-Based Resources and Digital Health Interventions to Manage Mental Health

Subtheme 1: Pros and Cons of Individuals Searching the Internet for Information About Mental Health

Across all focus groups, staff welcomed clients searching the Internet for information about mental health problems because it allowed people to access potentially helpful information at any time and in any place, without the need to ask staff:

It's instant for them at a time when they're needing answers...It's there at their fingertips. They don't have to wait...until the clinic opens to speak to the CPN. [Participant 15, Focus group 3, Community mental health team]

Indeed, several participants in both focus groups in secondary care psychological services described instances where clients had gone to extensive lengths to educate themselves about their mental health using information that had been retrieved on the Internet. This had sometimes been beneficial before beginning therapy:

...she'd done a lot of research herself...so when she came into therapy she was in a very different place than a lot of people because she kind of already started herself. [Participant 20, Focus group 4, Secondary care psychological services]

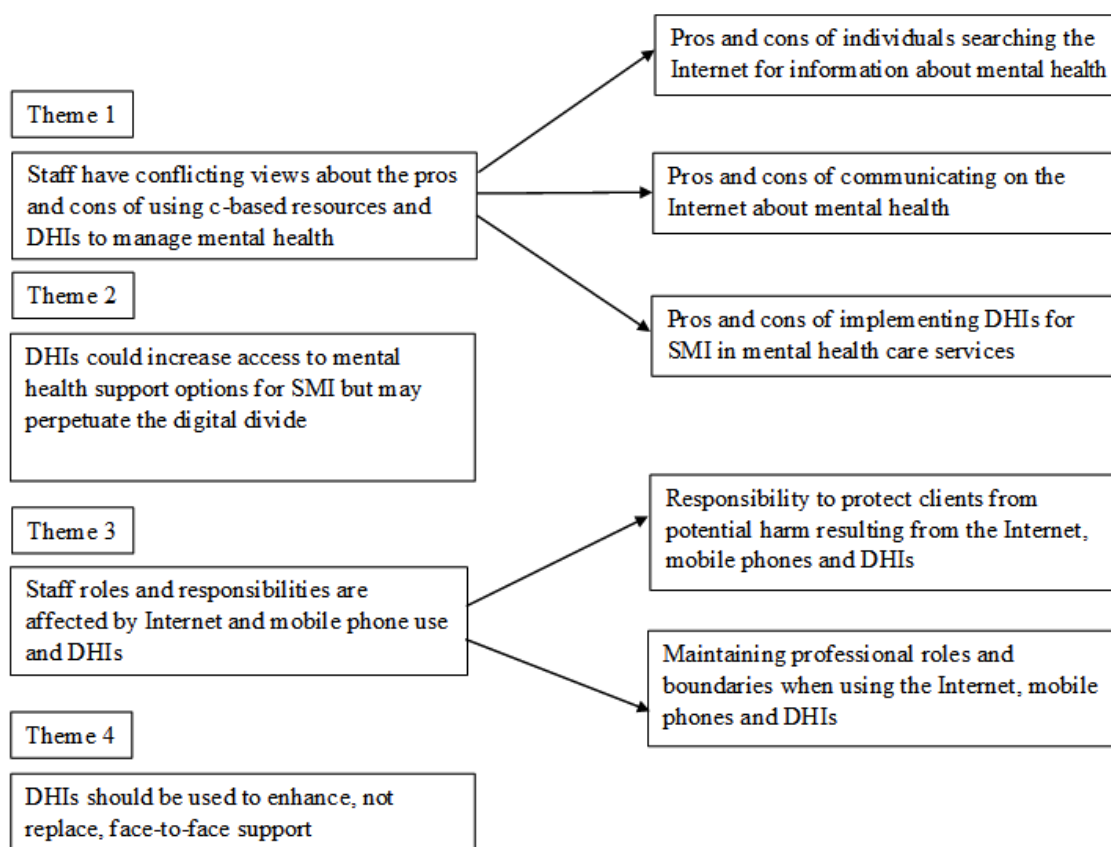
Table 1. Summary of participant characteristics (N=20).

Demographic information	n (% or range)
Overall sample	
Mean age in years	42.35 (27-62)
Gender	
Female	16 (80%)
Male	4 (20%)
Ethnicity	
White British	16 (80%)
White Irish	2 (10%)
British Pakistani	1 (5%)
White other	1 (5%)
Job role and technology ownership information	
Focus group 1 (secondary care psychological services)	
Job title	
Clinical psychologist	7 (100%)
Mean time working in mental health services, years	14.67 (12-21)
Mean technology comfort level	5.5 (4-6) ^a
Mobile phone ownership	7 (100%)
Smartphone ownership	7 (100%)
Tablet computer ownership	4 (57%)
Social media use	6 (86%)
Focus group 2 (rehabilitation unit)	
Job title	
Staff nurse	3 (75%)
Support worker	1 (25%)
Mean time working in mental health services, years	14.5 (5.5-19)
Mean technology comfort level	4.25 (1-6) ^a
Mobile phone ownership	4 (100%)
Smartphone ownership	3 (75%)
Tablet computer ownership	3 (75%)
Social media use	3 (75%)
Focus group 3 (community mental health team)	
Job title	
Occupational therapist	2 (50%)
Clinical practice nurse	1 (25%)
Community team lead	1 (25%)
Mean time working in mental health services (range)	12.75 (5-16)
Mean technology comfort level	5.75 (5-6) ^a
Mobile phone ownership	4 (100%)
Smartphone ownership	4 (100%)
Tablet computer ownership	4 (100%)
Social media use	4 (100%)

Demographic information	n (% or range)
Focus group 4 (secondary care psychological services)	
Job title	
Clinical psychologist	3 (75%)
Psychological therapist	2 (25%)
Mean time working in mental health services	19.6 (15-25.92)
Mean technology comfort level	5 (5-5) ^a
Mobile phone ownership	5 (100%)
Smartphone ownership	5 (100%)
Tablet ownership	4 (80%)
Social media use	3 (60%)

^a1=extremely uncomfortable and 6=extremely comfortable.

Figure 1. Diagram of themes.



Additionally, several clinical psychologists and psychotherapists in focus groups 1 and 4 had used Web-based resources within sessions with clients, which had been a valuable component of the session and helped normalize experiences:

There are some good YouTube videos...around compassion focussed therapy...we've done that together...so I guess if it's done in a clinical setting in a careful way it's been massively useful...in terms of normalising particularly and de-shaming. [Participant 6, Focus group 1, Secondary care psychological services]

Across all focus groups, staff also revealed that they searched the Internet for information about their own mental and physical health care needs. Consequently, they understood and related to clients' information-seeking and were generally willing to embrace, encourage, and, if needed, guide this behavior. Indeed, staff expressed that they would specifically want to see psychoeducation included within future digital health interventions. These comments reflect current Internet information-seeking behaviors by both staff and clients alike and suggest that staff would be positive about the provision of psychoeducational material in digital health interventions.

Although many of the experiences that staff shared were positive, concerns were raised about the abundance of unregulated Web-based material relating to mental health. Specifically, Web-based information could be biased, inaccurate, and misleading and, in all focus groups, staff described situations where clients had engaged in what they perceived as harmful or damaging behaviors as a direct result of reading information on unregulated websites:

I had a client in the past who bought... something...from America. He thought it was gonna cure his mental health problem...he ended up on the ward...but that was his belief that he read it on the Internet that if he got this substance it would make him better. [Participant 17, Focus group 4, Secondary care psychological services]

Concerns were also expressed about Web-based information surrounding topics such as religion, conspiracy theories, and antipsychiatry messages. These were perceived as having the potential to reduce engagement with services and medication adherence and fuel distressing beliefs often associated with severe mental health problems:

...you can find information saying all psychiatry is the work of Satan and you can find sites that say don't see a psychiatrist... [Participant 9, Focus group 2, Rehabilitation unit]

It can feed your delusions. [Participant 11, Focus group 2, Rehabilitation unit]

The term *trusted websites* was, therefore, mentioned frequently, with specific examples of charitable and national organizations. Private company websites such as pharmaceutical companies, private counseling and psychotherapy services, and unmoderated chat rooms were viewed as untrustworthy sources of information. Although staff noted that they themselves actively engaged in Web-based information-seeking, they had concerns about the vulnerability of clients. Specifically, staff felt that they had the training and experience to filter potentially biased or inaccurate information but that the general public (including clients) may not have such capabilities. Therefore, staff were keen to see the promotion of greater awareness regarding the potential dangers of unregulated websites.

In summary, staff expressed many positive and negative experiences of clients searching the Internet for information about mental health. Specifically, Web-based information had been a helpful resource before, and in-conjunction with, face-to-face therapy and could be accessed at any time clients needed information. However, negative experiences of clients accessing unhelpful Web-based content had led to concerns regarding the quality and trustworthiness of Web-based information.

Subtheme 2: Pros and Cons of Communicating on the Internet About Mental Health

Participants detailed many benefits of interacting with others via the Internet. In particular, staff in all groups had experienced clients' receiving helpful support from peers via Web-based forums and social media websites. The anonymous nature of forums and the ability to communicate with others who had

faced similar experiences were viewed as potential reasons why people may feel more comfortable expressing themselves via these platforms in comparison to face-to-face environments:

A lot of the forums you have pseudonyms and stuff don't you...so you do feel more open and able to express yourself and your opinions more freely. [Participant 6, Focus group 1, Secondary care psychological services]

Social media websites and forums were also viewed as a place where individuals could vent and feel like they had spoken with another person, even if they do not have a close social network, are unable to leave the house, or not comfortable speaking with others face-to-face:

People who struggle to relate to other people...they don't have to leave their comfort zone in a way to almost be with people. It's kind of an interim position perhaps. [Participant 18, Focus group 4, Secondary care psychological services]

The positive experiences of social media websites and forums reflect the perceived utility of these resources as pathways to receive peer support and to connect with others with a shared understanding.

Staff in all focus groups were, however, concerned that discussing mental health problems on forums and social media websites could lead to individuals being bullied, trolled, or taken advantage of by others. One participant working in secondary care psychological services speculated whether the occurrence of negative Web-based behaviors such as cyberbullying could be because of the faceless nature of forums and some social media websites, which could lead to people not seeing the distress that negative comments can cause. Other participants acknowledged this viewpoint and agreed that clients they had seen had made similar observations:

Is there something about the internet though that can attract some negativity that people wouldn't say in real life to people...you can sort of not see the impact of what you say... [Participant 5, Focus group 1, Secondary care psychological services]

Staff across groups also described instances in which they felt clients had disclosed what they believed had been too much personal information on the Internet. They felt that such disclosures had the potential to cause embarrassment, distress, and lead to others targeting and taking advantage of the person who had posted this information. Of particular concern to all participants was that the Internet could increase opportunities to communicate with others in ways that were seen to enhance risk of self-harm and suicide:

We...had a bunch of girls who were communicating via Facebook...they all had a suicide pact together... [Participant 13, Focus group 3, Community mental health team]

Staff suggested strategies that could be used to manage this, such as ensuring that forums are moderated. Staff working in a community mental health team even suggested that NHS Trusts should offer their own moderated forums for clients to

engage with, reflecting the level of importance staff placed on forum provision and moderation.

In summary, staff believed the opportunity to connect with others with a shared understanding and the potential for accessible peer support was a benefit of Web-based communication and could be incorporated into future digital health interventions. However, staff had experienced or were concerned about the potential drawbacks of cyberbullying and trolling, overdisclosures, and Web-based communication about engaging in suicidal behaviors.

Subtheme 3: Pros and Cons of Implementing Digital Health Interventions for Severe Mental Health Problems in Mental Health Care Services

The anonymous nature of digital health interventions was viewed as beneficial in comparison to face-to-face support because there may be times and situations where individuals feel more comfortable disclosing sensitive information to a digital device, rather than another person. Additionally, staff in the community mental health team and secondary care mental health services observed that clients could sometimes be reluctant to complete paper-based exercises because of concerns about others finding these materials. Therefore, people may feel more comfortable using digital health interventions because of the increased privacy and reduced risk of others being able to find hard copies of therapy materials:

We've had clients who have wanted to record but are fearful of somebody finding paper so I think it could give some sort of privacy confidentiality... [Participant 20, Focus group 4, Secondary care psychological services]

However, staff in all focus groups raised fears that companies or individuals could be able to hack digital devices and obtain sensitive user information and responses. These concerns reflect the dilemma that although digital health interventions may increase privacy, this may still be limited because of the potential security issues associated with using technology.

Staff were also asked about the use of digital devices to monitor thoughts, feelings, and experiences in-the-moment. Responses to symptom monitoring via apps were largely positive and staff across groups identified times when clients had found it difficult to remember how they had been feeling since the last session or appointment they attended. Therefore, digital devices were viewed as a potential method for people to record symptoms and experiences in the moment, offering the opportunity to discuss and reflect on over time. Indeed, one staff member specifically searched for an app for a client to help identify triggers and patterns:

...I was sort of looking at that as a way of getting her to monitor her moods over a period to try to understand a bit better the pattern of what was happening with her and why. [Participant 14, Focus group 3, Community mental health team]

However, staff working in secondary care psychological services and a community mental health team felt continuous monitoring may become tiresome and could lead people to unhelpfully dwell on experiences. Therefore, the suggestion was made that

monitoring via digital devices should also involve recording positive events for people to identify, recognize, and acknowledge.

Across all focus groups, digital health interventions were seen as useful for some people because it may be easier for them to be honest about their feelings when asked on a faceless device rather than by another person. Conversely, concerns were raised that the faceless nature of digital health interventions may lead to people underreporting the severity of their symptoms to reduce the levels of care they receive, although others might exaggerate symptoms to increase care:

...you don't know whether that person's racking it up... [Participant 9, Rehabilitation unit]

...it could be like I have no symptoms no problems right now, can I get out of hospital now? [Participant 11, Rehabilitation unit]

Staff responses regarding the potential benefits and concerns about digital health interventions reflect the mixed views toward this approach. Specifically, concerns regarding data confidentiality and truthfulness of responses need to be addressed to ensure that staff feel comfortable recommending clients to receive digital health interventions.

Theme 2: Digital Health Interventions Could Increase Access to Mental Health Support Options for Severe Mental Health Problems but May Perpetuate the Digital Divide

Regular Internet and mobile phone use was viewed as the norm, particularly for the younger generation and, therefore, seen as a mechanism to improve access to mental health support. However, there was the recognition that many people do not have the technology skills required to use digital health interventions. Staff working in a residential unit noted that many clients showed very limited technology skills and feared this would pose a significant barrier to providing digital health interventions within services, thus perpetuating the digital divide:

I do get asked quite a lot. I've got a phone I don't know how to send a text, can you send a text for me? But it's that basic... [Participant 8, Focus group 2, Rehabilitation unit]

A technology skills training program was suggested as one possible solution to overcoming this barrier. Staff also revealed that some clients did not have ownership of, or access to, the Internet or mobile phones and even those who did would lose their phones and change numbers frequently. These perceptions led to concerns about how individuals would be able to access digital health interventions. When asked about the NHS supplying devices for digital health interventions, staff in all groups felt the NHS should not provide the required technology because of concerns that tablets and mobile phones may get lost, sold, or damaged. Additionally, staff in a rehabilitation unit and community mental health team believed that other health care needs such as medication should take precedence over the provision of digital health interventions. Conversely, a smaller number of participants within these groups argued that digital health interventions could allow more people to have

access to support options, which could reduce the levels of staff needed and save the NHS money. The reflective journal completed by the interviewer detailed the observation that the NHS funding digital health interventions was a particularly contentious issue and raised animated responses from all participants. A note made in the journal after the focus group with the community mental health team reflects this point:

I am beginning to see a pattern emerging with participants displaying particularly strong views towards the idea of the NHS funding devices. As soon as the digital divide barrier is raised by participants, the view that the NHS should not pay for devices is raised almost immediately. When I then try to explore why, this question is met with polite laughter at the thought that the NHS should make these provisions. [Interviewer, Reflective journal, Focus group 3, Community mental health team]

Therefore, the overall position of staff was that the NHS would not have the resources required to supply the devices needed to deliver digital health interventions.

Although potential issues regarding access and capacity were raised, participants in all focus groups were still able to recall experiences of clients actively engaging with digital devices to self-manage their mental health, including (1) accessing information about medication, diagnoses, symptoms, personal stories, and coping strategies; (2) using forums and social media websites to discuss mental health; (3) using mobile phone cameras to photograph formulations during therapy sessions; (4) using alarms and calendars on mobile phones for appointment and medication reminders; and (5) using apps to receive already existing self-management options.

Findings from this theme suggest the digital divide may be a barrier that prevents mental health care staff from supporting the implementation of digital health interventions into clinical practice. Specifically, concerns were raised by participants about clients' basic technology skills and ownership, and staff questioned how some would be able to afford access to digital health interventions. However, this theme also identified the potential facilitator to implementation that some individuals and staff are already using digital devices for self-management.

Theme 3: Digital Health Interventions' Impact on Staff Roles and Responsibilities

Subtheme 1: Responsibility to Protect Clients From Potential Harm

Staff reported a strong sense of responsibility toward clients engaging with digital devices. This was particularly evident in a focus group involving participants working in a residential unit that was soon to be serviced with a tablet computer for use by clients. Staff felt they would need to limit the amount of time that clients could access the tablet, monitor and control websites and apps visited, and conduct risk assessments before allowing access:

We'd supervise, we'd restrict, we'd filter, we'd feedback... [Participant 11, Focus group 2, Rehabilitation unit]

This perceived responsibility seemed to stem from fearing that clients may use the tablet to access websites containing potentially inappropriate content such as extreme beliefs written by others, antipsychiatry messages, pornographic material, and gambling websites, which may exacerbate symptoms and decrease engagement with services. However, 2 participants noted that, despite these concerns, access should still be provided to ensure that clients are given the opportunity to live autonomous lives. Additionally, prior experiences of clients writing status updates on their social media profiles surrounding delusional beliefs had led to staff in this service needing to intervene by contacting social media websites and restricting client access. Therefore, it was apparent that staff felt they needed to protect some clients' because of their perceived vulnerability to Web-based content and overdisclosure. The reflective journal completed by the interviewer after this focus group detailed the emotional response from participants:

I get the sense that staff feel a huge burden of responsibility towards protecting their clients from harm and take this responsibility incredibly seriously. Staff expressed strong concerns that they would be required to supervise clients using the tablet, when their time would be better spent elsewhere. It felt like staff believed tablets could be positive, but the limited staff resources would mean the provision of tablets at this time would be a burden for staff; not a helpful addition. Whilst conversations remained positive, two participants did raise their voices and spoke emotionally about their fears regarding the additional responsibilities and work pressures associated with the acquisition of a tablet for the unit. [Interviewer, Reflective journal, Focus group 2, Rehabilitation Unit]

Staff participating in the focus groups within secondary care psychological services and a community mental health team also raised concerns about perceived responsibility. For example, several staff said they would recommend reputable websites or apps to clients; however, others were uncomfortable making recommendations because of their responsibility if these resources were unhelpful. Indeed, in one focus group, participants expressed a wish for more detailed information about NHS-endorsed websites and apps that they could recommend to clients:

If I was thinking of an app for a service user, you're a bit uncomfortable recommending... [Participant 14, Focus group 3, Community mental health team]

That's what we were taking about developing weren't we something like a directory of things that we could use... [Participant 15, Focus group 3, Community mental health team]

Additionally, staff in all focus groups were worried about their moral, legal, and professional obligations with regard to assessing risk information such as suicidal ideation and behaviors if clients were monitoring symptoms via digital devices:

...if somebody's really low and threatening suicide, what responsibility do you have for that; what would

be their expectations? [Participant 19, Focus group 4, Secondary care psychological services]

What if it gets to you when you're in an appointment and you can't respond to it until the next day? [Participant 18, Focus group 4, Secondary care psychological services]

A potential solution identified by staff working in secondary care services and a community mental health team was that clients could bring their own symptom reports to appointments. Not only did staff feel this would give clients control over the information they shared, they also felt the level of burden and responsibility on themselves would be minimized. This proposal received particularly strong responses from all participants in these focus groups, as noted in a comment in the reflective journal made by the interviewer after the fourth focus group:

Staff made the really interesting suggestion in the first focus group that rather than receive symptom monitoring responses automatically, they would prefer to receive them from the client to address the power imbalance and minimise the burden associated with automatic responses. Therefore, I decided to explore this further in subsequent focus groups. Participants seemed particularly animated and excited at the potential for technology to be used in this way, which was demonstrated through non-verbal communication such as nodding in agreement and smiling and through verbal acknowledgements of agreement. These positive responses were a stark contrast to the proposal of automatic symptom monitoring, which generated immediate disapproval from all but one participant across groups [Interviewer, Reflective journal, Focus group 4, Secondary care psychological services]

Staff working in secondary care services also described devoting time within sessions to reflect on friendships clients had formed on the Internet over topics such as suicide pacts and self-harm strategies. Additionally, staff in these focus groups had experiences of providing psychoeducation to address misinformation that clients had obtained on the Internet. These past experiences had contributed toward concerns about the availability of unregulated Web-based material and Web-based discussions surrounding mental health.

To summarize, staff recounted several experiences of clients accessing Web-based content that led to negative consequences. Therefore, staff felt paternalistic toward clients' access to this content. Additionally, concerns regarding their own knowledge of websites and apps prevented some from making recommendations and concerns raised about the potential legal, moral, and ethical implications regarding automatic symptom monitoring need to be considered during implementation.

Subtheme 2: Maintaining Professional Roles and Boundaries

Staff were not directly asked about how the Internet and mobile phones affected their professional boundaries with clients; however, the issue naturally arose during all focus groups and was discussed at length. For example, participants reported concerns about clients sending friend requests over social media websites, the availability of personal information on the Internet

that may affect professional relationships with clients, and fears that others may see personal social media posts that they disagree with and subsequently report. For this reason, many staff said they did not use social media websites or limited the amount of personal information they disclosed on the Internet.

Staff in focus group 1 (secondary care psychological services) also detailed situations in which they had used text messages (short message service, SMS) to remind clients about upcoming appointments; although, one participant noted this would only be for the first few appointments to avoid taking too much responsibility. Additionally, there were differing opinions expressed by community mental health team staff regarding sending text messages to clients. Some staff shared their personal mobile phone numbers, with the understanding that there would be limits as to when clients could contact them, whereas others were concerned about breaches in data confidentiality and the risk of clients contacting them outside working hours. Indeed, the focus group transcript and reflective journal maintained by the interviewer revealed a debate between participants regarding the boundary issues associated with staff and client mobile phone communication:

I text a few of mine...I don't do it with everybody but they do respond well to it... [Participant 12, Focus group 3, Community mental health team]

I think you have to be very careful what data is relayed in a text. If it's simple facts of phone numbers or dates and times fine. [Participant 13, Focus group 3, Community mental health team]

...and they have your number then so you don't want to be giving it out to people who might be contacting you. [Participant 11, Focus group 3, Community mental health team]

Monitoring clients' social media profiles for information about daily functioning and risk was unanimously criticized in all groups as a misuse of trust and power, which could potentially damage the therapeutic relationship.

I think it could actually be quite damaging...especially if your clients have quite paranoid thoughts.. [Participant 3, Focus group 1, Secondary care psychological services]

You should respect that everything they want to bring to that session that's what they want to talk about... [Participant 2, Focus group 1, Secondary care psychological services]

The suggestion of staff accessing clients' social media profiles was the topic that seemed to provoke the most emotive responses from participants during focus groups. The interviewer noted in the reflective journals that responses often involved verbal utterances of disagreement such as tutting and shocked laughter and nonverbal cues such as shaking heads and raising eyebrows. The importance participants placed on this topic was also reflected in focus group 1 responses to the interviewer asking how they found taking part in the research:

Fine particularly that social media [question]... [Participant 6, Focus group 1, Secondary care psychological services]

Especially when it comes to researchers who are obviously very very far removed from the real world or (.) working with people with complex mental health problems on therapy you know they might think things are a good idea...so if there's any way that we can kind of you know just inform their thinking a little bit. [Participant 7, Focus group 1, Secondary care psychological services]

Additionally, staff wanted to receive mobile phone symptom assessments directly from clients themselves rather than automatically via an app, and only one participant outwardly expressed the preference for receiving these automatically. This was so clients should take ownership of their data and choose what to share, thus ensuring that staff were not placed in the expert role.

Theme 4: Digital Health Interventions Should Be Used to Enhance, Not Replace, Face-to-Face Support

The self-directed nature of digital health interventions was also viewed by all groups as an empowering way people could take control of, and responsibility for, their own mental health care needs:

It gives them some control doesn't it. It can be empowering... [Participant 16, Focus group 4, Secondary care psychological services]

However, across groups, staff held the unanimous belief that digital health interventions should never be offered as a replacement to face-to-face support. Instead, it was suggested that digital health interventions should be used to extend support options available. For example, one participant suggested that app-based symptom monitoring could be implemented by services as a method for routine outcome monitoring to evaluate changes throughout therapy. Additionally, staff working in secondary care psychological services suggested that digital health interventions could be used at the end of therapy to allow clients to access coping mechanisms and strategies they had developed during sessions:

The ones that do...the best in follow up are the ones that have kept their letters and maps and have kept everything kind of accessible and have continued to use them so I guess that these could be transferable to some sort of technology. [Participant 19, Focus group 4, Secondary care psychological services]

Staff in both focus groups in secondary care services were against the idea of clients using solely self-directed digital health interventions because of fears that individuals would be left alone to deal with any issues that surface. Therefore, they suggested that members of their care team might be able to support clients using digital health interventions during routine home visits. Interestingly, staff working in a community mental health team were willing to support engagement with digital health interventions; one participant suggested that staff could take tablet computers to clients' homes to work through digital health interventions together:

...if there were tablets that could work outside the community that we could show and go through the process to show how simple it (an app) is and what

they could potentially gain from it, I think there could be a definite place for it. [Participant 15, Focus group 3, Community mental health team]

The novel ideas described by participants reflect their overall view that digital health interventions have the potential to be used within existing services, but there was a strong view that digital health interventions should not replace in-person support:

It shouldn't be used to replace face to face, but it should be used to enhance. [Participant 8, Focus group 2, Rehabilitation unit]

Such views seemed to stem from the need for a strong therapeutic relationship in delivering support for people with severe mental health problems, and staff expressed the concern that digital health interventions could not and should not attempt to mimic this relationship:

I've seen computer programmes where it almost tries to offer a therapeutic relationship and it gives kind of fake empathy...It is terrible and it kind of made me a bit annoyed just watching it... [Participant 5, Focus group 1, Secondary care psychological services]

Staff in secondary care psychological services also noted that you can never take a *one size fits all* approach in therapy and that clinical formulations are needed. Therefore, staff were concerned that digital health interventions would not allow the personalization needed to deliver effective therapy. Cautions about digital health interventions were also based on previous experiences of cost-cutting strategies implemented in NHS services, and staff were therefore concerned that digital health interventions may be used as an excuse to reduce staffing costs and care provisions in severe mental health problems:

...it's substituting proper therapy for something that isn't proper therapy and anticipating or hoping that people will get better and it being a way of actually saving money and resources. [Participant 16, Focus group 4, Secondary care psychological services]

The strong position held by staff regarding their views that digital health interventions should never attempt to replace face-to-face care was reflected in the repetitious comments made about this viewpoint. The interviewer noted in the reflective journal that the recurring nature of these comments indicated that this was a significant potential factor affecting the likelihood of implementation:

Following initial reviews of these transcripts, I am yet again struck by the repetitive viewpoint expressed by staff that we should never attempt to replace in-person support with DHIs. During focus groups, it felt like staff could list a significant number of benefits of DHIs, but this overarching concern led to caution. If staff hold such dogmatic views about this issue, it may be a significant barrier to the implementation of DHIs in secondary care services. [Interviewer, Reflective journal, Data analysis]

Discussion

Principal Findings

This study sought to examine the experiences and views of mental health care staff toward clients with severe mental health problems using the Internet and mobile phones to manage their mental health and the hypothetical acceptability of digital health interventions for severe mental health problems to identify facilitators and barriers to implementation in secondary care services. Staff had a wide range of both positive and negative experiences of clients with severe mental health problems using the Internet and mobile phones for self-management, and staff were cautious, but optimistic, about the implementation of digital health interventions.

Web-based information-seeking was viewed positively and staff welcomed the incorporation of psychoeducation material into digital health interventions, suggesting that this could be well received by staff and service users alike. Concerns surrounding the abundance of unregulated Web-based material echo previous qualitative work, where individuals experiencing severe mental health problems also queried the trustworthiness of information from Internet sources and preferred information from organizational and charitable websites, rather than private companies or chat rooms [5,9]. Such skepticism surrounding the reliability of information found on the Internet may be warranted. A recent search for schizophrenia-related videos on the video-sharing website YouTube, revealed that only 34% accurately portrayed schizophrenia [28]. Additionally, mental health-related information on the Internet is reportedly of poor quality [29], and many websites are biased toward providing information about biological causes and medical treatment options [30]. However, a more recent study has reported that the quality of Web-based information specifically for severe mental health problems is of relatively good quality [31]. It has been suggested that health care professionals should direct clients to appropriate trusted websites to combat issues regarding the reliability of Web-based information [32]. In this study, staff endorsed this suggestion; however, some were concerned about their own limited knowledge surrounding websites and apps. Therefore, some participants expressed a need for a catalogue of evidence-based and NHS-endorsed resources they could recommend to clients.

Recently, the NHS introduced an early version of the once defunct NHS Digital Apps Library that contains a list of NHS-approved apps for numerous physical and mental health care needs [4]. Globally, the American Psychiatric Association has developed an evaluation model for use by staff to determine the appropriateness of apps for clients [33], and in Australia, the mindhealthconnect website, supported by the Australian government, lists a range of *trusted* Web-based tools and apps for people to self-manage their mental health and well-being [34]. Given the enthusiasm of participants to receive information regarding credible websites and apps, it is likely that these resources would be helpful for staff to review and implement. Therefore, efforts must be made to ensure that staff are made aware of, and encouraged to use, these new resources.

It has been suggested that social media websites and forums could be used to deliver interventions and provide peer support options for people experiencing severe mental health problems [35,36]. Early findings have indicated that this approach could be feasible and acceptable [37-39] and that individuals already actively access these platforms to receive support [40,41]. Although staff outlined several fears about clients engaging with social media websites and forums, they also described situations where clients had been able to connect with others on the Internet with a shared understanding. Therefore, the use of social media websites and forums to deliver interventions may be valued and utilized by people with severe mental health problems, although staff concerns such as forum moderation must be considered for successful implementation. Additionally, researchers have proposed that social media profiles may contain valuable information about individuals' daily lives and functioning, which could be a useful tool for clinicians to make assessments and diagnoses [42]. Staff were unanimously against viewing clients' social media profiles and viewed this behavior as a misuse of power; therefore, staff attitudes would be a significant barrier to the implementation of this approach in services.

Staff appeared to be paternalistic toward clients' access and use of the Internet and mobile phones, with a perceived need to guide clients toward the right information; this was particularly true for staff working in a rehabilitation unit. Gatekeeping and paternalism by staff is not restricted to Internet access and digital health interventions. For example, staff have also been found to be paternalistic when deciding whether to refer clients to clinical trials [43] and treatment options clients should receive [44]. Involving clients in a shared decision-making process with regards to Internet, mobile phone, and digital health intervention access is therefore key, and rather than preventing access, clients should instead be encouraged to speak with staff to help make decisions regarding access together.

Although some staff believed that digital devices could increase access to evidence-based interventions, concerns regarding client access and ability to use such devices were raised. These perceptions about technology access and ownership somewhat contradict recent findings in the field. For example, a recent meta-analysis indicated a narrowing gap in mobile phone ownership between the general population and individuals experiencing psychosis [45]. Numerous studies since this review have indicated relatively high technology access and ownership by people who experience severe mental health problems [46-48]. However, although there has been a reduction in the digital divide since 2011, some people with severe mental health problems remain digitally excluded [49]. Therefore, those delivering digital health interventions should remain mindful of access issues within this population and ensure digital exclusion is minimized. For example, staff suggested that technology skills training programs could be offered to ensure people are able to fully engage with digital health interventions. Additionally, staff did not feel the NHS should provide digital devices for people to receive interventions because of fears that clients may lose or sell mobile phones and tablets. In contrast to this viewpoint, technology return rates have been high (86% and 95%, respectively) in two studies where digital devices

were provided for participants with severe mental health problems [50,51]. This suggests that staff concerns regarding individuals' capabilities of maintaining and returning digital devices may be inaccurate, and researchers should report device return rates to determine whether such concerns are warranted.

Staff were generally optimistic toward using mobile phone apps for symptom monitoring but expressed concerns about their responsibility when receiving symptom reports from clients' because of the fear of missing risk disclosures. Therefore, staff stated a preference for receiving symptom reports from clients directly within sessions, rather than automatically. This somewhat contradicts the current direction of mobile phone apps for symptom monitoring in this population, which, although can be used by clients to share with their care team, tend to deliver symptom reports to a central server for staff to use to identify indications of relapse [52,53]. Therefore, issues surrounding the legal and moral responsibilities of staff when viewing automatic symptom reports and their comfort in implementing such approaches in practice need to be considered.

Staff in all groups repeatedly expressed the concern that digital health interventions could not, and should not, replace face-to-face care and should instead be used as an adjunct and as a method to extend choice. Such fears seemed to stem from the belief that the therapeutic relationship between client and therapist is key, and digital health interventions could never replace or mimic this relationship. There is some evidence to indicate that individuals can form a positive therapeutic alliance with self-directed digital health interventions [54,55]. However, further work is required to fully understand the therapeutic relationship in the context of digital health interventions to address the concerns expressed by staff.

Study Limitations

Findings must be interpreted in the context of some limitations. First, half the sample were clinical psychologists. Therefore, experiences of clients engaging with websites and apps and views toward using digital health interventions may be different to individuals working in other roles. Participants were mental health care staff working in the NHS in the North West of England; implications regarding implementation are, therefore, limited to NHS mental health services. Participants reported generally high levels of comfort using technology themselves, which may have resulted in them finding digital health interventions more acceptable than staff who are less comfortable using technology. Staff involved in each focus group were part of the same team and, in all cases, the service lead also participated in the focus group. Therefore, staff may have been more cautious when sharing information about their views than if focus groups had involved staff with no prior relationships. Conversely, the close working relationships observed within each focus group may have enabled participants to feel more comfortable speaking openly and honestly about their views. To explore this potential limitation further, the reflective journals kept by the interviewer were reviewed for commentary about the group dynamics observed. Specifically, positive interactions during all focus groups and the absence of any conflicts between members were noted. Furthermore, the interviewer noted that service leads did not differ from other

participants in the duration or number of experiences expressed and all the participants seemed to welcome and acknowledge opposing viewpoints. A strength of the focus group design is that it allows people to generate ideas through discussions with each other. However, an associated limitation with this approach is that the data generated are dependent on the individuals within each group, so individual perspectives may not be discussed and social pressures may impede members giving differing opinions from the group consensus. However, to minimize the interdependency of participants, group dynamics were managed by the interviewer so that each group member had the opportunity to present their views, and the interviewer kept a reflective journal throughout data collection and analysis to reflect on group dynamics. Finally, because of the practicality and time pressures for mental health care staff taking part in focus groups, we were advised to conduct focus groups within teams, rather than invite mental health staff to separate focus groups. Ideally, sample characteristics across focus groups are homogenous; however, to minimize participant burden, we accepted groups would be heterogeneous in nature. That said, across all four focus groups commonalities in experiences and viewpoints were stark despite differing job roles and any differences in viewpoints were noted in the results section

It is often considered best practice to return interview transcripts to participants for member checking. It was not possible to return transcripts to participants for this purpose because of the potential breaches in privacy and different viewpoints presented within focus groups. Finally, the research team have previous and current involvement in projects implementing digital health interventions for severe mental health problems. Although the researchers were mindful about reducing potential biases, it is important to acknowledge that such experiences may still affect the interpretation and analysis of data.

Implications for Clinical Practice and Implementation

The concerns raised by staff regarding client access to potentially harmful Web-based content reflects the need for a comprehensive, accessible, and widely disseminated resource containing links to approved websites for clients to access. Additionally, some staff expressed limited knowledge about websites and mobile phone apps they could recommend to clients and were concerned about making unhelpful recommendations. Therefore, Web-based libraries containing information about approved websites and apps such as the NHS Digital Apps Library [4] must be presented to staff as a potential resource they can use to identify relevant options they can recommend to clients. Additionally, paternalistic viewpoints were expressed toward clients accessing the Internet and mobile phones and staff acknowledged that Web-based misinformation and communication had often needed to be addressed in therapy. Therefore, mental health care staff must be prepared to explore and address these issues in clinical practice. Furthermore, the exploratory nature of the qualitative methodology led to the identification of new and interesting staff perspectives that have not yet been explored. Therefore, researchers could use the viewpoints identified in this study to inform the design of future surveys to explore quantitatively whether these views are prevalent on a larger scale.

This study also reports numerous facilitators and barriers to the implementation of digital health interventions for severe mental health problems in secondary mental health care services. Staff views align with the general theory of implementation, which details the key constructs that influence the implementation of complex interventions in health care settings [56]. These findings in relation to this theory suggest that technology skills training for staff and clients alike must be delivered to foster capability. Additionally, further reporting of technology return rates in clinical trials delivering digital health interventions and considerations for funding devices in service settings are needed to ensure capacity for implementation. The cautious optimism shown by staff suggests there is the potential to implement digital health interventions for severe mental health problems in secondary care services, but the identified barriers must be considered and addressed before implementation. Digital health interventions for severe mental health problems are not routinely offered in treatment because of the need to establish a more concrete evidence base. Therefore, clients are often only referred to these management options as part of a clinical trial. Although the exploration of continuous investment by staff cannot currently be determined, if digital health interventions are to be implemented within secondary care services, examination of continuous contributions by staff must be made.

Conclusions

This study is the first, to our knowledge, to qualitatively explore the experiences and attitudes of mental health care staff toward

individuals with severe mental health problems using the Internet, mobile phones, and digital health interventions to manage their mental health. Findings showed that staff had both positive and negative experiences of using the Internet and mobile phones for self-management. Additionally, a range of facilitators and barriers to implementation were identified. Although staff were generally positive about current use and able to detail many experiences where clients had found engaging with these resources helpful, some concerns were expressed regarding trustworthy websites and the security of digital health interventions. Therefore, continued and improved identification and cataloguing of evidence-based resources on the Internet and digital health interventions must be made to facilitate staff comfort in referring clients to manage their health care needs digitally. Staff approached the idea of digital health interventions with cautious optimism, but concerns regarding legal and moral responsibilities and fears over a diminished therapeutic relationship must be addressed before implementation. Importantly, staff endorsed the provision of digital health interventions for severe mental health problems as an adjunct to face-to-face support but held the fear that digital health interventions would be used as a cost-cutting strategy. Therefore, to ensure implementation, digital health interventions should be presented to frontline staff as a tool to enhance care and extend choice.

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Conflicts of Interest

NB is a PhD student investigating how technology can be used to deliver interventions for people who experience severe mental health problems. SB and FL are both principal investigators on clinical trials implementing digital health interventions for severe mental health problems.

Multimedia Appendix 1

Topic guide used in focus groups with mental healthcare staff.

[PDF File (Adobe PDF File), 98KB - [mental_v4i4e52_app1.pdf](#)]

References

1. National Institute for Health and Care Excellence (NICE). Nice. Computerised cognitive behaviour therapy for depression and anxiety URL: <https://www.nice.org.uk/guidance/ta97> [accessed 2017-02-04] [WebCite Cache ID 6rbadnq6C]
2. National Health Service (NHS). England.nhs.uk. Five year forward view URL: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf> [accessed 2017-06-30] [WebCite Cache ID 6rbbDOEKc]
3. National Health Service Choices. Nhs.uk. Online mental health services URL: <http://www.nhs.uk/conditions/online-mental-health-services/Pages/introduction.aspx> [accessed 2017-06-30] [WebCite Cache ID 6rbbObLlt]
4. National Health Services (NHS). Apps.beta.nhs. Find digital tools to help manage and improve your health URL: <https://apps.beta.nhs.uk/> [accessed 2017-06-30] [WebCite Cache ID 6rbbb8bdD]
5. Aref-Adib G, O'Hanlon P, Fullarton K, Morant N, Sommerlad A, Johnson S, et al. A qualitative study of online mental health information seeking behaviour by those with psychosis. BMC Psychiatry 2016 Jul 11;16:232. [Medline: 27400874]
6. Birnbaum M, Rizvi A, Correll C, Kane JM. Role of social media and the Internet in pathways to care for adolescents and young adults with psychotic disorders and non-psychotic mood disorders. Early Interv Psychiatry 2015;23 [FREE Full text]

7. Lal S, Nguyen V, Theriault J. Seeking mental health information and support online: experiences and perspectives of young people receiving treatment for first-episode psychosis. *Early Interv Psychiatry* 2016 Jan 26 [Epub ahead of print]. [Medline: [26810026](#)]
8. Schrank B, Sibitz I, Unger A, Amering M. How patients with schizophrenia use the internet: qualitative study. *J Med Internet Res* 2010 Dec 19;12(5):e70 [FREE Full text] [doi: [10.2196/jmir.1550](#)] [Medline: [21169176](#)]
9. Townsend L, Zippay A, Caler K, Forenza B. Technology and opportunity: people with serious mental illness and social connection. *J Soc Social Work Res* 2015 Feb 25;7(2):371-393. [doi: [10.1086/686882](#)]
10. Villani M, Kovess-Masfety V. How do people experiencing schizophrenia spectrum disorders or other psychotic disorders use the Internet to get information on their mental health? Literature review and recommendations. *JMIR Ment Health* 2017 Jan 03;4(1):e1 [FREE Full text] [doi: [10.2196/mental.5946](#)] [Medline: [28049620](#)]
11. Carper M, McHugh R, Barlow D. The dissemination of computer-based psychological treatment: A preliminary analysis of patient and clinician perceptions. *Admin Policy Ment Health* 2013 Mar;40(2):87-95. [Medline: [22001968](#)]
12. Gun SY, Titov N, Andrews G. Acceptability of Internet treatment of anxiety and depression. *Australas Psychiatry* 2011 Jun;19(3):259-264. [doi: [10.3109/10398562.2011.562295](#)] [Medline: [21682626](#)]
13. Pierce B, Twohig MP, Levin ME. Perspectives on the use of acceptance and commitment therapy related mobile apps: results from a survey of students and professionals. *J Contextual Behav Sci* 2016 Oct;5(4):215-224.
14. Schueller SM, Washburn JJ, Price M. Exploring mental health providers' interest in using web and mobile-based tools in their practices. *Internet Interv* 2016 May;4(2):145-151 [FREE Full text] [doi: [10.1016/j.invent.2016.06.004](#)] [Medline: [28090438](#)]
15. Sinclair C, Holloway K, Riley G, Auret K. Online mental health resources in rural Australia: clinician perceptions of acceptability. *J Med Internet Res* 2013 Sep 05;15(9):e193 [FREE Full text] [doi: [10.2196/jmir.2772](#)] [Medline: [24007949](#)]
16. Stallard P, Richardson T, Velleman S. Clinicians' attitudes towards the use of computerized cognitive behaviour therapy (cCBT) with children and adolescents. *Behav Cogn Psychother* 2010 Oct;38(5):545-560. [doi: [10.1017/S1352465810000421](#)] [Medline: [20615273](#)]
17. Vigerland S, Ljótsson B, Gustafsson FB, Hagert S, Thulin U, Andersson G, et al. Attitudes towards the use of computerized cognitive behaviour therapy (cCBT) with children and adolescents: a survey among Swedish mental health professionals. *Internet Interv* 2014 Jul;1(3):111-117. [doi: [10.1016/j.invent.2014.06.002](#)]
18. Berry N, Lobban F, Emsley R, Bucci S. Acceptability of interventions delivered online and through mobile phones for people who experience severe mental health problems: a systematic review. *J Med Internet Res* 2016 May 31;18(5):e121. [Medline: [27245693](#)]
19. Bucci S, Barrowclough C, Ainsworth J, Morris R, Berry K, Machin M, et al. Using mobile technology to deliver a cognitive behaviour therapy-informed intervention in early psychosis (Actissist): study protocol for a randomised controlled trial. *Trials* 2015 Sep 10;16:404 [FREE Full text] [doi: [10.1186/s13063-015-0943-3](#)] [Medline: [26357943](#)]
20. Hidalgo-Mazzei D, Mateu A, Reinares M, Murri A, Del Mar Bonnín C, Varo C, et al. Psychoeducation in bipolar disorder with a SIMPLE smartphone application: feasibility, acceptability and satisfaction. *J Affect Disord* 2016 Aug;200:58-66. [Medline: [27128358](#)]
21. Proudfoot J, Parker G, Manicavasagar V, Hadzi-Pavlovic D, Whitton A, Nicholas J, et al. Effects of adjunctive peer support on perceptions of illness control and understanding in an online psychoeducation program for bipolar disorder: a randomised controlled trial. *J Affect Disord* 2012 Dec 15;142((1-3)):98-105. [Medline: [22858215](#)]
22. Smith DJ, Griffiths E, Poole R, di Florio A, Barnes E, Kelly M, et al. Beating Bipolar: exploratory trial of a novel Internet-based psychoeducational treatment for bipolar disorder. *Bipolar Disord* 2011;13(5-6):571-577. [Medline: [22017225](#)]
23. Murray G, Leitan ND, Berk M, Thomas N, Michalak E, Berk L, et al. Online mindfulness-based intervention for late-stage bipolar disorder: pilot evidence for feasibility and effectiveness. *J Affect Disord* 2015 Jun 01;178:46-51. [Medline: [25795535](#)]
24. Donovan CL, Poole C, Boyes N, Redgate J, March S. Australian mental health worker attitudes towards cCBT: what is the role of knowledge? Are there differences? Can we change them? *Internet Interv* 2015 Nov;2(4):372-381. [doi: [10.1016/j.invent.2015.09.001](#)]
25. East ML, Havard BC. Mental health mobile apps: from infusion to diffusion in the mental health social system. *JMIR Ment Health* 2015;2(1):e10 [FREE Full text] [doi: [10.2196/mental.3954](#)] [Medline: [26543907](#)]
26. Stewart DW, Shamdasani PN, Rook DW. *Focus Groups: Theory and Practice*. Thousand Oaks, CA: Sage Publications; 2007.
27. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77-101 [FREE Full text] [doi: [10.1191/1478088706qp063oa](#)]
28. Nour MM, Nour MH, Tsatalou O, Barrera A. Schizophrenia on YouTube. *Psychiatr Serv* 2017 Jan;68(1):70-74. [doi: [10.1176/appi.ps.201500541](#)]
29. Reavley N, Jorm AF. The quality of mental disorder information websites: A review. *Patient Edu Couns* 2011 Nov;85(2):e16-e25. [Medline: [21087837](#)]
30. Read J, Cain A. A literature review and meta-analysis of drug company-funded mental health websites. *Acta Psychiatr Scand* 2013 Dec;128(6):422-433. [doi: [10.1111/acps.12146](#)] [Medline: [23662697](#)]

31. Grohol JM, Slimowicz J, Granda R. The quality of mental health information commonly searched for on the Internet. *Cyberpsychol Behav Soc Netw* 2014 Apr;17(4):216-221. [doi: [10.1089/cyber.2013.0258](https://doi.org/10.1089/cyber.2013.0258)] [Medline: [24237287](#)]
32. Monteith S, Glenn T, Bauer M. Searching the internet for health information about bipolar disorder: some cautionary issues. *Int J Bipolar Disord* 2013 Oct 17;1:22. [doi: [10.1186/2194-7511-1-22](https://doi.org/10.1186/2194-7511-1-22)]
33. American Psychiatric Association (APA). Psychiatry. App evaluation model URL: <https://www.psychiatry.org/psychiatrists/practice/mental-health-apps/app-evaluation-model> [accessed 2017-06-30] [WebCite Cache ID 6rbl3Yq3s]
34. Mindhealthconnect. Apps and online programs URL: <http://www.mindhealthconnect.org.au/apps-online-self-help-programs> [accessed 2017-06-30] [WebCite Cache ID 6rbkA3wv3]
35. Naslund JA, Aschbrenner KA, Marsch LA, Bartels SJ. The future of mental health care: peer-to-peer support and social media. *Epidemiol Psychiatr Sci* 2016 Apr;25(2):113-122 [FREE Full text] [doi: [10.1017/S2045796015001067](https://doi.org/10.1017/S2045796015001067)] [Medline: [26744309](#)]
36. Torous J, Keshavan M. The role of social media in schizophrenia evaluating risks, benefits, and potential. *Curr Opin Psychiatry* 2016;29(3):190-195. [doi: [10.1097/YCO.0000000000000246](https://doi.org/10.1097/YCO.0000000000000246)] [Medline: [26967314](#)]
37. Alvarez-Jimenez M, Alcazar-Corcoles MA, González-Blanch C, Bendall S, McGorry PD, Gleeson JF. Online, social media and mobile technologies for psychosis treatment: a systematic review on novel user-led interventions. *Schizophr Res* 2014 Jun;156(1):96-106. [Medline: [24746468](#)]
38. Lal S, Dell'Elce J, Tucci N, Fuhrer R, Tamblyn R, Malla A. Preferences of young adults with first-episode psychosis for receiving specialized mental health services using technology: a survey study. *JMIR Ment Health* 2015 May 20;2(2):e18. [Medline: [26543922](#)]
39. Naslund JA, Aschbrenner KA, Marsch LA, Bartels SJ. Feasibility and acceptability of Facebook for health promotion among people with serious mental illness. *Digit Health* 2016 Nov;2. [doi: [10.1177/2055207616654822](https://doi.org/10.1177/2055207616654822)]
40. Berry N, Lobban F, Belousov M, Emsley R, Nenadic G, Bucci S. #WhyWeTweetMH: understanding why people use Twitter to discuss mental health problems. *J Med Internet Res* 2017 Apr 05;19(4):e107 [FREE Full text] [doi: [10.2196/jmir.6173](https://doi.org/10.2196/jmir.6173)] [Medline: [28381392](#)]
41. Highton-Williamson E, Priebe S, Giacco D. Online social networking in people with psychosis: a systematic review. *Int J Soc Psychiatry* 2015 Feb;61(1):92-101. [Medline: [25381145](#)]
42. Appelbaum PS, Kopelman A. Social media's challenges for psychiatry. *World Psychiatry* 2014 Feb;13(1):21-23 [FREE Full text] [doi: [10.1002/wps.20085](https://doi.org/10.1002/wps.20085)] [Medline: [24497238](#)]
43. Bucci S, Butcher I, Hartley S, Neil ST, Mulligan J, Haddock G. Barriers and facilitators to recruitment in mental health services: care coordinators' expectations and experience of referring to a psychosis research trial. *Psychol Psychother* 2015 Sep;88(3):335-350. [doi: [10.1111/papt.12042](https://doi.org/10.1111/papt.12042)] [Medline: [25257960](#)]
44. Holtum S. How included are mental health service users in decisions about their medication? *Ment Health Soc Incl* 2016;20(3):141-148. [doi: [10.1108/MHSI-05-2016-0015](https://doi.org/10.1108/MHSI-05-2016-0015)]
45. Firth J, Cotter J, Torous J, Bucci S, Firth J, Yung AR. Mobile phone ownership and endorsement of "mHealth" among people with psychosis: a meta-analysis of cross-sectional studies. *Schizophr Bull* 2016;42(2):448-455. [Medline: [26400871](#)]
46. Gay K, Torous J, Joseph A, Pandya A, Duckworth K. Digital technology use among individuals with schizophrenia: results of an online survey. *JMIR Ment Health* 2016 May 04;3(2):e15. [Medline: [27146094](#)]
47. Gitlow L, Abdelaal F, Etienne A, Hensley J, Krukowski E, Toner M. Exploring the current usage and preferences for everyday technology among people with serious mental illness. *Occup Ther Ment Health* 2017 Mar 01;33(1):1-14. [doi: [10.1080/0164212X.2016.1211061](https://doi.org/10.1080/0164212X.2016.1211061)]
48. Thomas N, Foley F, Lindblom K, Lee S. Are people with severe mental illness ready for online interventions? Access and use of the Internet in Australian mental health services. *Australas Psychiatry* 2017 Jun;25(3):257-261. [Medline: [28139947](#)]
49. Robotham D, Satkunanathan S, Doughty L, Wykes T. Do we still have a digital divide in mental health? A five year survey follow-up. *J Med Internet Res* 2016 Nov 22;18(11):e309. [Medline: [27876684](#)]
50. Biagianti B, Schlosser D, Nahum M, Woolley J, Vinogradov S. Creating live interactions to mitigate barriers (CLIMB): a mobile intervention to improve social functioning in people with chronic psychotic disorders. *JMIR Ment Health* 2016;3(4):e52. [doi: [10.2196/mental.6671](https://doi.org/10.2196/mental.6671)]
51. Granholm E, Ben-Zeev D, Link PC, Bradshaw KR, Holden JL. Mobile Assessment and Treatment for Schizophrenia (MATS): a pilot trial of an interactive text-messaging intervention for medication adherence, socialization, and auditory hallucinations. *Schizophr Bull* 2012 May;38(3):414-425. [Medline: [22080492](#)]
52. Bardram JE, Frost M, Szántó K, Marcu G. The MONARCA self-assessment system: a persuasive personal monitoring system for bipolar patients. 2012 Presented at: 2nd ACM SIGHIT International Health Informatics Symposium; January 28-30, 2012; Miami, FL, USA p. 21-30. [doi: [10.4108/icst.pervasivehealth.2011.246050](https://doi.org/10.4108/icst.pervasivehealth.2011.246050)]
53. Palmier-Claus JE, Ainsworth J, Machin M, Barrowclough C, Dunn G, Barkus E, et al. The feasibility and validity of ambulatory self-report of psychotic symptoms using a smartphone software application. *BMC Psychiatry* 2012;12:172. [doi: [10.1186/1471-244X-12-172](https://doi.org/10.1186/1471-244X-12-172)]
54. Barazzzone N, Cavanagh K, Richards DA. Computerized cognitive behavioural therapy and the therapeutic alliance: a qualitative enquiry. *Br J Clin Psychol* 2012 Nov;51(4):396-417. [Medline: [23078210](#)]

55. Clarke J, Proudfoot J, Whitton A, Birch MR, Boyd M, Parker G, et al. Therapeutic alliance with a fully automated mobile phone and web-based intervention: secondary analysis of a randomised controlled trial. *JMIR Ment Health* 2016 Feb 25;3(1):e10. [Medline: [26917096](#)]
56. May C. Towards a general theory of implementation. *Implement Sci* 2013 Feb 13;8:18. [Medline: [23406398](#)]

Abbreviations

cCBT: computerized cognitive behavioral therapy

NHS: National Health Service

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Original Paper

A Mobile Text Message Intervention to Reduce Repeat Suicidal Episodes: Design and Development of Reconnecting After a Suicide Attempt (RAFT)

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Abstract

Background: Suicide is a leading cause of death, particularly among young people. Continuity of care following discharge from hospital is critical, yet this is a time when individuals often lose contact with health care services. Offline brief contact interventions following a suicide attempt can reduce the number of repeat attempts, and text message (short message service, SMS) interventions are currently being evaluated.

Objective: The aim of this study was to extend postattempt caring contacts by designing a brief Web-based intervention targeting proximal risk factors and the needs of this population during the postattempt period. This paper details the development process and describes the realized system.

Methods: To inform the design of the intervention, a lived experience design group was established. Participants were asked about their experiences of support following their suicide attempt, their needs during this time, and how these could be addressed in a brief contact eHealth intervention. The intervention design was also informed by consultation with lived experience panels external to the project and a clinical design group.

Results: Prompt outreach following discharge, initial distraction activities with low cognitive demands, and ongoing support over an extended period were identified as structural requirements of the intervention. Key content areas identified included coping with distressing feelings, safety planning, emotional regulation and acceptance, coping with suicidal thoughts, connecting with others and interpersonal relationships, and managing alcohol consumption.

Conclusions: The RAFT (Reconnecting AFTER a suicide attempt) text message brief contact intervention combines SMS contacts with additional Web-based brief therapeutic content targeting key risk factors. It has the potential to reduce the number of repeat suicidal episodes and to provide accessible, acceptable, and cost-effective support for individuals who may not otherwise seek face-to-face treatment. A pilot study to test the feasibility and acceptability of the RAFT intervention is underway.

KEYWORDS

suicide, attempted; emergency service, hospital; continuity of patient care; text messaging; Internet

Introduction

Hospital-treated deliberate self-harm (DSH) is the single strongest risk factor for subsequent suicide, and repeat episodes and suicide are key clinical outcomes [1]. With a 1-year repetition rate of 15%, and 30% in those with a history of previous episodes [2,3], engaging with and treating self-harming patients soon after they present to the emergency department (ED) is important for reducing future suicidal behavior. The risk of repetition is highest in the first month after discharge; however, the risk remains elevated for at least 12 months [3].

Ongoing care after discharge is critical, and a failure to provide rapid and effective follow-up after DSH is associated with increased risk of further DSH, suicidal behavior, and death by suicide [4]. However, a data linkage study of 67,035 hospital-admitted DSH cases from 2005 to 2011 in the Australian state of New South Wales found that only 63% of patients received any mental health care within the public system following discharge [5], with only 41% having contact with a community mental health service in the month following discharge from an inpatient admission [6]. There is therefore a need to provide additional outreach and support following discharge.

A meta-analysis found that postdischarge brief contact interventions, such as letters, postcards, crisis cards, and telephone calls, were associated with a significant reduction in the number of repeat episodes per participant, although nonsignificant reductions were observed in the number of patients with any repeat attempt [7]. In addition to showing promising clinical outcomes, brief contact interventions overcome some of the barriers to implementation of more intensive forms of aftercare, including resource limitations and difficulty in engaging patients in ongoing treatment. Therapy-based interventions are generally expensive and require delivery by mental health professionals within traditional services, making them difficult to implement and potentially hard to access. Furthermore, a substantial number of patients are unable or unwilling to engage in face-to-face treatment but may be willing to engage with a lower intensity intervention.

There is increasing interest in the use of e-mental health interventions to overcome the barriers to traditional therapeutic interventions, including in the field of suicide prevention [8,9], but such interventions rarely support individuals following a suicide attempt [10]. There is, however, an increasing research focus on technology-supported brief contact interventions, and simple *caring contact* text messages (short message service, SMS) are currently being trialed [11,12]. We developed the RAFT (Reconnecting AFTER a suicide attempt) intervention to extend the scope of these text message contacts by including additional links to Web-based brief therapeutic content targeting proximal risk factors. We report on the development of the intervention, which was codesigned with lived experience

groups and an expert panel and is designed for patients who have been recently discharged from the ED.

Methods

Various frameworks have been proposed for participatory design and codesign of e-mental health interventions. Following the Patient-Clinician-Designer framework [13], we sought to engage those with lived experience of a suicide attempt, health care professionals, and designers throughout the design process (with the research team contributing expertise to the latter 2 stakeholder groups).

Lived Experience Design Group

Recognizing the importance of lived experience in the implementation of this project, a lived experience design group was established to inform its design. The project-specific design group was recruited through the Black Dog Institute's website and social media channels, through a research register of people who had previously consented to be contacted about research projects, as well as through partner organizations. Potential participants were asked to contact a member of the research team to screen for eligibility. Participants had a history of a suicide attempt, but not in the immediately preceding month, and were not currently experiencing severe suicidal ideation (if a current suicide plan, means, or intent was endorsed). Eligibility was initially based on an age of 18 to 25 years, which was later broadened to 18 to 65 years. Ethics approval for the design group was obtained through the University of New South Wales Human Research Ethics Committee (HC14272).

A total of 16 potential participants contacted the research team, expressing interest in the lived experience design group, 14 of whom were female. Five individuals were ineligible because of current severe suicidal ideation ($n=4$) or a suicide attempt within the previous month ($n=1$). Four individuals were eligible but could not attend a focus group because of scheduling constraints. The remaining 7 eligible individuals were scheduled to attend 2 focus groups (comprising 3 and 4 participants, respectively); however, 3 participants did not attend the second session, so this was conducted as a one-to-one interview with the one attending participant. All 4 design group participants were female.

Discussions were audio-recorded, then transcribed by a member of the research team. A second researcher reviewed the transcripts and the recordings to ensure accuracy. A member of the team then undertook thematic analysis of the transcripts, following Braun and Clarke [14], and developed an initial coding scheme. A second researcher then reviewed the coding, and any disagreements were resolved by discussion until consensus was achieved.

Content Development

A clinical design group was also established for this project to capture a range of researcher and clinician perspectives. The 5

members of this group had expertise in e-mental health, clinical psychology, liaison psychiatry, emergency medicine, drug and alcohol services, and mental health epidemiology.

On the basis of the analysis of the focus group discussions, a high-level design incorporating the broad content areas and mode of delivery was created by the research team and presented to the clinical design team. Through a group-setting guided discussion, the following aspects of the intervention design were established: the relative importance and scheduling of the identified content areas, thematic and therapeutic connections between content areas, and low-intensity interventions or resources that can be provided for each content area.

Design Refinement

Following the clinical design group discussion, the research team developed a comprehensive draft of all content (SMS text messages and Web-based content) within the intervention. The importance of continued engagement with people with lived experience was recognized, as were the challenges of recruiting and scheduling for the initial focus groups. Therefore, the existing Centre for Research Excellence in Suicide Prevention's Lived Experience Committee (CRESPEL) and the Black Dog Institute's Lived Experience Advisory Panel (BDILEAP) were approached. Members of these groups were invited to provide verbal or written feedback on the draft content as well as a number of look-and-feel options developed by a creative agency. These groups, along with clinical and research teams, included both women and men. Therefore, engagement with these groups also allowed a broader range of lived experience perspectives to be incorporated into the design process.

Implementation and Testing

Following these rounds of consumer and clinical feedback, a prototype implementation of the RAFT intervention was developed. Members of the clinical design group and the CRESPEL were invited to test the realized system, and verbal or written feedback was provided on the overall user experience and usability, as well as the content and its presentation. The system was iteratively updated in response to the feedback received.

Results

Design Process

Our first discussions with the lived experience design group focused on what help and support was available to participants following their suicide attempt, what was helpful and not helpful, what support they would have liked to have received, and the scope for incorporating such strategies into an electronic health (eHealth) intervention. During these initial discussions, the concept of follow-up by SMS text messages was supported as follows:

I think it would have been useful to me...I just needed any contact from anybody, and when I saw the system, and when I was told the system was supposed to respond in a certain way for 48 hours and they didn't—it really hurt me. [P1]

Compared with other forms of follow-up contact, SMS text messages were broadly preferred, as seen in the quote below:

Generally speaking I quite appreciate phone calls, but I think after a suicide attempt I perhaps wouldn't have appreciated that so much. [P4]

However, it was acknowledged that some may not find such contact helpful; one of the participant described how the contact may indeed be perceived as:

...personification of a health system that sees you as a problem instead of a person. [P2]

When asked about what techniques participants had found helpful following their suicide attempt, distraction activities such as games, drawing and coloring were described. One of the participants stated:

...where you can just play games as a way to keep yourself, your mind busy. I did have Sudoku books, which I did a lot of. And I did a lot of those dot paintings with textas. [P3]

Participants highlighted that these activities were typically of low-intensity, as expressed by one of the participants:

...not much energy either...[an activity] that is achievable. [P2]

In addition to these short-term strategies, participants also identified longer-term support, which was helpful following their suicide attempt. One participant stated:

...any sort of approach which looks at acceptance, and I mean, emotion regulation was very important for me. [P4]

Participants frequently described difficulties in communicating with friends and family following their suicide attempt:

My best friend at the time stopped talking to me for 3 weeks. [P2]

I've been walked past as though I don't exist by other family members. [P1]

When asked about the scheduling of messages, participants indicated frequent messages would be useful, but not too frequent:

I think [the first message should be] the day after discharge. [P4]

...maybe every 2-3 days as the default...I would say a maximum of a week because otherwise you're not taking care of yourself enough. [P2]

I'd say one a day, but that would probably get irritating too. So probably I'd do that for a few days, and then extend it. [P3]

Although the possible duration of messaging was not directly discussed, participants described a general need for longer-term care as follows:

...our hospitals [are] very acute driven...and they do that very well, but I think with mental illness, you need to get at the chronic illness, and how you manage that on a longer timeframe...I think I may not have ever have got to the second [suicide attempt] if

I had been cared for in a way that had a longer term vision. [P4]

On the basis of the lived experience discussions described above, the following key topic areas were identified: initial distraction activities to cope with distressing feelings, emotional regulation and acceptance, and interpersonal relationships. The clinical design group expanded upon these areas to also include safety planning, as part of a best-practice safety protocol; coping with suicidal thoughts, as an extension of emotional acceptance; and managing alcohol use, as this is a proximal risk factor. The needs for prompt outreach following discharge, initial content with low cognitive demands, and ongoing support over an extended period were also endorsed. To match this trajectory, an initial contact within 24 hours was proposed, followed by weekly messages related to the topics identified above, then monthly reminders until 12 months.

The content of the SMS text messages and additional Web-based content related to the identified topics was then drafted, with feedback obtained from the clinical design group and the CRESP LEC. Two proposed user interface wireframes were designed, with feedback also obtained from the clinical design group, CRESP LEC and BDI LEAP. Following both sets of feedback, the specifications were finalized, and the realized system is described below.

System Design

The aim of RAFT is to provide a text message-based follow-up intervention, combining regular SMS contacts and links to Web-based therapeutic content and resources focused on the 6 content areas. These key areas, identified through thematic

analysis, include coping with distressing feelings, safety planning, emotional regulation and acceptance, coping with suicidal thoughts, connecting with others and interpersonal relationships, and managing alcohol consumption. The sequence of SMS text messages is intended to start with low cognitive demands for the early SMS text messages during the initial crisis period, with additional therapeutic components introduced later. Each SMS text message contains a brief message related to the content area, with a link to information and brief therapeutic content on the study website.

SMS Text Message Component

Upon registration, users automatically receive a series of personalized text messages at a predefined schedule. The first text message (coping with distressing feelings) is sent within 24 hours of user registration, with messages related to the other topics sent weekly until week 6. Each message is customized with the recipient's given name and signed by the team from their presenting hospital. Messages also express the treating clinician's wish that the person is well and invite them to recontact their relevant local health service if needed. Each message also contains a unique link to the relevant Web content (Figure 1).

Following the 6 weekly SMS text messages during this immediate postdischarge period, the participant then receives monthly reminder messages until just over 12 months have passed (Figure 2). The final message is delayed slightly to avoid the anniversary date of the index presentation. These messages contain reminders to revisit the Web-based content or to contact a crisis service or a health professional if required.

Figure 1. Example of the first text message (coping with distressing feelings). Customized text is shown in [square brackets].

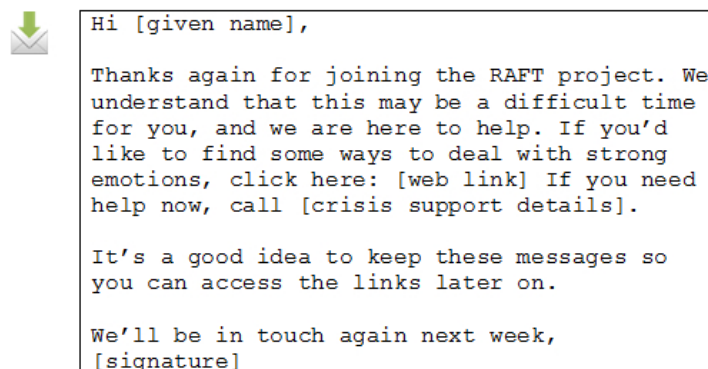


Figure 2. Example of a monthly reminder message. Customized text is shown in [square brackets].

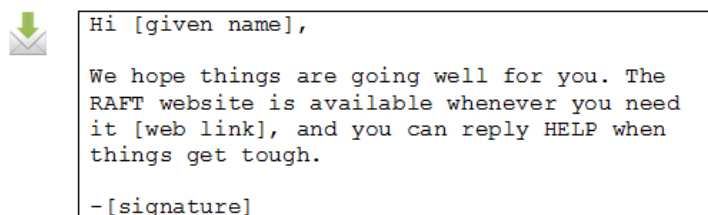


Figure 3. Example of automatic response to the HELP keyword, providing local crisis support, national crisis support, and emergency service details. Customized text is shown in [square brackets].

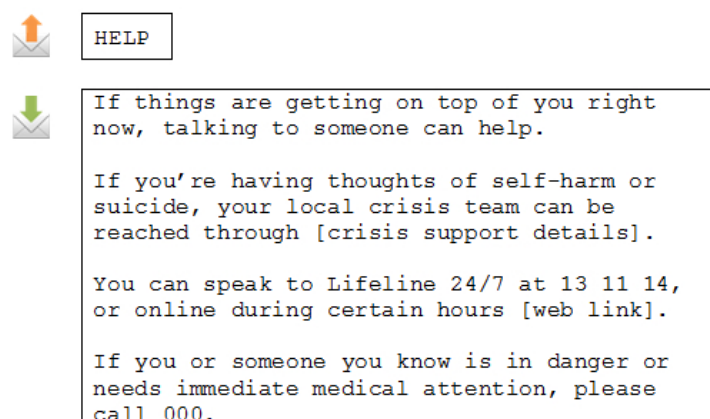
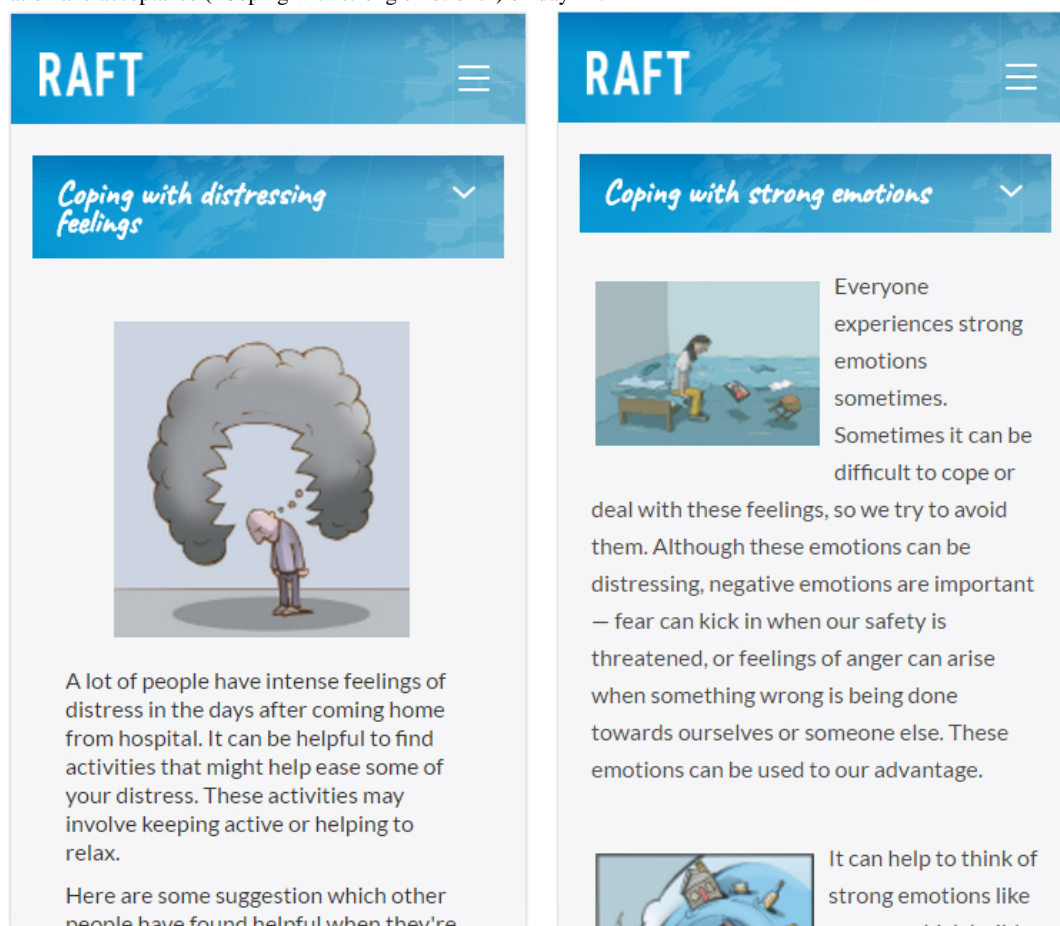


Figure 4. Sample screenshots from the webpages related to the first and third text messages. Left: “Coping with distressing feelings” on day 0. Right: Emotional regulation and acceptance (“Coping with strong emotions”) on day 14.



As part of the safety protocol, participants can reply to any message at any time with the keyword “HELP.” This triggers an automated response containing contact details of their local acute care team, the national Lifeline crisis telephone line, and if the participant feels in immediate danger, the emergency services (triple zero; Figure 3). The local acute care team is suggested as the first point-of-call to encourage appropriate triage to self-care or local health services. In addition to the “HELP” keyword, participants are able to opt out of further participation at any time by replying “STOP” to stop receiving future messages.

Web Component

If a user clicks on one of the links contained within the text messages, the relevant content within the study website is loaded. The content for each of the six content areas is described below. Figure 4 shows sample screenshots of the Web content.

Day 0: Coping With Distressing Feelings

This section aims to help participants cope with the distressing feelings present in the immediate period following discharge from hospital. It attempts to normalize feelings of distress and provides simple emotional regulation strategies, including

distraction and calming activities. It offers strategies that members of the lived experience design group found helpful, including links to other free apps and resources, and includes listening to music, engaging with art, practicing mindfulness, playing games, and coloring. Participants are also able to enter their own activities and rate whether each activity is helpful for them.

Day 7: Safety Planning

One week post attempt, this section encourages participants to create a safety plan in case a crisis reemerges. The rationale for a safety plan is described by Stanley and Brown [15], who suggest that the participant can create one on their own or with help from a friend or family member. Links are provided to a safety planning app or a downloadable document. The participant is reminded that the activities they found useful from the previous section can be included in their safety plan.

Day 14: Emotional Regulation and Acceptance

After 2 weeks, additional brief therapeutic content is presented. This section is based on acceptance and commitment therapy and encourages learning acceptance of strong emotions and effective emotional regulation techniques. Links are provided to brief Web-based mindfulness audio recordings for when the participant feels distressed, while also balancing the need for active regulation: participants are again referred back to any activities they found useful from the first section.

Day 21: Coping With Suicidal Thoughts

After 3 weeks, the participant is introduced to cognitive strategies that may be useful if suicidal thoughts reemerge. Thought defusion strategies are suggested and presented as a case study tailored to the participant's gender. These strategies include recognition of unhelpful or *bully* thoughts, observing and naming these thoughts, and questioning their accuracy and utility.

Day 28: Connecting With Others and Interpersonal Relationships

After 4 weeks, an additional case study is presented in relation to managing interpersonal relationships and solving relationship difficulties. Helpful and unhelpful communication styles, thinking styles, and interpersonal behaviors are highlighted, along with encouragement to apply these to the participant's own relationships.

Day 35: Managing Alcohol Consumption

The final content area focuses on managing alcohol consumption, a proximal risk factor for suicidal behaviors. The section starts with the AUDIT-C screener [16], and if this indicates potentially harmful drinking behaviors, the participant is encouraged to visit the Healthier Drinking Choices website, a localized Australian version of the Down Your Drink brief intervention [17].

Each webpage becomes available when the corresponding SMS text message is sent. Participants can browse back through earlier sections related to any previous messages and are not required to view the content in sequence. To assess which content areas are most relevant, engagement with both the text messages and Web components of the intervention are

automatically measured. Measures include the proportion of messages that fail to deliver; whether participants withdraw or opt out of future messages through the "STOP" keyword and at what point; which links are most frequently clicked and when; and which pages are viewed on the study website, how often, and when.

Discussion

Principal Findings

We have presented the consumer-informed development and design of the RAFT SMS-based brief contact intervention. RAFT extends existing SMS text message brief contact interventions [11,12] through the inclusion of links to Web-based brief therapeutic content that the user can choose to access anytime. These links cover a range of factors, including coping with distressing feelings, safety planning, emotional regulation and acceptance, coping with suicidal thoughts, connecting with others and interpersonal relationships, and managing alcohol consumption. The intervention has been developed with extensive consultation with lived experience groups. To assess the feasibility and acceptability of the RAFT brief contact intervention, a 12-month pilot study is currently underway at 3 participating emergency departments across Australia.

Our design process identified some similar themes as those identified by Cooper et al in their analysis of requirements for a brief contact intervention [18]. Common features include the need for proactive follow-up immediately following discharge from the ED, with messages of support and encouragement with relevant support contacts. Cooper et al also identified some uncertainty about the optimal contact intensity and duration. We did not, however, identify reservations about the use of mobile phones as a contact method. This may be because of increased mobile phone adoption in the intervening years. Also, our advertising material mentioned the development of an eHealth intervention, therefore the design group participants in this study may have been more willing to accept a mobile phone-based strategy. This work also complements that by Ranney et al, who codesigned a brief intervention in the ED setting for high-risk patients with symptoms of depression and recent history of peer-violence [19,20]. Both interventions have been designed by focusing on current coping strategies as a target for SMS text message follow-ups. However, the target populations are different, with Ranney excluding those who are acutely suicidal.

While following a Patient-Clinician-Designer framework to engage multiple stakeholders, our approach did not seek to bring those with lived experience in direct contact with health care professionals. This was intended to be sensitive to participants' needs [13], where such crossover may have created a more intimidating environment or reduced participants' openness to discuss their experiences with existing services. Others have, however, reported that such interactions can lead to the creation of new design ideas in the mental health setting [21,22].

The RAFT intervention has been designed to be readily accessible to a large proportion of the population and has the

potential to readily scale to other clinical services and settings. Although designed for an Australian setting, the content and support services can be readily adapted for international settings. This brief intervention may also be more acceptable to a younger population and those who are unable or unwilling to receive face-to-face treatment.

Limitations

A number of limitations are acknowledged in the development of the RAFT intervention. First, the project-specific lived experience design group only contained 4 participants and, therefore, it is unlikely that the experiences described represent the full range of lived experience. Furthermore, the group was exclusively female, possibly reflecting the gender disparity between suicide attempts and completed suicides, and additional targeted recruitment attempts were unsuccessful. Therefore, the acceptability for male participants is unclear and will be determined through the pilot study.

Our screening process only captured whether a participant was in the relevant age range for this formative research study, and we did not collect further demographic details. Additional data collection may have allowed further insights into the suitability of this intervention for specific age ranges; however, such data are not available. Individuals' history of suicidal behavior may also have provided additional insights; however, we focused on coping strategies subsequent to their suicide attempt rather than the actual attempt or preceding events.

SMS text messaging may be considered a relatively simple or old technology, particularly when compared with smartphone apps. However, apps may encounter a higher barrier to adoption in the ED setting, with limited feasibility for downloading and installing an app during the routine discharge process. Text

messaging is also available to a larger proportion of the population, including lower income participants who may not own a modern smartphone, although the Web-based content may not be fully accessible to these participants. The messaging infrastructure also allows for longer term automatic deployment with fewer ongoing maintenance and update requirements than an app.

The automated text messages proposed in this system may be perceived by some as an extension of a health care system that does not care, as described by one participant. Other participants, however, described that any follow-up would be appreciated, especially as personal follow-up is often promised but not always delivered. It may be possible to extend this automated SMS system with additional keyword responses; for example, the "HELP" message could trigger a follow-up phone call from a crisis service.

Conclusions

We have developed a new SMS text message-based brief contact intervention, delivered over 12 months following an ED presentation for a suicide attempt, which expands previous caring contact interventions with additional Web-based brief therapeutic content. Such an approach has the potential to reduce the number of repeat episodes of suicidal behavior and to reach young people at risk of self-harm and suicide who are unable or unwilling to undergo face-to-face treatment with health professionals. Our pilot study aims to assess the acceptability and feasibility of delivering this intervention through an ED setting. Widespread mobile phone technology allows RAFT to be readily deployed at scale and is likely to be more acceptable to a younger target audience than alternative clinical therapeutic options.

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Authors' Contributions

All authors contributed to the preparation and approval of the manuscript for publication.

Conflicts of Interest

None declared.

References

1. Carroll R, Metcalfe C, Gunnell D. Hospital presenting self-harm and risk of fatal and non-fatal repetition: systematic review and meta-analysis. PLoS One 2014 Feb 28;9(2):e89944 [FREE Full text] [doi: [10.1371/journal.pone.0089944](https://doi.org/10.1371/journal.pone.0089944)] [Medline: [24587141](https://pubmed.ncbi.nlm.nih.gov/24587141/)]
2. Owens D, Horrocks J, House A. Fatal and non-fatal repetition of self-harm. Systematic review. Br J Psychiatry 2002 Sep;181:193-199 [FREE Full text] [Medline: [12204922](https://pubmed.ncbi.nlm.nih.gov/12204922/)]

3. Carter GL, Clover KA, Bryant JL, Whyte IM. Can the Edinburgh Risk of Repetition Scale predict repetition of deliberate self-poisoning in an Australian clinical setting? *Suicide Life Threat Behav* 2002;32(3):230-239. [doi: [10.1521/suli.32.3.230.22175](https://doi.org/10.1521/suli.32.3.230.22175)]
4. Meehan J, Kapur N, Hunt IM, Turnbull P, Robinson J, Bickley H, et al. Suicide in mental health in-patients and within 3 months of discharge. National clinical survey. *Br J Psychiatry* 2006 Feb;188:129-134 [FREE Full text] [doi: [10.1192/bjp.188.2.129](https://doi.org/10.1192/bjp.188.2.129)] [Medline: [16449699](https://pubmed.ncbi.nlm.nih.gov/16449699/)]
5. NHMRC Centre of Research Excellence in Suicide Prevention. Black Dog Institute. 2015. Care after a suicide attempt URL: <https://www.blackdoginstitute.org.au/docs/default-source/research/careafterasuicideattempt02-09-15.pdf> [accessed 2017-11-08] [WebCite Cache ID 6uoYIYqK9]
6. Spittal MJ, Shand F, Christensen H, Brophy L, Pirkis J. Community mental health care after self-harm: a retrospective cohort study. *Aust N Z J Psychiatry* 2017;51(7):727-725. [doi: [10.1177/0004867416676366](https://doi.org/10.1177/0004867416676366)]
7. Milner AJ, Carter G, Pirkis J, Robinson J, Spittal MJ. Letters, green cards, telephone calls and postcards: systematic and meta-analytic review of brief contact interventions for reducing self-harm, suicide attempts and suicide. *Br J Psychiatry* 2015 Mar;206(3):184-190 [FREE Full text] [doi: [10.1192/bjp.bp.114.147819](https://doi.org/10.1192/bjp.bp.114.147819)] [Medline: [25733570](https://pubmed.ncbi.nlm.nih.gov/25733570/)]
8. Christensen H, Batterham PJ, O'Dea B. E-health interventions for suicide prevention. *Int J Environ Res Public Health* 2014 Aug 12;11(8):8193-8212 [FREE Full text] [doi: [10.3390/ijerph110808193](https://doi.org/10.3390/ijerph110808193)]
9. Lai MH, Maniam T, Chan LF, Ravindran AV. Caught in the web: a review of web-based suicide prevention. *J Med Internet Res* 2014 Jan 28;16(1):e30 [FREE Full text] [doi: [10.2196/jmir.2973](https://doi.org/10.2196/jmir.2973)] [Medline: [24472876](https://pubmed.ncbi.nlm.nih.gov/24472876/)]
10. Larsen ME, Nicholas J, Christensen H. A systematic assessment of smartphone tools for suicide prevention. *PLoS One* 2016 Apr 13;11(4):e0152285 [FREE Full text] [doi: [10.1371/journal.pone.0152285](https://doi.org/10.1371/journal.pone.0152285)] [Medline: [27073900](https://pubmed.ncbi.nlm.nih.gov/27073900/)]
11. Berrouiguet S, Alavi Z, Vaiva G, Courtet P, Baca-García E, Vidailhet P, et al. SIAM (Suicide intervention assisted by messages): the development of a post-acute crisis text messaging outreach for suicide prevention. *BMC Psychiatry* 2014 Nov 18;14:294 [FREE Full text] [doi: [10.1186/s12888-014-0294-8](https://doi.org/10.1186/s12888-014-0294-8)] [Medline: [25404215](https://pubmed.ncbi.nlm.nih.gov/25404215/)]
12. Comtois K. Feasibility and Acceptability of Caring Contacts via Text: Increasing Connection with Marines and Soldiers to Prevent Suicide Attempts and Ideation. 2015 Presented at: 28th World Congress of the International Association for Suicide Prevention; June 16-20, 2015; Montréal, Québec, Canada URL: http://crise.ca/iasp2015/default_118.html
13. Marcu G, Bardram JE, Gabrielli S. A framework for overcoming challenges in designing persuasive monitoring and feedback systems for mental illness. : IEEE; 2011 Presented at: 2011 5th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops; 23-26 May 2011; Dublin, Ireland. [doi: [10.4108/icst.pervasivehealth.2011.246097](https://doi.org/10.4108/icst.pervasivehealth.2011.246097)]
14. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77-101. [doi: [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)]
15. Stanley B, Brown GK. Safety planning intervention: a brief intervention to mitigate suicide risk. *Cogn Behav Pract* 2012;19:256-264 [FREE Full text] [doi: [10.1016/j.cbpra.2011.01.001](https://doi.org/10.1016/j.cbpra.2011.01.001)]
16. Bush K, Kivlahan DR, McDonnell MB, Fihn SD, Bradley KA. The AUDIT alcohol consumption questions (AUDIT-C): an effective brief screening test for problem drinking. Ambulatory Care Quality Improvement Project (ACQUIP). Alcohol Use Disorders Identification Test. *Arch Intern Med* 1998 Sep 14;158(16):1789-1795. [Medline: [9738608](https://pubmed.ncbi.nlm.nih.gov/9738608/)]
17. Linke S, Brown A, Wallace P. Down your drink: a web-based intervention for people with excessive alcohol consumption. *Alcohol Alcohol* 2004;39(1):29-32 [FREE Full text] [Medline: [14691071](https://pubmed.ncbi.nlm.nih.gov/14691071/)]
18. Cooper J, Hunter C, Owen-Smith A, Gunnell D, Donovan J, Hawton K, et al. "Well it's like someone at the other end cares about you." A qualitative study exploring the views of users and providers of care of contact-based interventions following self-harm. *Gen Hosp Psychiatry* 2011;33(2):166-176. [doi: [10.1016/j.genhosppsych.2011.01.009](https://doi.org/10.1016/j.genhosppsych.2011.01.009)] [Medline: [21596210](https://pubmed.ncbi.nlm.nih.gov/21596210/)]
19. Ranney ML, Choo EK, Cunningham RM, Spirito A, Thorsen M, Mello MJ, et al. Acceptability, language, and structure of text message-based behavioral interventions for high-risk adolescent females: a qualitative study. *J Adolesc Health* 2014 Jul;55(1):33-40 [FREE Full text] [doi: [10.1016/j.jadohealth.2013.12.017](https://doi.org/10.1016/j.jadohealth.2013.12.017)] [Medline: [24559973](https://pubmed.ncbi.nlm.nih.gov/24559973/)]
20. Ranney ML, Freeman JR, Connell G, Spirito A, Boyer E, Walton M, et al. A depression prevention intervention for adolescents in the emergency department. *J Adolesc Health* 2016 Oct;59(4):401-410. [doi: [10.1016/j.jadohealth.2016.04.008](https://doi.org/10.1016/j.jadohealth.2016.04.008)] [Medline: [27267141](https://pubmed.ncbi.nlm.nih.gov/27267141/)]
21. Birbeck N, Lawson S, Morrissey K, Rapley T, Olivier P. Self Harmony: Rethinking Hackathons to Design and Critique Digital Technologies for Those Affected by Self-Harm. New York NY, USA: Association for Computing Machinery; 2017 Presented at: CHI Conference on Human Factors in Computing Systems; May 6-11, 2017; Denver, Colorado, USA p. 146-157. [doi: [10.1145/3025453.3025931](https://doi.org/10.1145/3025453.3025931)]
22. Thieme A, McCarthy J, Johnson P, Phillips S, Wallace J, Lindley S, et al. Challenges for Designing new Technology for Health and Wellbeing in a Complex Mental Healthcare Context. New York, NY, USA: Association for Computing Machinery; 2016 Presented at: Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems; 7-12 May 2016; San Jose, California p. 2136-2149. [doi: [10.1145/2858036.2858182](https://doi.org/10.1145/2858036.2858182)]

Abbreviations

BDI LEAP: Black Dog Institute's Lived Experience Advisory Panel

CRISP LEC: Centre for Research Excellence in Suicide Prevention's Lived Experience Committee

DSH: deliberate self-harm

ED: emergency department

RAFT: Reconnecting AFTER a suicide attempt

SMS: short message service

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Original Paper

Transdiagnostic, Psychodynamic Web-Based Self-Help Intervention Following Inpatient Psychotherapy: Results of a Feasibility Study and Randomized Controlled Trial

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Abstract

Background: Mental disorders have become a major health issue, and a substantial number of afflicted individuals do not get appropriate treatment. Web-based interventions are promising supplementary tools for improving health care for patients with mental disorders, as they can be delivered at low costs and used independently of time and location. Although psychodynamic treatments are used frequently in the face-to-face setting, there has been a paucity of studies on psychodynamic Web-based self-help interventions.

Objective: The objective of this study was to determine the feasibility and preliminary efficacy of a transdiagnostic affect-focused psychodynamic Web-based self-help intervention designed to increase emotional competence of patients with mental disorders.

Methods: A total of 82 psychotherapy inpatients with mixed diagnoses were randomized into two groups. Following discharge, the intervention group (IG) got access to a guided version of the intervention for 10 weeks. After a waiting period of 10 weeks, the wait-list control group (WLCG) got access to an unguided version of the intervention. We reported the assessments at the beginning (T0) and at the end of the intervention, resp. the waiting period (T1). The primary outcome was satisfaction with the treatment at T1. Secondary outcome measures included emotional competence, depression, anxiety, and quality of life. Statistical analyses were performed with descriptive statistics (primary outcome) and analysis of covariance; a repeated measurement analysis of variance was used for the secondary outcomes. Effect sizes were calculated using Cohen *d* and data were analyzed as per protocol, as well as intention-to-treat (ITT).

Results: Patients were chronically ill, diagnosed with multiple diagnoses, most frequently with depression (84%, 58/69), anxiety (68%, 47/69), personality disorder (38%, 26/69), and depersonalization-derealization disorder (22%, 15/69). A majority of the patients (86%, 36/42) logged into the program, of which 86% (31/36) completed the first unit. Satisfaction with the units mastered was rated as good (52%, 16/31) and very good (26%, 9/31). However, there was a steady decline of participation over the course of the program; only 36% of the participants (13/36) participated throughout the trial completing at least 50% of the sessions. According to the ITT analysis, participants improved statistically significantly and with moderate effect sizes (Cohen *d*) compared with the WLCG regarding depression ($d=0.60$), quality of life ($d=0.53$), and emotional competence ($d=0.49$). Effects were considerably stronger for the completers with respect to depression ($d=1.33$), quality of life ($d=0.83$), emotional competence ($d=0.68$), and general anxiety ($d=0.62$).

Conclusions: Although overall program satisfaction and benefit of the program were favorable with respect to the indicators of emotional disorders, the rate of completion was low. Our findings point to the need to target the intervention more specifically to the needs and capabilities of participants and to the context of the intervention.

Trial Registration: Clinicaltrials.gov NCT02671929; <https://clinicaltrials.gov/ct2/show/NCT02671929> (Archived by WebCite at <http://www.webcitation.org/6ntWg1yWb>)

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KEYWORDS

psychoanalytic psychotherapy; emotion-focused therapy; inpatients; aftercare; Internet; clinical trial

Introduction

Background

Mental disorders have become a major health issue worldwide. According to Jacobi et al [1], the 12-month prevalence for mental disorders in Germany was 27.7%, affecting 17.8 million people in the course of 1 year. Despite a broad range of available mental health treatments with established efficacy, less than 50% of individuals afflicted by a mental disorder utilized appropriate health services [1]. Among the reasons for low utilization of mental health care are long waiting times, fear of stigmatization, and time demands of outpatient psychotherapy [2].

Web-based interventions have been considered promising supplementary tools, as they can be delivered at low costs and used independently of time and location [3]. Several meta-analyses have shown medium to high efficacy [4-6], comparable with classical face-to-face therapy [6,7]. In their meta-analyses, Andrews et al [5] concluded that Web-based interventions were well accepted, for example, 86% of participants were satisfied. In a recent study by Richards et al [8], 68% of participants were satisfied with an Web-based intervention for depression.

Web-based self-help interventions have been used in different clinical contexts, for example, self-help for participants with mild to moderate severity of mental complaints [9], combined with outpatient or inpatient psychotherapy [10], or as an aftercare following inpatient treatment [11,12]. In a recent trial by Klein et al [13] with 1013 participants, the effectiveness of a Web-based self-help program for the treatment of mild to moderate depression in different clinical and nonclinical settings could be demonstrated with a between-group effect size of $d=0.39$ post treatment (3 months) and $d=0.32$ in the follow-up (6 months) compared with the usual care (psychological and pharmacological treatments).

Although participants recruited over the Internet fared well, applicability of Web-based self-help interventions for primary care patients has been mixed. Gilbody et al [14] found no benefits of cognitive-behavioral Web-based self-help programs for depression, which had been found efficacious in multiple Web-based trials, compared with the usual care by the general practitioner. Uptake and completion were low despite regular telephone support. While acknowledging potential benefits of the program, participants were struggling with the challenges of their illness, lack of support, and limited personalization of content [15].

In Germany, inpatient psychotherapy is indicated when outpatient psychotherapy has not been sufficient, and severe or multimorbid mental disorders significantly impair activities of daily living and work ability [16]. Although symptoms are expected to improve considerably by inpatient psychotherapy, they may worsen following discharge, particularly when the therapeutic process is not continued by outpatient psychotherapy [17,18].

Although psychodynamic methods are used frequently in outpatient and inpatient treatments in the face-to-face setting [19], the field of Web-based interventions has been dominated so far by cognitive behavioral interventions [6,20,21]. Psychodynamic Web-based interventions have only been developed recently [9,12,22]. Due to the worldwide need for health systems to meet a rising demand for psychotherapeutic treatments, it seems to be logical to take up the challenge from the psychodynamic perspective and develop Web-based interventions, which could improve the shortage [23] of psychotherapeutic treatments.

Efficacy and effectiveness have been proved for psychodynamic psychotherapies for different disorders [24,25], and a recent meta-analysis by Diener et al [26] indicated that facilitation of the affective experience and expression of patients in psychotherapy could further improve treatment results. The affect-focused psychodynamic intervention developed by Johansson et al [27] was based on the affect phobia therapy model by McCullough and Andrews [28] and an adaptation of the concept of mindfulness [29] as outlined in an American self-help book [30]. The affect phobia model postulates that people have become fearful of their feelings, as these had been discouraged, invalidated, or ridiculed by significant persons earlier in their lives [28]. On the basis of the biographical vignettes of patients' life and treatment experiences, the self-help program guides participants to experience and express their emotions and thus to confront and overcome their maladaptive fears.

Johansson et al [9] recruited participants with depression or anxiety disorders over the Internet. They compared the intervention group (IG) with a control group that received basic support and clinical monitoring of symptoms but no treatment modules or any specific psychotherapeutic support. The between-group effect sizes in the randomized controlled trial (RCT) were moderate ($d=0.48$ for anxiety; $d=0.77$ for depression), and remission rates were significantly higher in the IG compared with the control group.

Objectives

The primary goal of this study was to test the feasibility of a psychodynamic Web-based self-help intervention for psychosomatic inpatients. For this purpose, we translated and adapted the self-help book *Living Like You Mean It* to the German language and health care system. Unlike Johansson et al [9], we did not recruit via Internet, through advertisement, but rather included participants of inpatient or day clinic treatment before discharge. As facilitation of emotional experience is one of the core processes in psychodynamic psychotherapy [31], we enlarged the scope of the transdiagnostic study to a broad range of mental disorders.

Beyond that, we wanted to gather first hints of efficacy of the intervention regarding emotional competence, depression, and anxiety with an RCT.

Hypotheses

On the basis of a previous study [9], we hypothesized that at least 75% of the participants of the IG will be “very satisfied” or “mainly satisfied” with the intervention, and that at least 50% of them will complete all 8 units.

Furthermore, we expected the participants of the IG to show significantly higher emotional competence, lower depression, and anxiety scores at the end of the intervention compared with the participants of the control group.

Methods

Recruitment

Becker et al [10] had described that inpatients and day clinic patients of the Department of Psychosomatic Medicine and Psychotherapy who were above the age of 18 years and had Internet access and an email address were eligible to participate. Patients with acute suicidality, psychosis, current alcohol or drug addiction, and a lifetime diagnosis of schizophrenia, schizoaffective, bipolar, or organic psychiatric disorder were excluded. Patients were informed about the study and its rationale in an information session during their inpatient or day clinic treatment. After giving written informed consent, eligible patients were coded and randomized by block randomization at a ratio of 1:1 with the help of the computer software Research Randomizer provided in the Web by Urbaniak and Plous [32]. Upon discharge, they received their log-in to the Web-based self-help intervention.

Intervention

The intervention was based on the self-help book *Living Like You Mean It* by Ronald J Frederick [30], which the Swedish work group around Gerhard Andersson recently adapted in their trial [9,27]. We translated the original English manuscript and adapted the content to the German health care system and culture. We compared our version with the Swedish one, and we translated and revised the tasks [9]. The program was piloted with psychotherapy inpatients and thoroughly revised by experts (2 experienced psychotherapists of our clinic).

In this book, 8 units—corresponding to the chapters—cover four steps: enhancing awareness of one’s emotions and related

defenses, regulating the anxiety that emerges when feared emotions are approached, fully experiencing, and mindfully expressing emotions to other people [10]. All units are presented online in a consecutive order, supplemented with questions and tasks for the participants to work through after completion of each unit. Among various exercises, mindfulness was included as text instructions and audio files according to Kabat-Zinn [29]. Attending to bodily felt experience was regarded as a major venue for feeling and regulating emotions.

Upon discharge from inpatient or day clinic treatment, the IG got access to the intervention for 10 weeks when they first logged onto the platform (Multimedia Appendix 1). Participation was free of charge. To complete the intervention within 10 weeks, participants were asked to do one unit (Multimedia Appendix 2) per week. Only when participants had answered all questions in the unit’s tasks (Multimedia Appendix 3) and transmitted them to the Web-based therapist, a unit was considered to have been completed. Encouraging feedback was delivered within 2 weekdays after transmission of their replies by a trained psychologist who was supervised by 2 experienced psychotherapists, familiar with the intervention.

Control Condition

The study was performed using a wait-list control design to evaluate the efficacy of the intervention developed. Patients in the wait-list control group (WLCG) started their intervention 10 weeks after discharge from inpatient or day hospital treatment, when the intervention of the IG had ended. Additionally, the WLCG received an unguided version of the intervention and therefore did not receive feedback from a Web-based therapist (to be analyzed separately).

Outcomes

All questionnaires were given online. Assessments were performed at discharge from the clinic (T0), at the end of the intervention of the IG (T1), 2 months later for follow-up assessment (T2; only IG), and at the end of the intervention of the WLCG (T3; only WLCG).

Primary Endpoint

Satisfaction with the intervention in the IG as the primary endpoint was measured with one item of the German version of the Client Satisfaction Questionnaire (CSQ-8) [33] at T1. The item “How satisfied are you with the Web-based self-help program overall?” was rated on a 4-point Likert scale (“very satisfied,” “mostly satisfied,” “slightly satisfied,” “rather dissatisfied”). We used this item instead of the scale score because it was more appropriate to compare the results with the original Swedish study [9], which reported frequencies of overall satisfaction (82%) with the Web-based self-help intervention on which our program was based.

Additionally, we assessed satisfaction on a weekly basis with the item “Please rate the unit as a whole.” on a 5-point Likert scale (“very good,” “good,” “satisfactory,” “bad,” “very bad”).

Additionally, participants rated their satisfaction with each unit completed on a 5-point Likert scale from “bad” to “very good.”

Secondary Endpoints

Emotional competence was assessed with the German version of the 27-item Emotion-Regulation Skills Questionnaire (ERSQ) [34]. As items range from 0 to 4, they are summed up to a score from 0 to 108. Internal consistency is high (Cronbach alpha=.90).

The Patient Health Questionnaire-9 (PHQ-9) [35] was used to assess depressive symptoms. Adding the scores of the 9 items (from 0-3), the total score ranges from 0 to 27. Scores below 5 are labeled minimal, scores between 5 and 9 mild, from 10 to 14 as moderate, and above 14 as severe depressive symptoms. Psychometric properties are sound with Cronbach alpha ranging between .86 and .89.

Anxiety was assessed by the General Anxiety Disorder-7 (GAD-7) [36,37], which is based on the same Likert scale and has corresponding cut-offs as the PHQ-9. Its validity has been verified and its Cronbach alpha of .92 demonstrated a sufficient reliability.

Depersonalization was assessed with the 2-item version of the Cambridge Depersonalization Scale (CDS-2) [38] describing the feeling of being detached from one's body, thoughts, or emotions. The CDS-2 sum score (range 0-6, scoring format is identical with the GAD-2) correlates strongly with clinician rated depersonalization severity ($r=.77$) with a sensitivity of 78.9% and a specificity of 85.7%.

Quality of life was measured with the reliable and valid European Health Interview Survey Quality of Life 8-item index (EUROHIS-QOL-8) [39], a shortened version of the World Health Organization Quality of Life Instrument-Abbreviated Version (WHOQOL-BREF) using a Likert scale ranging from 0 to 4. A higher mean score indicates better quality of life.

The Rosenberg Self-Esteem Scale (RSE) [40] was used to assess self-esteem by 10-Likert scale items ranging from 0 to 3. Higher scores imply higher self-esteem. Internal consistency (Cronbach alpha=.84) and validity have been shown in a previous study [41].

The subjective prognosis of gainful employment (SPE) [42] assessed the subjective prognosis of gainful employment with 3 items, resulting in a score between 0 and 3, so that a higher score indicates a higher risk for work disability or early retirement.

The 8-item Somatic Symptom Scale (SSS-8) [43] is a reliable and valid self-report measure covering gastrointestinal, pain, fatigue, cardiopulmonary, and general somatic symptoms burden over the past 7 days (0 = "not at all" to 4 = "very much").

Symptoms of depression and anxiety were measured after completing every unit with the PHQ-4 [44]. The PHQ-4 is a very short, reliable, and valid combination of items from the PHQ-9 and the GAD-7, consisting of four items, two for anxiety and depression each.

Completion of units was determined objectively on the basis of entries in the database of the platform.

Statistical Methods

The primary outcome was evaluated with descriptive statistics. Secondary outcomes were analyzed by analysis of covariance (ANCOVA) controlling outcome variables by their baseline scores and a repeated measurement analysis of variance (ANOVA) for the weekly assessment of the PHQ-4. With the participants' written consent, diagnoses were taken from the clinical documentation of the Department of Psychosomatic Medicine and Psychotherapy. Effect sizes were calculated transforming the eta-squared from ANCOVA into Cohen d to estimate treatment effects controlled for the baseline score. Multiple imputations resulted in implausible results by overestimating effects because of missing data, especially in participants with less completed units. Therefore, last observation carried forward (LOCF) was used as a conservative approach in an intention-to-treat analysis (ITT). All analyses have been conducted with IBM SPSS Statistics version 23 [45].

As this was a feasibility study, no power analysis was conducted. Over the course of 20 weeks (from September 2015 to February 2016), consecutive patients (inpatient and day hospital) treated at the Department of Psychosomatic Medicine and Psychotherapy were invited to participate in the trial. As the clinic treats about 390 inpatients per year and we assumed a participation rate of approximately 30% [11], we expected a sample size of 66 patients.

Ethics and Data Security

Randomization of participants and storing of personal data were conducted by the Study Center of Mental Disorders at the University Medical Center Mainz. Management of the study, administration of the Internet platform, and therapeutic feedback for the patients in the IG were performed by psychologists of the Department of Psychosomatic Medicine and Psychotherapy. A firewall-protected Web server using a secure sockets layer-encrypted access to the platform itself and the database containing the log-in information hosted the study platform. All questionnaires were administered Web-based with SoSci Survey [46]. Patients logged in on the study platform using pseudonyms. As no personal data were stored on the Web server, personal data of users could not be identified.

The Ethics Committee of the Statutory Physician Board of the State of Rhineland-Palatinate approved the clinical protocol and written informed consent (Ref. No. 837.299.15-10067), and all procedures described in the clinical trial protocol (ClinicalTrials.gov Identifier: NCT02671929) follow the ICH-GCP guidelines and ethical principles described in the current revision of the Declaration of Helsinki. Local legal and regulatory requirements were abided.

Results

Study Flow and Patient Characteristics

Figure 1 shows the flow of participants in the study. Out of 144 patients approached, 115 patients participated in the study information session. Of these, 26.9% (31/115) declined to participate. Two patients willing to participate had to be excluded because they had no private Internet access.

A total of 82 participants were randomized to IG or WLCG. In addition, 86% (36/42) of the IG logged into the platform (values for WLCG were similar), and another 86% (31/36) completed the first unit. Nonstarters (IG: $n=6$; WLCG: $n=7$) were more often male than female (53.8% vs 46.2%) and more likely to be part-time employed than starters but not on a statistical significant level.

Furthermore, 7 patients dropped out, 4 from the IG and 3 from the WLCG group; the reasons that they named were health problems ($n=3$), lack of time ($n=2$), and problems of dealing with the Web-based intervention ($n=1$), and one patient gave no response. Dropouts were older (mean 50.80, SD 7.92 vs mean 39.06, SD 14.36) than participants ($t_{6,3}=2.96$, $P=.02$, $d=1.37$); otherwise, there were no differences. At the end of the treatment phase, waiting period (T1), 61% (50/82) of randomized participants completed the assessment.

Participants who completed the T1 assessment did not differ from those participants who dropped out concerning sociodemographic characteristics and baseline mental symptoms. For all outcome analyses, patients were excluded when the baseline assessment (T0) was missing ($n=13$). A total of 69 participants were analyzed after substituting in the missing data based on LOCF.

In the IG, 13 participants completed the intervention, that is, logged into the intervention continuously for 10 weeks and finished at least 50% of the units. Table 1 shows the demographic and medical baseline data, separately for the IG and the WLCG.

The majority of participants were female and unmarried; mean age was 40 years (IG: mean 38.92, SD 12.66; WLCG: mean 41.00, SD 16.00). Despite good education, only slightly over half of them were working or in training. Most frequent main diagnoses were affective, anxiety, and personality disorders, followed by depersonalization-derealization disorder and somatoform disorders. Substance abuse, eating disorders, and obsessive-compulsive disorders, etc, were classified as “others” in the table according to the International Statistical Classification of Diseases, Tenth Revision [47]. The majority (83%, 57/69) had more than one diagnosis.

As the baseline data (T0) in Table 1 show slight differences exist between IG and WLCG on entry into the study. The IG had lower scores of depersonalization-derealization symptoms

(CDS-2) than the WLCG (ITT: $P=.02$, Completer: $P=.01$). Furthermore, the completer in the IG reported a higher quality of life at baseline than the WLCG ($P=.04$).

Primary Outcome

The majority was mostly (57%, 12/21) or very satisfied (38%, 8/21); only one participant (5%, 1/21) was slightly dissatisfied (based on the one item of the CSQ-8). Asked whether they would do the Web-based self-help program once more if they needed help, more than half of the participants (57%, 12/21) said “definitely yes,” about one third (29%, 6/21) said, “I believe so,” and only few (14%, 3/21) answered, “I do not believe so.” As overall satisfaction in the CSQ-8 at T1 was only rated by a small proportion of participants who had completed assessments at termination ($n=21$), we also analyzed ratings of the quality of the units mastered in the Web-based self-help program. For this purpose, we used the ratings for the last session completed by each participant. On the basis of total 31 responses, satisfaction was judged as very good (29%, 9/31), good (52%, 16/31), satisfactory (16%, 5/31), and bad (3%, 1/31). Thus, overall satisfaction exceeded our expectations of 75%.

The total score of the CSQ-8 in the IG (mean 26.33, SD 2.89) was above the cut-off (24.5), which indicates a high treatment satisfaction as calculated in a large sample of inpatients of psychosomatic rehabilitation [48].

Secondary Outcomes

Table 2 shows descriptive statistics for secondary outcomes, and Table 3 presents the test statistics.

Tables 2 and 3 show that the IG improved regarding the secondary outcome criteria, whereas the WLCG deteriorated. Compared with the WLCG, there were significant benefits in the IG regarding depressive symptoms, quality of life, and a trend to improvement regarding emotional competence in the ITT analyses (LOCF). Effect size differences were in the moderate range. Among completers of the intervention, there were significant improvements regarding emotional competence, depression, anxiety, and quality of life. Effect size differences were large (depression, quality of life) to moderate.

Psychological complaints in the course of the intervention assessed with the PHQ-4 did not change over time in the IG using a repeated measurement ANOVA with LOCF ($F_{7,210}=0.66$; $P=.70$).

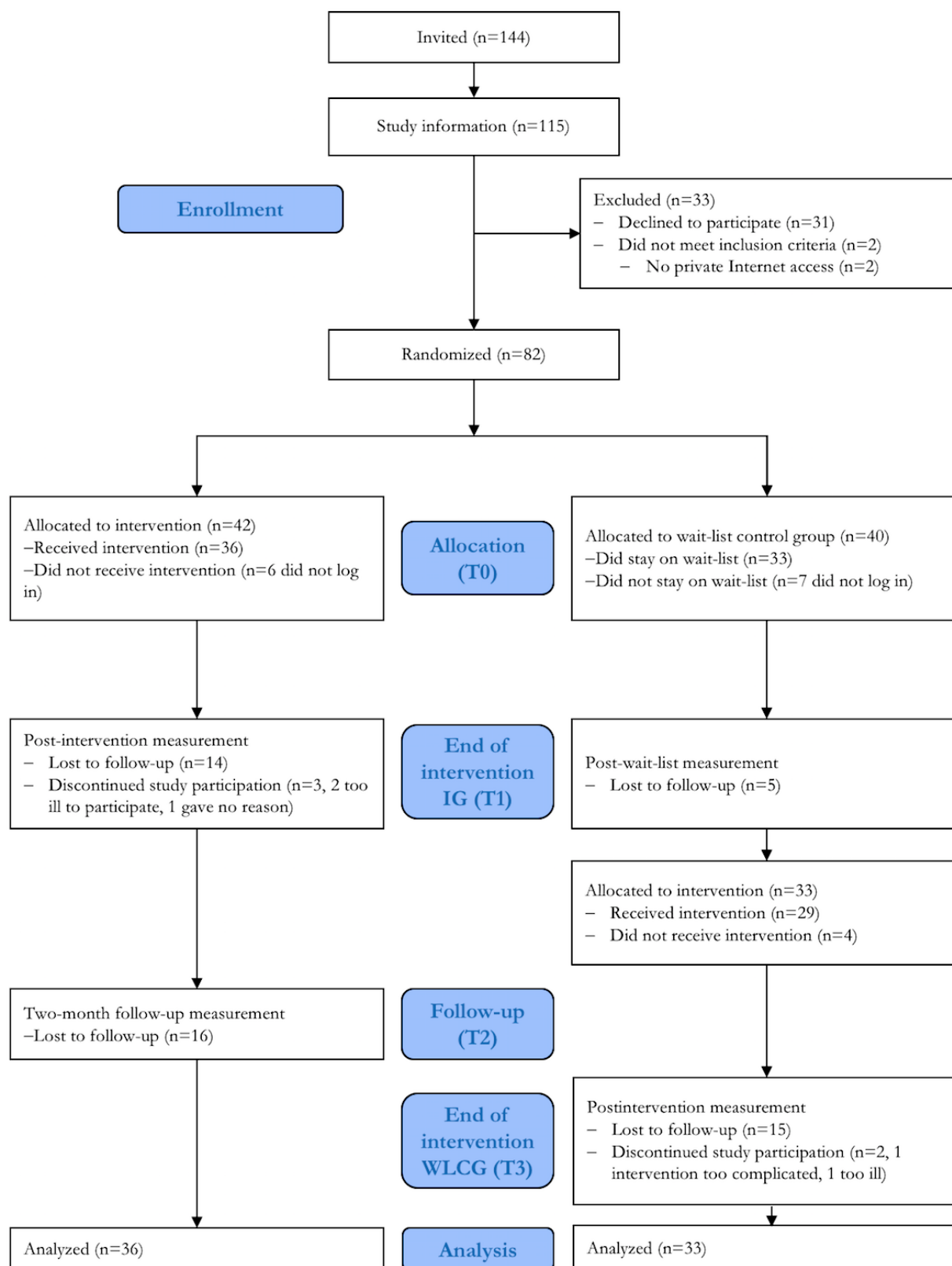
Figure 1. The CONSORT (Consolidated Standards of Reporting Trials) flow diagram.

Table 1. Demographic and medical data of study participants.

Demographic and medical data	IG ^a (n=36), n (%)	WLCG ^b (n=33), n (%)	Total (N=69) ^c , n (%)
Sex			
Female	29 (81)	20 (61)	49 (71)
Male	7 (19)	13 (39)	20 (29)
Marital status			
Single	23 (64)	19 (61)	42 (63)
Married	8 (22)	9 (29)	17 (25)
Separated, divorced, widowed	5 (14)	3 (10)	8 (12)
Education			
No, lower, or other graduation	6 (17)	1 (4)	7 (11)
Middle secondary	9 (25)	16 (51)	25 (37)
Higher secondary	21 (58)	14 (45)	35 (52)
Employment			
Full-time	13 (36)	7 (21)	20 (29)
Part-time	7 (19)	4 (12)	11 (16)
Apprenticeship	4 (11)	1 (3)	5 (7)
Retired	3 (8)	3 (9)	6 (9)
Not working	3 (8)	15 (46)	18 (26)
Other	6 (17)	3 (9)	9 (13)
Medical diagnoses^d			
Affective disorders (F30-F34)	27 (75)	31 (94)	58 (84)
Anxiety disorders (F40-F41)	21 (58)	26 (79)	47 (68)
Personality disorders (F60-F69)	12 (33)	14 (42)	26 (38)
Depersonalization-derealization disorder (F48.1) ^e	4 (11)	11 (33)	15 (22)
Somatoform (F45)	3 (8)	3 (9)	6 (9)
Others (including F1x; F42; F50)	18 (50)	14 (42)	32 (46)
Ongoing outpatient psychotherapy at intake			
Yes	13 (36)	12 (39)	25 (37)
No	23 (64)	18 (58)	41 (61)

^aIG: intervention group.^bWLCG: wait-list control group.^cWith the exception of gender, data on 2 persons missing.^dMultiple diagnoses; International Statistical Classification of Diseases (ICD-10) codes in parenthesis.^eSignificant difference between groups; $\chi^2_1=4.7$, $P=.03$, Cramer $V=.26$.

Table 2. Descriptive statistics of outcome criteria at baseline and at the end of the intervention: intervention group (total, completers) versus wait-list control group.

Outcomes	T0 ^a			T1 ^b		
	IG _{total} ^c (n=36), mean (SD) ^d	IG _{comp} (n=13) ^e , mean (SD)	WLCG _{total} ^f (n=33), mean (SD)	IG _{total} (n=36), mean (SD)	IG _{comp} (n=13), mean (SD)	WLCG _{total} (n=33), mean (SD)
Emotion Regulation Skills Questionnaire (ERSQ)	61.75 (17.13)	66.85 (8.58)	60.09 (15.22)	63.84 (18.24)	69.92 (13.85)	56.24 (15.60)
Patient Health Questionnaire 9 (PHQ-9)	11.92 (5.46)	10.08 (4.92)	12.06 (5.7)	11.06 (6.49)	7.23 (3.92)	13.15 (5.89)
Generalized Anxiety Disorder Assessment (GAD-7)	10.53 (4.9)	9.46 (5.17)	10.61 (5.15)	10.11 (5.42)	7.23 (4.13)	10.30 (5.25)
European Health Interview Survey Quality of Life 8 (EUROHIS-QOL-8)	2.04 (0.69)	2.38 (0.47)	1.98 (0.62)	2.15 (0.88)	2.65 (0.73)	1.87 (0.66)
Rosenberg Self-Esteem Scale (RSE)	18.83 (7.31)	22.46 (5.30)	20.42 (6.45)	17.08 (8.33)	19.61 (7.02)	17.39 (6.92)
Somatic Symptom Scale (SSS-8)	11.42 (5.54)	8.92 (4.46)	11.76 (6.65)	11.06 (6.13)	8.69 (5.28)	12.64 (6.73)
Cambridge Depersonalization Scale Short Version (CDS-2)	1.47 (1.89)	1.15 (1.46)	2.76 (2.61)	1.31 (1.69)	0.69 (0.95)	2.55 (2.39)
Subjective prognosis of gainful employment (SPE)	1.36 (1.27)	0.69 (1.03)	1.15 (1.18)	1.17 (1.21)	0.46 (0.97)	1.03 (1.10)

^aT0: Baseline.^bT1: End of intervention.^cIG: intervention group.^dSD: standard deviation.^eCompleters of the IG (10 weeks log-in and >50% of the units completed).^fWLCG: wait-list control group.**Table 3.** Test statistics: intention-to-treat (ITT) and completer analyses comparing intervention group (ITT, completers) and wait-list control group.

Outcomes	T0 ^a				T1 ^b					
	ITT ^c		Completer		ITT		Completer			
	<i>t</i> ₆₇	<i>P</i>	<i>t</i> ₄₄	<i>P</i>	<i>F</i> _{1,66}	<i>P</i>	<i>d</i>	<i>F</i> _{1,43}	<i>P</i>	<i>d</i>
Emotion Regulation Skills Questionnaire (ERSQ)	0.42	.67	1.50	.14	3.89	.05	0.49	4.98	.03	0.68
Patient Health Questionnaire-9 (PHQ-9)	0.11	.92	1.10	.28	6.01	.02	0.60	19.01	<.001	1.33
Generalized Anxiety Disorder Assessment (GAD-7)	0.07	.95	0.68	.50	0.02	.88	0.00	4.09	.049	0.62
European Health Interview Survey Quality of Life 8 (EUROHIS-QOL-8)	0.38	.70	2.12	.04	4.63	.04	0.53	7.35	.01	0.83
Rosenberg Self-Esteem Scale (RSE)	0.96	.34	1.01	.32	0.81	.37	0.22	0.12	.73	0.11
Somatic Symptom Scale (SSS-8)	0.23	.82	1.41	.17	2.41	.01	0.38	1.51	.23	0.38
Cambridge Depersonalization Scale Short Version (CDS-2)	2.33	.02	2.63	.01	0.70	.41	0.21	2.03	.08	0.55
Subjective prognosis of gainful employment (SPE)	0.71	.48	1.23	.23	0.15	.70	0.09	1.60	.21	0.39

^aT0: baseline; *t* test with test statistics (*t*_{df}), level of significance (*P*).^bT1: End of intervention; analysis of covariance with *F* test statistics (*F*_{df}), level of significance (*P*) and effect size (Cohen *d*).^cITT: Intention-to-treat.

Discussion

Principal Findings

Web-based self-help interventions have proven effective in treating different kinds of mental disorders across a broad range of health contexts as single intervention as well as supplements to face-to-face treatments. However, although about half of face-to-face interventions in Germany have been psychodynamic, there has been little research on psychodynamic Web-based self-help. We have chosen affect-focused psychodynamic psychotherapy, which has proven an effective Web-based treatment for anxiety and depression [9]. As the original trial yielded promising results on the basis of the patients with generalized anxiety disorder recruited over the Internet, we decided to test the feasibility and efficacy of psychodynamic Web-based self-help for a wider range of patients from clinical practice. We proceeded similarly to Farchione et al [49], who studied a unified protocol for a transdiagnostic emotion-focused cognitive behavioral therapy for emotional disorders. Similar to Moses and Barlow [50], we presumed that avoidance of emotional experience is a widespread factor in mental disorders [31], and we therefore enlarged the scope of the transdiagnostic study to a broad range of mental disorders. On the basis of the previous findings [9], we had expected improvement of depression, anxiety, and emotional competence.

In addition, our purpose was shifted from a single intervention to aftercare following inpatient or day clinic psychotherapy. Keeping these substantial differences to the previous trial in mind, our primary aim was to investigate the feasibility of our intervention.

Acceptance was good, that is, only 26.9% (31/115) of those attending the information session declined participation. Of those randomized to the IG, the great majority (86%, 36/42) logged into the program, and of these, 86% (31/36) completed the first unit (similar values were found for the WLCG). Satisfaction was rated highly at 95% (20/21). Due to the high proportion of missing data at the follow-up assessment, we additionally used the ratings for individual sessions completed, which still met our expectations of at least 75% satisfied, that is, rated as good (52%, 16/31) and very good (29%, 9/31). However, there was a steady decline of participation from unit 1 to unit 8; only 13/36 participants (36%) were actively participating throughout the entire program, completing at least 50% of the units. Similar to a trial by Gilbody et al [14,15], the major reasons for dropping out of the program were that it was considered too demanding and exhausting. Indeed, participants reported spending an average of 5 hours per week with the program, which can be considered a barrier to completion.

However, results pointed to considerable benefit from participation in the program. According to the conservative estimates of ITT analysis with LOCF, participants improved significantly and with moderate effect sizes compared with the WLCG with improvements in depression, quality of life, and emotional competence (trend). Effects of the small number of completers were considerably stronger. In line with previous findings [9], they reached strong effects regarding depression

and anxiety and moderate effects regarding emotional processing.

Although we had proposed that Web-based self-help may fill a gap between inpatient treatment and aftercare, we had not anticipated that 82% (18/22) in the IG and 68% (18/27) in the WLCG continued previous psychotherapy or started a new face-to-face treatment during our trial. We cannot be sure whether continuing or starting psychotherapy may have further discouraged participation in the Web-based self-help program because of additional time demands, and we cannot tell whether psychotherapists were informed of program participation by their patients and whether they were encouraging or discouraging toward participation by their patients.

Limitations

There was a striking discrepancy between overall program satisfaction and benefit and the low rate of completion of the program, which we had not anticipated. This stands in contrast to the previous trial by Johansson et al [9], where 84% of patients with anxiety or depressive disorders completed all modules, receiving comparable encouragement by a therapist. Although Johansson et al [9] had recruited participants over the Internet, we recruited patients who had just undergone lengthy and intensive psychotherapy on an inpatient or day hospital basis. Comparisons between trials need to be cautioned by the greater diagnostic heterogeneity, which we had sought by purpose. Clearly, the participants in the study of Johansson et al [9] had a higher symptom load at the start than our group, which may have motivated patients to follow through with the program and limited the gains, which could be achieved in our trial.

A strength of this study was that we applied it in a clinical setting, recruiting patients from mental health care treatment. However, following intensive inpatient psychotherapy, our effect sizes can be expected to be smaller compared with trials when patients are recruited for primary Web-based treatment. Our findings alert us to the significance of the context of additional mental health treatments. An ongoing psychotherapy may have further diminished motivation and time for Web-based treatment, which was present in a substantial part of our IG but almost absent in the Swedish group. Although both groups resembled each other in terms of age, gender, and education, unlike the Swedish participants, our patient group was predominantly single and a high percentage was not working. From our clinical point of view, we would see this as being indicative of a chronically sick sample, with a considerable comorbidity of personality disorders, whose difficulties in life adjustment may have well impeded the ability to follow through a Web-based program that requires substantial self-directed effort.

As this was a feasibility study, the sample was small, particularly in the completer group. Therefore, we cannot differentiate compliance and success between subgroups (eg, the presence or absence of personality disorder, the structure of work, or outpatient psychotherapy).

Unfortunately, it is also not possible to compare the effects at the end of the intervention between the IG and the WLCG

because participants of the WLCG only got access to the intervention after a waiting period of 10 weeks.

Conclusions

Our findings point to the requirement to target the intervention more specifically to the needs and capabilities of participants and the context of traditional mental health care. Although participants were satisfied with our intervention and gained significant benefits, the majority was not willing or able to follow it through to completion. To reduce the considerable

weekly time demands, we have increased flexibility of participation differentiating between the required and optional exercises and extended the time allotted. To increase familiarity and compliance under less challenging conditions, we plan to offer participation to future patients routinely during inpatient treatment—given positive experiences in a recent trial combining deprexis24 with inpatient psychotherapy [51]. We believe that initiating the program in a structured and supportive therapeutic setting may make it easier to continue program participation when participants are on their own during aftercare.

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Conflicts of Interest

RJF is the author of the book used as a basis for the treatment manual. All other authors declare that they have no conflicts of interest.

Multimedia Appendix 1

Screenshot of the Home page.

[[JPG File, 98KB - mental_v4i4e41_app1.jpg](#)]

Multimedia Appendix 2

Screenshot of unit 2 of the intervention.

[[JPG File, 141KB - mental_v4i4e41_app2.jpg](#)]

Multimedia Appendix 3

Screenshot of task 1 from unit 2 of the intervention.

[[JPG File, 146KB - mental_v4i4e41_app3.jpg](#)]

Multimedia Appendix 4

CONSORT EHEALTH form V1.6.

[[PDF File \(Adobe PDF File\), 677KB - mental_v4i4e41_app4.pdf](#)]

References

1. Jacobi F, Höfler M, Strehle J, Mack S, Gerschler A, Scholl L, et al. Mental disorders in the general population. Study on the health of adults in Germany and the additional module mental health (DEGS1-MH). *Nervenarzt* 2016;87(1):88-90. [doi: [10.1007/s00115-013-3961-y](https://doi.org/10.1007/s00115-013-3961-y)] [Medline: [24441882](#)]
2. van Beljouw I, Verhaak P, Prins M, Cuijpers P, Penninx B, Bensing J. Reasons and determinants for not receiving treatment for common mental disorders. *Psychiatr Serv* 2010 Mar;61(3):250-257. [doi: [10.1176/ps.2010.61.3.250](https://doi.org/10.1176/ps.2010.61.3.250)] [Medline: [20194401](#)]
3. Giesemann A, Böckermann M, Pietrowsky R. Internetbasierte Gesundheitsinterventionen. *Psychotherapeut* 2015 Jun 20;60(5):433-440. [doi: [10.1007/s00278-015-0038-3](https://doi.org/10.1007/s00278-015-0038-3)]
4. Barak A, Hen L, Boniel-Nissim M, Shapira N. A comprehensive review and a meta-analysis of the effectiveness of Internet-based psychotherapeutic interventions. *J Technol Hum Serv* 2008 Jul 03;26(2-4):109-160. [doi: [10.1080/15228830802094429](https://doi.org/10.1080/15228830802094429)]
5. Andrews G, Cuijpers P, Craske MG, McEvoy P, Titov N. Computer therapy for the anxiety and depressive disorders is effective, acceptable and practical health care: a meta-analysis. *PLoS One* 2010;5(10):e13196 [[FREE Full text](#)] [doi: [10.1371/journal.pone.0013196](https://doi.org/10.1371/journal.pone.0013196)] [Medline: [20967242](#)]

6. Andersson G, Cuijpers P, Carlbring P, Riper H, Hedman E. Guided Internet-based vs. face-to-face cognitive behavior therapy for psychiatric and somatic disorders: a systematic review and meta-analysis. *World Psychiatry* 2014 Oct;13(3):288-295 [FREE Full text] [doi: [10.1002/wps.20151](https://doi.org/10.1002/wps.20151)] [Medline: [25273302](https://pubmed.ncbi.nlm.nih.gov/25273302/)]
7. Cuijpers P, Donker T, van Straten A, Li J, Andersson G. Is guided self-help as effective as face-to-face psychotherapy for depression and anxiety disorders? A systematic review and meta-analysis of comparative outcome studies. *Psychol Med* 2010 Dec;40(12):1943-1957. [doi: [10.1017/S0033291710000772](https://doi.org/10.1017/S0033291710000772)] [Medline: [20406528](https://pubmed.ncbi.nlm.nih.gov/20406528/)]
8. Richards D, Murphy T, Viganó N, Timulak L, Doherty G, Sharry J, et al. Acceptability, satisfaction and perceived efficacy of "Space from Depression" an internet-delivered treatment for depression. *Internet Interv* 2016 Sep;5:12-22. [doi: [10.1016/j.invent.2016.06.007](https://doi.org/10.1016/j.invent.2016.06.007)]
9. Johansson R, Björklund M, Hornborg C, Karlsson S, Hesser H, Ljótsson B, et al. Affect-focused psychodynamic psychotherapy for depression and anxiety through the Internet: a randomized controlled trial. *PeerJ* 2013;1:e102 [FREE Full text] [doi: [10.7717/peerj.102](https://doi.org/10.7717/peerj.102)] [Medline: [23862104](https://pubmed.ncbi.nlm.nih.gov/23862104/)]
10. Becker J, Zwerenz R, Johansson R, Frederick RJ, Andersson G, Beutel ME. Using a transdiagnostic, psychodynamic online self-help intervention to maintain inpatient psychosomatic treatment effects: study protocol of a feasibility study. *Internet Interv* 2016 Sep;5:30-35. [doi: [10.1016/j.invent.2016.07.003](https://doi.org/10.1016/j.invent.2016.07.003)]
11. Ebert D, Tarnowski T, Gollwitzer M, Sieland B, Berking M. A transdiagnostic internet-based maintenance treatment enhances the stability of outcome after inpatient cognitive behavioral therapy: a randomized controlled trial. *Psychother Psychosom* 2013;82(4):246-256. [doi: [10.1159/000345967](https://doi.org/10.1159/000345967)] [Medline: [23736751](https://pubmed.ncbi.nlm.nih.gov/23736751/)]
12. Zwerenz R, Gerzymisch K, Edinger J, Holme M, Knickenberg RJ, Spörl-Dösch S, et al. Evaluation of an internet-based aftercare program to improve vocational reintegration after inpatient medical rehabilitation: study protocol for a cluster-randomized controlled trial. *Trials* 2013 Jan 25;14:26 [FREE Full text] [doi: [10.1186/1745-6215-14-26](https://doi.org/10.1186/1745-6215-14-26)] [Medline: [23351836](https://pubmed.ncbi.nlm.nih.gov/23351836/)]
13. Klein JP, Berger T, Schröder J, Späth C, Meyer B, Caspar F, et al. Effects of a psychological Internet intervention in the treatment of mild to moderate depressive symptoms: results of the EVIDENT study, a randomized controlled trial. *Psychother Psychosom* 2016;85(4):218-228. [doi: [10.1159/000445355](https://doi.org/10.1159/000445355)] [Medline: [27230863](https://pubmed.ncbi.nlm.nih.gov/27230863/)]
14. Gilbody S, Littlewood E, Hewitt C, Brierley G, Tharmanathan P, Araya R, REEACT Team. Computerised cognitive behaviour therapy (cCBT) as treatment for depression in primary care (REEACT trial): large scale pragmatic randomised controlled trial. *Br Med J* 2016;351:h5627 [FREE Full text] [Medline: [26559241](https://pubmed.ncbi.nlm.nih.gov/26559241/)]
15. Knowles SE, Lovell K, Bower P, Gilbody S, Littlewood E, Lester H. Patient experience of computerised therapy for depression in primary care. *Br Med J Open* 2015 Nov 30;5(11):e008581. [doi: [10.1136/bmjopen-2015-008581](https://doi.org/10.1136/bmjopen-2015-008581)] [Medline: [26621513](https://pubmed.ncbi.nlm.nih.gov/26621513/)]
16. Zipfel S, Herzog W, Kruse J, Henningsen P. Psychosomatic medicine in Germany: more timely than ever. *Psychother Psychosom* 2016;85(5):262-269. [doi: [10.1159/000447701](https://doi.org/10.1159/000447701)] [Medline: [27509065](https://pubmed.ncbi.nlm.nih.gov/27509065/)]
17. Franz M, Seidler D, Jenett D, Schäfer R, Wutzler U, Kämmerer W, et al. Psychodynamically oriented inpatient psychotherapy of depressive disorders - First findings from a naturalistic, multicenter study. *Z Psychosom Med Psychother* 2015;61(1):19-35. [doi: [10.13109/zptm.2015.61.1.19](https://doi.org/10.13109/zptm.2015.61.1.19)] [Medline: [25831982](https://pubmed.ncbi.nlm.nih.gov/25831982/)]
18. Zeeck A, Wietersheim JV, Weiss H, Beutel M, Hartmann A. The INDDep study: inpatient and day hospital treatment for depression - symptom course and predictors of change. *BMC Psychiatry* 2013 Mar 26;13:100 [FREE Full text] [doi: [10.1186/1471-244X-13-100](https://doi.org/10.1186/1471-244X-13-100)] [Medline: [23531019](https://pubmed.ncbi.nlm.nih.gov/23531019/)]
19. Leichsenring F, Leibling E. Psychodynamic psychotherapy: a systematic review of techniques, indications and empirical evidence. *Psychol Psychother* 2007 Jun;80(Pt 2):217-228. [doi: [10.1348/147608306X117394](https://doi.org/10.1348/147608306X117394)] [Medline: [17535596](https://pubmed.ncbi.nlm.nih.gov/17535596/)]
20. Buntrock C, Ebert DD, Lehr D, Smit F, Riper H, Berking M, et al. Effect of a web-based guided self-help intervention for prevention of major depression in adults with subthreshold depression: a randomized clinical trial. *J Am Med Assoc* 2016 May 3;315(17):1854-1863. [doi: [10.1001/jama.2016.4326](https://doi.org/10.1001/jama.2016.4326)] [Medline: [27139058](https://pubmed.ncbi.nlm.nih.gov/27139058/)]
21. Hedman E, Ljótsson B, Kaldo V, Hesser H, El Alaoui S, Kraepelien M, et al. Effectiveness of Internet-based cognitive behaviour therapy for depression in routine psychiatric care. *J Affect Disord* 2014 Feb;155:49-58. [doi: [10.1016/j.jad.2013.10.023](https://doi.org/10.1016/j.jad.2013.10.023)] [Medline: [24238951](https://pubmed.ncbi.nlm.nih.gov/24238951/)]
22. Becker J, Beutel ME, Gerzymisch K, Schulz D, Siepmann M, Knickenberg RJ, et al. Evaluation of a video-based Internet intervention as preparation for inpatient psychosomatic rehabilitation: study protocol for a randomized controlled trial. *Trials* 2016 Jun 13;17(1):287 [FREE Full text] [doi: [10.1186/s13063-016-1417-y](https://doi.org/10.1186/s13063-016-1417-y)] [Medline: [27296249](https://pubmed.ncbi.nlm.nih.gov/27296249/)]
23. Patel V, Maj M, Flisher AJ, De Silva MJ, Koschorke M, Prince M, WPA Zonal and Member Society Representatives. Reducing the treatment gap for mental disorders: a WPA survey. *World Psychiatry* 2010 Oct;9(3):169-176 [FREE Full text] [Medline: [20975864](https://pubmed.ncbi.nlm.nih.gov/20975864/)]
24. Leichsenring F, Rabung S, Leibling E. The efficacy of short-term psychodynamic psychotherapy in specific psychiatric disorders: a meta-analysis. *Arch Gen Psychiatry* 2004 Dec;61(12):1208-1216. [doi: [10.1001/archpsyc.61.12.1208](https://doi.org/10.1001/archpsyc.61.12.1208)] [Medline: [15583112](https://pubmed.ncbi.nlm.nih.gov/15583112/)]
25. Fonagy P. The effectiveness of psychodynamic psychotherapies: an update. *World Psychiatry* 2015 Jun;14(2):137-150 [FREE Full text] [doi: [10.1002/wps.20235](https://doi.org/10.1002/wps.20235)] [Medline: [26043322](https://pubmed.ncbi.nlm.nih.gov/26043322/)]

26. Diener MJ, Hilsenroth MJ, Weinberger J. Therapist affect focus and patient outcomes in psychodynamic psychotherapy: a meta-analysis. *Am J Psychiatry* 2007 Jun;164(6):936-941. [doi: [10.1176/ajp.2007.164.6.936](https://doi.org/10.1176/ajp.2007.164.6.936)] [Medline: [17541054](https://pubmed.ncbi.nlm.nih.gov/17541054/)]
27. Johansson R, Frederick RJ, Andersson G. Using the internet to provide psychodynamic psychotherapy. *Psychodyn Psychiatry* 2013 Dec;41(4):513-540. [doi: [10.1521/pdps.2013.41.4.513](https://doi.org/10.1521/pdps.2013.41.4.513)] [Medline: [24283446](https://pubmed.ncbi.nlm.nih.gov/24283446/)]
28. McCulloch L, Andrews S. Assimilative integration: short-term dynamic psychotherapy for treating affect phobias. *Clin Psychol* 2001;8(1):82-97. [doi: [10.1093/clipsy.8.1.82](https://doi.org/10.1093/clipsy.8.1.82)]
29. Kabat-Zinn J. *Wherever You Go, There You Are: Mindfulness Meditation in Everyday Life*. New York City: Hachette Books; 1994.
30. Frederick RJ. *Living Like You Mean It: Use the Wisdom and Power of Your Emotions to Get the Life You Really Want*. Hoboken: Wiley; 2009.
31. Subic-Wrana C, Beutel ME, Knebel A, Lane RD. Theory of mind and emotional awareness deficits in patients with somatoform disorders. *Psychosom Med* 2010 May;72(4):404-411. [doi: [10.1097/PSY.0b013e3181d35e83](https://doi.org/10.1097/PSY.0b013e3181d35e83)] [Medline: [20223925](https://pubmed.ncbi.nlm.nih.gov/20223925/)]
32. Urbaniak GC, Plous S. Randomizer. Research Randomizer (Version 3.0) URL: <https://www.randomizer.org/> [accessed 2017-09-14] [WebCite Cache ID 6fTqdAOcV]
33. Schmidt J, Lamprecht F, Wittmann W. Satisfaction with inpatient management. Development of a questionnaire and initial validity studies. *Psychother Psychosom Med Psychol* 1989;39:248-255.
34. Berking M, Znoj H. Development and validation of a questionnaire for standardized self-reports of emotional competences. *Z Klin Psychol Psychiatr Psychother* 2008 Jan;56(2):141-153. [doi: [10.1024/1661-4747.56.2.141](https://doi.org/10.1024/1661-4747.56.2.141)]
35. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med* 2001 Sep;16(9):606-613 [FREE Full text] [Medline: [11556941](https://pubmed.ncbi.nlm.nih.gov/11556941/)]
36. Löwe B, Decker O, Müller S, Brähler E, Schellberg D, Herzog W, et al. Validation and standardization of the Generalized Anxiety Disorder screener (GAD-7) in the general population. *Med Care* 2008 Mar;46(3):266-274. [doi: [10.1097/MLR.0b013e318160d093](https://doi.org/10.1097/MLR.0b013e318160d093)] [Medline: [18388841](https://pubmed.ncbi.nlm.nih.gov/18388841/)]
37. Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med* 2006 May 22;166(10):1092-1097. [doi: [10.1001/archinte.166.10.1092](https://doi.org/10.1001/archinte.166.10.1092)] [Medline: [16717171](https://pubmed.ncbi.nlm.nih.gov/16717171/)]
38. Michal M, Glaesmer H, Zwerenz R, Knebel A, Wiltink J, Brähler E, et al. Base rates for depersonalization according to the 2-item version of the Cambridge Depersonalization Scale (CDS-2) and its associations with depression/anxiety in the general population. *J Affect Disord* 2011 Jan;128(1-2):106-111. [doi: [10.1016/j.jad.2010.06.033](https://doi.org/10.1016/j.jad.2010.06.033)] [Medline: [20674036](https://pubmed.ncbi.nlm.nih.gov/20674036/)]
39. Brähler E, Mühlhan H, Albani C, Schmidt S. Teststatistische Prüfung und Normierung der deutschen Versionen des EUROHIS-QOL Lebensqualität-Index und des WHO-5 Wohlbefindens-Index. *Diagn* 2007 Apr;53(2):83-96. [doi: [10.1026/0012-1924.53.2.83](https://doi.org/10.1026/0012-1924.53.2.83)]
40. Roth M, Decker O, Herzberg PY, Brähler E. Dimensionality and norms of the Rosenberg self-esteem scale in a German general population sample. *Eur J Psychol Assess* 2008 Jan;24(3):190-197. [doi: [10.1027/1015-5759.24.3.190](https://doi.org/10.1027/1015-5759.24.3.190)]
41. von Collani G, Herzberg PY. Eine revidierte Fassung der deutschsprachigen Skala zum Selbstwertgefühl von Rosenberg. *Z Differ Diagn Psychol* 2003 Mar;24(1):3-7. [doi: [10.1024/0170-1789.24.1.3](https://doi.org/10.1024/0170-1789.24.1.3)]
42. Mittag O, Raspe H. A brief scale for measuring subjective prognosis of gainful employment: findings of a study of 4279 statutory pension insureds concerning reliability (Guttman scaling) and validity of the scale. *Rehabilitation (Stuttg)* 2003 Jun;42(3):169-174. [doi: [10.1055/s-2003-40095](https://doi.org/10.1055/s-2003-40095)] [Medline: [12813654](https://pubmed.ncbi.nlm.nih.gov/12813654/)]
43. Gierk B, Kohlmann S, Kroenke K, Spangenberg L, Zenger M, Brähler E, et al. The somatic symptom scale-8 (SSS-8): a brief measure of somatic symptom burden. *JAMA Intern Med* 2014 Mar;174(3):399-407. [doi: [10.1001/jamainternmed.2013.12179](https://doi.org/10.1001/jamainternmed.2013.12179)] [Medline: [24276929](https://pubmed.ncbi.nlm.nih.gov/24276929/)]
44. Löwe B, Wahl I, Rose M, Spitzer C, Glaesmer H, Wingenfeld K, et al. A 4-item measure of depression and anxiety: validation and standardization of the Patient Health Questionnaire-4 (PHQ-4) in the general population. *J Affect Disord* 2010 Apr;122(1-2):86-95. [doi: [10.1016/j.jad.2009.06.019](https://doi.org/10.1016/j.jad.2009.06.019)] [Medline: [19616305](https://pubmed.ncbi.nlm.nih.gov/19616305/)]
45. IBM Corp. *IBM SPSS Statistics for Windows, Version 23.0*. Armonk, NY: IBM Corp; 2014.
46. Leiner D. Soscisurvey. URL: <https://www.soscisurvey.de/> [accessed 2017-09-14] [WebCite Cache ID 6fTrhb5LH]
47. Weltgesundheitsorganisation. *Internationale Klassifikation psychischer Störungen: ICD-10 Kapitel V (F). Diagnostische Kriterien für Forschung und Praxis*. Bern: Huber; 2006.
48. Kriz D, Nübling R, Steffanowski A, Wittmann WW, Schmidt J. Patientenzufriedenheit in der stationären rehabilitation: psychometrische reanalyse des ZUF-8 auf der basis multizentrischer stichproben verschiedener indikation. *Z Med Psychol* 2008;17:67-79.
49. Farchione TJ, Fairholme CP, Ellard KK, Boisseau CL, Thompson-Hollands J, Carl JR, et al. Unified protocol for transdiagnostic treatment of emotional disorders: a randomized controlled trial. *Behav Ther* 2012 Sep;43(3):666-678 [FREE Full text] [doi: [10.1016/j.beth.2012.01.001](https://doi.org/10.1016/j.beth.2012.01.001)] [Medline: [22697453](https://pubmed.ncbi.nlm.nih.gov/22697453/)]
50. Moses E, Barlow D. A new unified treatment approach for emotional disorders based on emotion science. *Curr Dir Psychol Sci* 2006;15(3):146-150.

51. Zwerenz R, Becker J, Knickenberg RJ, Hagen K, Dreier M, Wölfling K, et al. Enhancing inpatient psychotherapeutic treatment with online self-help: study protocol for a randomized controlled trial. *Trials* 2015 Mar 17;16:98 [FREE Full text] [doi: [10.1186/s13063-015-0620-6](https://doi.org/10.1186/s13063-015-0620-6)] [Medline: [25872505](https://pubmed.ncbi.nlm.nih.gov/25872505/)]

Abbreviations

ANCOVA: analysis of covariance

ANOVA: analysis of variance

CDS-2: Cambridge Depersonalization Scale

CSQ-8: Client Satisfaction Questionnaire

ERSQ: Emotion Regulation Skills Questionnaire

EUROHIS-QOL-8: European Health Interview Survey Quality of Life 8-item index

GAD-7: General Anxiety Disorder Screener

IG: intervention group

ITT: intention-to-treat

LOCF: last observation carried forward

PHQ-9: Patient Health Questionnaire

RCT: randomized controlled trial

RSE: Rosenberg Self-Esteem Scale

SPE: Subjective prognosis of gainful employment scale

SSS-8: Somatic Symptom Scale

WLCG: wait-list control group

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Original Paper

Techniques for Improving Communication of Emotional Content in Text-Only Web-Based Therapeutic Communications: Systematic Review

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Abstract

Background: Web-based typed exchanges are increasingly used by professionals to provide emotional support to patients. Although some empirical evidence exists to suggest that various strategies may be used to convey emotion during Web-based text communication, there has been no critical review of these data in patients with chronic conditions.

Objectives: The objective of this review was to identify the techniques used to convey emotion in written or typed Web-based communication and assess the empirical evidence regarding impact on communication and psychological outcomes.

Methods: An electronic search of databases, including MEDLINE, CINAHL, PsycINFO, EMBASE, and the Cochrane Library was conducted to identify literature published from 1990 to 2016. Searches were also conducted using Google Scholar, manual searching of reference lists of identified papers and manual searching of tables of contents for selected relevant journals. Data extraction and coding were completed by 2 reviewers (10.00% [573/5731] of screened papers, at abstract/title screening stage; 10.0% of screened [69/694] papers, at full-text screening stage). Publications were assessed against the eligibility criteria and excluded if they were duplicates, were not published in English, were published before 1990, referenced animal or nonhuman subjects, did not describe original research, were not journal papers, or did not empirically test the effect of one or more nonverbal communication techniques (for eg, smileys, emoticons, emotional bracketing, voice accentuation, trailers [ellipsis], and pseudowords) as part of Web-based or typed communication on communication-related variables, including message interpretation, social presence, the nature of the interaction (eg, therapeutic alliance), patient perceptions of the interaction (eg, participant satisfaction), or psychological outcomes, including depression, anxiety, and distress.

Results: A total of 6902 unique publications were identified. Of these, six publications met the eligibility criteria and were included in a narrative synthesis. All six studies addressed the effect of smileys or emoticons on participant responses, message interpretation, or social presence of the writer. None of these studies specifically targeted chronic conditions. It was found that emoticons were more effective in influencing the emotional impact of a message than no cue and that smileys and emoticons

were able to convey a limited amount of emotion. No studies addressed other techniques for conveying emotion in written communication. No studies addressed the effects of any techniques on the nature of the interaction (eg, therapeutic alliance), patient perceptions of the interaction (eg, participant satisfaction), or psychological outcomes (depression, anxiety, or distress).

Conclusions: There is a need for greater empirical attention to the effects of the various proposed techniques for conveying emotion in Web-based typed communications to inform health service providers regarding best-practice communication skills in this setting.

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KEYWORDS

nonverbal communication; Internet; computer-assisted therapy

Introduction

The majority of people with chronic disease may experience some level of psychological distress in their lifetime [1,2]. Compared with the general population, depression is more prevalent in all disease groups, and anxiety is more prevalent in people living with chronic diseases such as cardiovascular disease, stroke, and cancer [1,2]. The heavy symptom burden associated with chronic conditions often translates into increased physical impairment and reduced functional capacity [3,4].

Various forms of psychological support have been found to improve physical and psychological outcomes in patients with chronic conditions [2,5,6]. Approaches for providing psychological support include face-to-face interventions such as clinician-led support groups, one-on-one, and group counseling; written interventions such as information booklets and therapy workbooks; telephone-based interventions, including telephone counseling; and comparatively newer Web-based modalities of support, including Web counseling (eg, synchronous Web-based chat or asynchronous email exchange). Web-based or computer-mediated communication can produce similar outcomes to face-to-face approaches for alleviating psychological burden in patients with chronic conditions and psychiatric and somatic disorders [5,7,8]. A 2014 meta-analysis by van Beugen et al [5] demonstrated that Internet-delivered therapy is comparable in efficacy with group-based face-to-face therapy. Similarly, a 2013 review of effectiveness studies by Andersson et al [7,8] found Internet-based therapy to be of equivalent effectiveness to face-to-face therapy in a group setting. Moreover, a 2014 systematic review and meta-analysis by Andersson et al [7] determined that Internet-based therapy produced overall effects equivalent to face-to-face therapy. Textual Web-based interactions can develop an effective alliance between a therapist and client [9] and may be helpful in relationship-building for those with social anxiety [10]. The systematic review and meta-analysis by Andersson et al [7] demonstrated equivalent effects of Internet-delivered therapy and face-to-face therapy for social anxiety disorder in favor of the Internet-based modality. Furthermore, Lundy and Drouin [10] found that those experiencing social anxiety reported greater feelings of interpersonal connectedness following engagement with a synchronous instant messaging platform, demonstrating the ability of text-only mediums of communication to contribute to psychological well-being. Accordingly, Web-based forms of communication are increasingly being adopted by both

government and nongovernment health services as an important mode for providing social and emotional support. Therefore, it is important that the communication parameters required for optimal effectiveness are well understood.

The advantages of Web-based or computer-mediated communication over face-to-face or telephone-based methods of providing psychological support include fewer limitations related to geographical location, staffing, resources, and timing of service provision, as well as anonymity for the patient [11]. It has been proposed that text-based communication techniques are construed by the Web patient in the same way that nonverbal communication methods are by the face-to-face client and that these Web-based communication methods can serve the same purpose in supporting positive interaction as in face-to-face situations [12]. However, a number of theories, such as the cuelessness model [13] and social information processing theory [14], suggest that a lack of visual and auditory cues presents challenges to the patient and provider in their attempts to convey emotional content via Web-based communication methods. The lack of nonverbal communication in Web-based exchanges is thought to limit message interpretation, create psychological distance, and reduce rapport [15]. Online communication techniques that have been suggested to counteract this lack of visual and auditory cues include smileys (stylized graphic images of facial expressions used to convey emotion or feeling), emoticons (use of American Standard Code for Information Interchange punctuation marks, numbers, and letters to create pseudofacial expressions to convey the writer's emotion or intended tone), emotional bracketing (using words or text to describe emotions in brackets), voice accentuation (bolding, underlining, or italicizing words or text), trailers (ellipses), and pseudowords (a fake word constructed from a string of letters).

Whereas telehealth has been highlighted as having potential relevance to this review, it is not considered to be directly applicable as it is outside the scope of the research question. Despite some definitions of telehealth, including broad concepts such as text-based communication between a health care professional and a patient without the presence of videoconferencing contact, the literature largely focuses on patient outcomes rather than conveyance of emotion. Furthermore, the literature regarding health care professional and patient relationships with respect to the provision of telehealth services seems to relate to emotional communication transmitted by tone of voice, posture, gaze, and eye contact, which is irrelevant to the explicit focus of this review (communication methods in Web-based text-only interactions).

Although some empirical evidence exists to suggest that Web-based or typed communication techniques have the ability to convey emotion [16] and are used in response to a need to convey emotion in text-only communications [17,18], there is no systematic review of the evidence to guide practitioners regarding the use of the available strategies. This review attempts to assess the effects of text-only (written or typed) Web-based communication on emotional experience. It also explores the implications for therapeutic communication with the aim of improving psychological outcomes for people with chronic disease.

The review aims to critically examine original research to identify experimental studies regarding Web-based communication methods to describe the following:

1. The number of empirical studies of techniques used to convey emotion in written or typed Web-based communication (eg, email counseling or Web counseling).
2. The effect of the identified techniques on communication-related variables, including message interpretation, social presence, the nature of the interaction (eg, therapeutic alliance), and patient perceptions of the interaction (eg, participant satisfaction).
3. The impact of the identified techniques on patient psychological outcomes, including depression, anxiety, and distress.

Methods

Design

An electronic search of databases, including MEDLINE, CINAHL, PsycINFO, EMBASE, and the Cochrane Library was conducted to identify literature published from 1990 to 2016. Searches were also conducted using Google Scholar, manual searching of reference lists of identified papers, and manual searching of tables of contents for selected relevant journals.

Table 1. Search terms utilized for each database.

Database	Search terms
MEDLINE	[Emotions OR satisfaction (kw) OR psychosocial (kw) OR Depressive Disorder OR distress (kw) OR Depression OR Anxiety OR Anxiety Disorders OR Professional-Patient Relations OR therapeutic alliance (kw)] AND [Electronic Mail OR e-therapy (kw) OR helpline (kw) OR ((computer or cyber or email* or web or online or internet or instant mess*) adj5 counsel*) (kw) OR ((cyber or email* or web or online or internet or instant mess*) adj5 therap*) (kw)].
EMBASE	[Emotion OR patient satisfaction OR psychosocial (kw) OR depression OR anxiety OR distress (kw) OR doctor patient relation OR therapeutic alliance (kw) OR professional-patient relations (kw)] AND [e-therapy (kw) OR helpline (kw) OR e-mail OR ((computer or cyber or email* or web or online or internet or instant mess*) adj5 counsel*) (kw) OR ((cyber or email* or web or online or internet or instant mess*) adj5 therap*) (kw)].
PsycINFO	[Emotions OR client satisfaction OR psychosocial factors OR depression (kw) OR depression (emotion) OR anxiety disorders OR anxiety OR distress OR therapeutic alliance] AND [Computer mediated communication OR electronic mail (kw) OR email (kw) OR electronic communication OR e-therapy (kw) OR online therapy OR ((computer or cyber or email* or web or online or internet or instant mess*) adj5 counsel*) (kw) OR ((cyber or email* or web or online or internet or instant mess*) adj5 therap*) (kw) OR helpline (kw)].
CINAHL	[Emotions OR Satisfaction OR Psychosocial OR Depressive Disorder OR Depression OR Distress OR Anxiety OR Anxiety Disorders OR Professional-Patient Relations OR Therapeutic Alliance] AND [Helpline OR Electronic Mail OR e-mail OR e-therapy OR Cybercounsel* OR Cybertherap* OR Online N5 counsel* OR Online N5 therap* OR Cyber N5 counsel* OR Cyber N5 therap* OR Computer N5 counsel* OR Email N5 counsel* OR Email N5 therap* OR Web N5 therap* OR Web N5 counsel* OR Internet N5 counsel* OR Internet N5 therap* OR Instant mess* N5 counsel*].

Search Strategy

Development of Search Strategy

Two medical librarians provided expert guidance on the development of the review's search strategy. The initial search strategy was developed and tested by the research team and forwarded to the first medical librarian for review regarding search terms and appropriate databases. There was significant overlap of search terms in the original and alternative search strategies, including *professional-patient relations*, *therapeutic alliance*, *computer*, *cyber*, *email**, *web*, *online*, *internet*, and *instant mess**. Strategies suggested by the first medical librarian, which were integrated into the final search strategy, included implementation of the adj5 function to search for 5 words or fewer apart from *counsel* and *therap*, explosion of certain medical subject headings or MeSH terms (*emotion*), and confirmation of the decision to exclude Sociological Abstracts from the list of databases searched because of the largely irrelevant results it yielded. The second medical librarian reviewed the final search strategy as a quality assurance exercise and ran an alternative approach to the search. The results of the alternative search strategy were exported into an EndNote X7.3.1 database and compared with the results of the original search strategy. This comparison demonstrated that the alternative search strategy did not yield any additional relevant content. The search terms utilized for each database is provided in Table 1.

Final Search Strategy

The search was limited to papers published from January 1, 1990 to December 31, 2016. The year 1990 was chosen as the starting point of the literature search strategy period as the availability of Web-based technology was greatly accelerated during the 1990s.

Study Inclusion and Exclusion

The inclusion criteria were developed to isolate studies that identified the effects of communication techniques used in typewritten Web-based communication. Variables that were only relevant to audiovisual communication were not sought. All eligible abstracts were examined for relevance following removal of duplicates. The full-text papers of potentially relevant original research studies were obtained and examined. A coding template was used to extract relevant data from the included publications. Publications were excluded if they were duplicates, were not published in English, were published before 1990, referenced animal or nonhuman subjects, did not describe original research, were not journal papers, or did not empirically test the effect of one or more nonverbal communication techniques (for eg, smileys, emoticons, emotional bracketing, voice accentuation, trailers [ellipsis], and pseudowords) in adults as part of Web-based, Web-based or typed communication on communication-related variables, including, for example, message interpretation, social presence, the nature of the interaction (such as therapeutic alliance), patient perceptions of the interaction (such as participant satisfaction), or psychological outcomes, including depression, anxiety, and distress.

Article abstracts were initially assessed against the eligibility criteria by MC and excluded if the study did not meet the inclusion criteria. A random subsample (10.0%) of included studies were categorized by 2 other authors (CP and HS) and compared with the coding of MC. An initial agreement of 83.0% was achieved, with any discrepancies resolved via discussion and recoded as necessary.

Classification and Inclusion of Publications by Focus Area

All publications which met the eligibility criteria were coded by CP, and 10.0% were independently coded by another author (AWB, agreement=91.0%) to determine the papers that focused on the following:

Techniques used to convey emotion in written or typed Web-based communication: publications that reported techniques used (eg, smileys, emoticons, emotional bracketing, voice accentuation, trailers [ellipsis], and pseudowords); communication modality (eg, Web-based chat and email); format of communication delivery (eg, asynchronous communication and synchronous communication); and one of the following:

1. The effect of the identified techniques on message interpretation and social presence: publications that reported effect on mood or perception of writer's commitment, perceived extraversion or sociality of writer, and perception of message (perceived emotion, attitude reception, or attention perception).
2. The effect of the identified techniques on the nature of the interaction: publications that reported effect on therapeutic alliance or working alliance.
3. The effect of the identified techniques on patient perceptions of the interaction: publications that reported effect on participant satisfaction.

4. The impact of the identified techniques on patient psychological outcomes: publications that reported effect on psychological outcomes, including depression, anxiety, and distress.

Classification and Inclusion of Publications by Design

The full-text of intervention studies was then assessed independently by 2 reviewers (MC and CP) regarding whether those studies met the minimum design criteria for classification as any one of a randomized controlled trial (RCT), a non-RCT, a controlled before and after study, or an interrupted time series study using the Cochrane Effective Practice and Organization of Care risk of bias criteria. There was perfect agreement (100.0%) between the 2 reviewers.

Data Extraction and Coding of Included Studies

To assess intervention effectiveness, data on each of the following variables were extracted by 2 authors (CP and DR) using an extraction coding table: author and year of publication, study setting; study design, sample characteristics (sample size, gender, and age), assessment based on inclusion and exclusion criteria, outcome measures, and study findings. An agreement of 96% was achieved (a single error was identified and corrected).

Results

A total of 6902 publications were identified using the search strategy (see [Figure 1](#) for PRISMA flow diagram) [19]. After duplicates were removed, 5731 publications were assessed against the eligibility criteria. The abstracts of nine individual publications were unable to be located. A total of six publications met the eligibility criteria and were included in the review. The studies excluded at the full-text stage either (1) described but did not test the techniques of interest or (2) described the effects of computer-mediated interventions but did not address the effect of any communication technique used within the intervention (over 90%). That is, whereas there are many studies that explore Web-based communication, the effects of the communication techniques themselves have not generally been isolated as part of the study design. None of the included studies specifically targeted chronic conditions. The six included studies are described in full in [Multimedia Appendix 1](#). The study data were not suitable for meta-analysis, as there was no commonality of measurement.

All of the six studies addressed the effect of smileys or emoticons on message response, message interpretation, or social presence of the writer. No studies addressed other techniques for conveying emotion in text-only typed communication. No studies addressed the effects of any text-only typed communication techniques on the nature of the interaction (eg, therapeutic alliance), patient perceptions of the interaction (eg, participant satisfaction), or psychological outcomes (depression, anxiety, or distress).

Four of the included studies found that the use of a smiley or emoticon is more effective than no cue in influencing the perceived emotion of an interaction [14,20-22]. Walther and D'Addario [16] established that the use of smileys or wink emoticons is unable to decrease the negative tone of a negatively

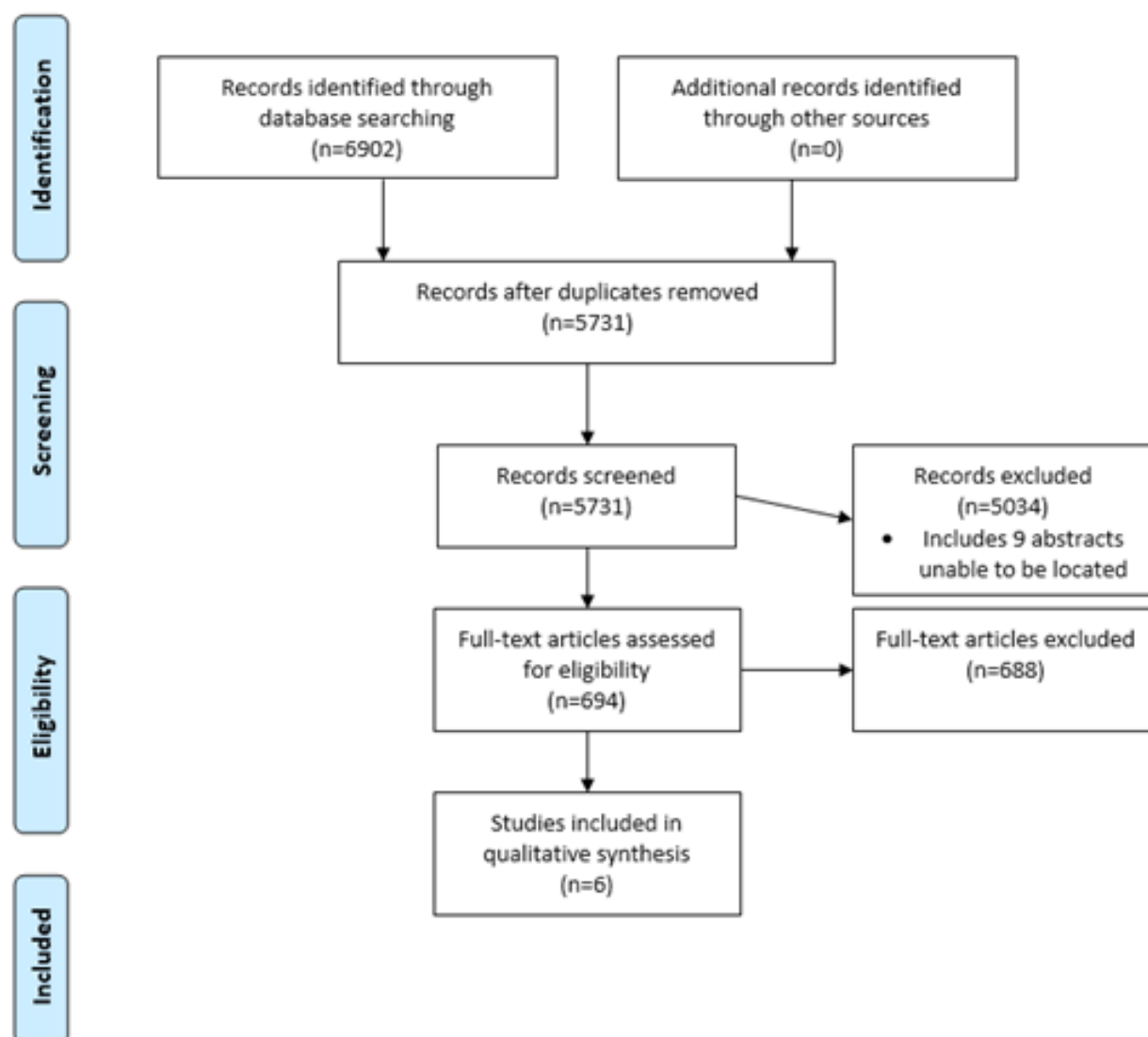
worded message. In addition, Walter and D'Addario [16] observed that the inclusion of any negative element (words or cue) caused the reader to experience a negative change in interpretation of the Web-based interaction. Thompson et al [22] demonstrated higher levels of arousal and increased smiling and reduced frowning when an emoticon is present, supporting the argument that use of an emoticon is more effective at eliciting a positive response in the viewer when compared with no cue. Furthermore, the findings of Thompson et al [22] support the notion that emoticons augment the emotional impact of a message by demonstrating increased smiling as a result of phrases conveying praise when an emoticon is present, compared with a praising statement when an emoticon is absent.

Walter and D'Addario [16] observed that words elicit a stronger response than emoticons, whereas a later study by Comesana et al [23] found the opposite effect—that smileys cause greater brain activity than words.

Lo [20], Ganster et al [21], and Wall et al [24] studied the effect of emoticons and smileys on perception and evaluation of the

writer's qualities (including perceived emotion, attitude, perception, commitment, extraversion, sociality, agreeableness, conscientiousness, and openness). Lo [20] observed the ability of emoticon use to affect perceived attitude (like vs dislike) and perceived attention of the writer in the interaction, whereas Ganster et al [21], in a study of cue valence effects on perceptions of the writer's personality, found that positive cue use (compared with negative cue use or cue absence) by the author denotes a greater perception of writer extraversion with no effect on their perceived commitment or sociality. Furthermore, Ganster et al [21] observed a stronger effect of smileys on the perceived commitment of the writer when compared with emoticons; however no effect on perceived extraversion or sociality of the author was found. Wall et al [24] provided more recent evidence for the effect on perception and evaluation of the writer's traits by demonstrating positive correlations between the writer's use of *happy* emoticons and the observer's assessment of qualities of agreeableness, conscientiousness, and openness.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement – flow chart of search strategy and paper selection.



Discussion

Principal Findings

Very few experimental studies have explored the effects of typed strategies to assist conveyance of emotion in text-only forms of communication. Although there are many studies of the efficacy of computer-mediated psychotherapeutic interventions, there were no studies exploring the impact of communication techniques for conveying emotion on the nature, perception, or outcomes of such interactions. The studies excluded at the full-text stage either described computer-mediated interventions without addressing the effect of communication techniques or were observational (described the use of rather than tested the effects of such techniques). No studies regarding communication techniques other than smileys and emoticons were identified. These two aspects of computer-mediated communication highlight important gaps in the evidence base regarding the delivery of supportive or therapeutic typed Web-based communication.

The six experimental studies identified indicate that smileys and emoticons do strengthen the perceived emotion in text-only messages. The work of Comesana et al [23] suggests that emoticons evoke a rapid and automatic emotional response even before the receiver is aware of what he or she has seen. Therefore, these techniques can be used to ameliorate the psychological distance and lack of social presence, which is theorized to occur in text-only communication as a result of the absence of social cues and retardation of impression formation [13,14]. Walter and D'Addario [16] and Thompson et al [22] found that the emotional tone of a message can be positively influenced through use of a smile or wink emoticon, suggesting the advantageous use of these emoticons in the therapeutic environment. Use of an emoticon is more effective than not using an emoticon in affecting the perceived emotion (positive or negative) of the interaction, also giving strength to the usefulness of these communication tools in Web-based interactions [20,22]. Similar to the findings of Lo [20], the study by Ganster et al [21] found that use of an emoticon or smiley conveys more positive (smile) or negative (frown) emotion when compared with the absence of a cue. Ganster et al [21] also found that smileys have a stronger effect than emoticons on the expression of the perceived commitment of the conversation moderator, which could be considered an important influence on working alliance in the therapeutic setting. Comesana et al [23] found that more brain activity on electroencephalogram was elicited by smileys over words and negative smiley-and-word pairings, again strengthening the argument for the use of smileys, while also encouraging sensitivity with respect to use of valenced text-only communication tools in Web-based interactions.

There appear to be some caveats on what smileys and emoticons can achieve as techniques for conveying emotion: positively valenced emoticons cannot counteract a negatively worded message, and there appears to be a particular sensitivity to negative smileys such that they may need to be utilized sparingly [23]. Furthermore, these studies have only explored the expression of a very limited range of emotions, that is, happy

or sad smileys or emoticons. The expression of, and response to, more complex emotions via smileys or emoticons is likely to be difficult, given that one nonexperimental study of the understanding of smileys found poor recognition of smileys or emoticons other than those relating to a limited range of emotions [25].

Current literature indicates that therapeutic interventions delivered Web-based can be as successful as the face-to-face versions [9,10], suggesting that computer-mediated communication can achieve a strong therapeutic alliance and working relationship. However, a lack of understanding of the most appropriate ways in which to optimize this relationship (including the communication of emotion) may be a limiting factor. The need for study of techniques for expressing more complex emotions in text-only Web-based exchanges is crucial. The Walther and D'Addario [16] study suggests that other techniques such as emotional bracketing may be even more powerful than smileys, given that positively or negatively worded statements were found to have a stronger effect than emoticons on perception. There is a need for empirical examination of the use of the emotional bracketing method in clinical settings to provide therapists with practical guidance on how to effectively use this technique in Web-based therapeutic environments. Further research should particularly focus on the effect of smileys, emoticons, and other communication techniques (including emotional bracketing) on factors including therapeutic alliance and participant satisfaction. Therapeutic alliance is a dependable predictor of a favorable clinical outcome [26]. Furthermore, future research has the potential to provide novel evidence on the impact of the identified techniques on patient psychological outcomes, including depression, anxiety, and emotional distress. There is compelling evidence to suggest that Web-based therapy is effective in improving clinical outcomes in patients with depression, anxiety, and emotional distress among chronic disease and cancer populations [27]; however, further research on the effects of Web-based communication techniques in these populations is lacking and requires prompt attention.

Limitations

It is important to acknowledge that the identified studies have been conducted with young and healthy nonclinical populations, rather than patient populations. This significantly limits the ability to generalize the findings to older people or to patient populations. For older people and patient populations, there is perhaps a greater need for sensitivity in conveying emotion in a text-only setting [28,29]. There have been previous intervention studies whereby successful interventions conducted in older people and chronic disease populations have demonstrated a heightened sensitivity with regard to communication methods to be a crucial element in interactions with these cohorts [28,29].

Conclusions

This review suggests that the use of a limited range of easily recognized smileys and emoticons could be cautiously encouraged in text-only therapeutic interactions for people in younger age groups. There is a need for further research on how to use communication techniques, including emoticons and

smileys, effectively in text-only interactions across a diverse range of ages and to inform evidence-based practice of therapists working in the Web-based domain. Furthermore, there is a need

for research focused on the communication of emotion in text-only Web-based interactions in a therapeutic clinical setting.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Data extracted from the four studies included in the review.

[[PDF File \(Adobe PDF File\), 37KB - mental_v4i4e46_app1.pdf](#)]

References

- Clarke DM, Currie KC. Depression, anxiety and their relationship with chronic diseases: a review of the epidemiology, risk and treatment evidence. *Med J Aust* 2009 Apr 6;190(7 Suppl):S54-S60. [Medline: [19351294](#)]
- Paul CL, Carey ML, Sanson-Fisher RW, Houlcroft LE, Turon HE. The impact of web-based approaches on psychosocial health in chronic physical and mental health conditions. *Health Educ Res* 2013 Jun;28(3):450-471 [[FREE Full text](#)] [doi: [10.1093/her/cyt053](#)] [Medline: [23660463](#)]
- Hopwood P, Stephens RJ. Depression in patients with lung cancer: prevalence and risk factors derived from quality-of-life data. *J Clin Oncol* 2000 Feb;18(4):893-903. [Medline: [10673533](#)]
- Kurtz ME, Kurtz JC, Stommel M, Given CW, Given B. Predictors of depressive symptomatology of geriatric patients with lung cancer-a longitudinal analysis. *Psychooncology* 2002;11(1):12-22. [Medline: [11835589](#)]
- van Beugen S, Ferwerda M, Hoeve D, Rovers MM, Spillekom-van Koulil S, van Middendorp H, et al. Internet-based cognitive behavioral therapy for patients with chronic somatic conditions: a meta-analytic review. *J Med Internet Res* 2014 Mar 27;16(3):e88 [[FREE Full text](#)] [doi: [10.2196/jmir.2777](#)] [Medline: [24675372](#)]
- Ehde DM, Dillworth TM, Turner JA. Cognitive-behavioral therapy for individuals with chronic pain: efficacy, innovations, and directions for research. *Am Psychol* 2014;69(2):153-166. [doi: [10.1037/a0035747](#)] [Medline: [24547801](#)]
- Andersson G, Cuijpers P, Carlbring P, Riper H, Hedman E. Guided Internet-based vs. face-to-face cognitive behavior therapy for psychiatric and somatic disorders: a systematic review and meta-analysis. *World Psychiatry* 2014 Oct;13(3):288-295 [[FREE Full text](#)] [doi: [10.1002/wps.20151](#)] [Medline: [25273302](#)]
- Andersson G, Hedman E. Effectiveness of guided Internet-based cognitive behavior therapy in regular clinical settings. *Verhaltenstherapie* 2013;23(3):140-148. [doi: [10.1159/000354779](#)]
- Cook JE, Doyle C. Working alliance in online therapy as compared to face-to-face therapy: preliminary results. *Cyberpsychol Behav* 2002 Apr;5(2):95-105. [Medline: [12025884](#)]
- Lundy BL, Drouin M. From social anxiety to interpersonal connectedness: relationship building within face-to-face, phone and instant messaging mediums. *Comput Human Behav* 2016 Jan;54:271-277. [doi: [10.1016/j.chb.2015.08.004](#)]
- Vilhauer RP. Computer-mediated and face-to-face communication in metastatic cancer support groups. *Palliat Support Care* 2014 Aug;12(4):287-297. [doi: [10.1017/S1478951513000126](#)] [Medline: [23768772](#)]
- Plumb MD. suu.edu. Cedar City, Utah: Southern Utah University; 2013. Non-verbal Communication in Instant Messaging URL: <https://www.suu.edu/hss/comm/masters/capstone/thesis/plumb-mi.pdf> [accessed 2017-10-03] [[WebCite Cache ID 6tvpZ0tbv](#)]
- Rutter DR, Stephenson GM. The role of visual communication in social interaction. *Curr Anthropol* 1979 Mar;20(1):124-125. [doi: [10.1086/202217](#)]
- Walther JB. Interpersonal effects in computer-mediated interaction: a relational perspective. *Communic Res* 1992 Feb 01;19(1):52-90. [doi: [10.1177/009365092019001003](#)]
- Rice RE, Love G. Electronic emotion: socioemotional content in a computer-mediated communication network. *Communic Res* 1987 Feb 01;14(1):85-108. [doi: [10.1177/009365087014001005](#)]

16. Walther JB, D'Addario KP. The impacts of emoticons on message interpretation in computer-mediated communication. *Soc Sci Comput Rev* 2001 Aug 01;19(3):324-347. [doi: [10.1177/089443930101900307](https://doi.org/10.1177/089443930101900307)]
17. Derks D, Bos AE, von Grumbkow J. Emoticons and social interaction on the Internet: the importance of social context. *Comput Human Behav* 2007 Jan;23(1):842-849. [doi: [10.1016/j.chb.2004.11.013](https://doi.org/10.1016/j.chb.2004.11.013)]
18. Derks D, Bos AE, von Grumbkow J. Emoticons in computer-mediated communication: social motives and social context. *Cyberpsychol Behav* 2008 Feb;11(1):99-101. [doi: [10.1089/cpb.2007.9926](https://doi.org/10.1089/cpb.2007.9926)] [Medline: [18275321](https://pubmed.ncbi.nlm.nih.gov/18275321/)]
19. Liberati A, Altman DG, Tetzlaff J, Mulrow C, Gøtzsche PC, Ioannidis JPA, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. *Br Med J* 2009;339:b2700. [doi: [10.1136/bmj.b2700](https://doi.org/10.1136/bmj.b2700)]
20. Lo SK. The nonverbal communication functions of emoticons in computer-mediated communication. *Cyberpsychol Behav* 2008 Oct;11(5):595-597. [doi: [10.1089/cpb.2007.0132](https://doi.org/10.1089/cpb.2007.0132)] [Medline: [18817486](https://pubmed.ncbi.nlm.nih.gov/18817486/)]
21. Ganster T, Eimler SC, Krämer NC. Same same but different!? The differential influence of smileys and emoticons on person perception. *Cyberpsychol Behav Soc Netw* 2012 Apr;15(4):226-230. [doi: [10.1089/cyber.2011.0179](https://doi.org/10.1089/cyber.2011.0179)] [Medline: [22394421](https://pubmed.ncbi.nlm.nih.gov/22394421/)]
22. Thompson D, Mackenzie IG, Leuthold H, Filik R. Emotional responses to irony and emoticons in written language: evidence from EDA and facial EMG. *Psychophysiology* 2016 Jul;53(7):1054-1062 [FREE Full text] [doi: [10.1111/psyp.12642](https://doi.org/10.1111/psyp.12642)] [Medline: [26989844](https://pubmed.ncbi.nlm.nih.gov/26989844/)]
23. Comesaña M, Soares AP, Perea M, Piñeiro AP, Fraga I, Pinheiro A. ERP correlates of masked affective priming with emoticons. *Comput Human Behav* 2013 May;29(3):588-595. [doi: [10.1016/j.chb.2012.10.020](https://doi.org/10.1016/j.chb.2012.10.020)]
24. Wall HJ, Kaye LK, Malone SA. An exploration of psychological factors on emoticon usage and implications for judgement accuracy. *Comput Human Behav* 2016;62:70-78. [doi: [10.1016/j.chb.2016.03.040](https://doi.org/10.1016/j.chb.2016.03.040)]
25. McDougald BR, Carpenter ED, Mayhorn CB. Emoticons: what does this one mean? 2011 Sep 01 Presented at: Proceedings of the Human Factors and Ergonomics Society Annual Meeting; 2011; Las Vegas p. 1948-1951. [doi: [10.1177/1071181311551406](https://doi.org/10.1177/1071181311551406)]
26. Ardito RB, Rabellino D. Therapeutic alliance and outcome of psychotherapy: historical excursus, measurements, and prospects for research. *Front Psychol* 2011 Oct 18;2:270. [doi: [10.3389/fpsyg.2011.00270](https://doi.org/10.3389/fpsyg.2011.00270)]
27. Gratzer D, Khalid-Khan F. Internet-delivered cognitive behavioural therapy in the treatment of psychiatric illness. *CMAJ* 2016 Mar 01;188(4):263-272 [FREE Full text] [doi: [10.1503/cmaj.150007](https://doi.org/10.1503/cmaj.150007)] [Medline: [26527829](https://pubmed.ncbi.nlm.nih.gov/26527829/)]
28. Rose JH, Radziewicz R, Bowmans KF, O'Toole EE. A coping and communication support intervention tailored to older patients diagnosed with late-stage cancer. *Clin Interv Aging* 2008;3(1):77-95 [FREE Full text] [Medline: [18488881](https://pubmed.ncbi.nlm.nih.gov/18488881/)]
29. Sparks L, Nussbaum JF. Health literacy and cancer communication with older adults. *Patient Educ Couns* 2008 Jun;71(3):345-350. [doi: [10.1016/j.pec.2008.02.007](https://doi.org/10.1016/j.pec.2008.02.007)] [Medline: [18374536](https://pubmed.ncbi.nlm.nih.gov/18374536/)]

Abbreviations

RCT: randomized controlled trial

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Original Paper

Qualitative Exploration of the Potential for Adverse Events When Using an Online Peer Support Network for Mental Health: Cross-Sectional Survey

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Abstract

Background: Online peer support networks are a growing area of mental health support for offering social connection, identity, and support. However, it has been reported that not all individuals have a positive experience on such networks. The potential for adverse events within a moderated online peer support network is a new area of research exploration.

Objective: The objective of the study was to determine if use of an online moderated peer networks leads to adverse events for users.

Methods: Four biannual online surveys (October 2014 to March 2016) were conducted by a large national UK mental health charity, with users of their online peer support network exploring personal safety, moderation, experiences on the site, and how the site could be improved. Data were analyzed using thematic analysis by 2 independent researchers using a priori themes: negative experiences of moderation, social exclusion, contagion, negative interactions with other users, online relationships, co-rumination and collusion, and other.

Results: In total, 2353 survey responses were logged with 197 (8.37%) documenting an adverse event of negative experience. A dominant theme of negative experiences of moderation emerged (73/197, 37.1%) with evidence of social exclusion (50/197, 25.4%). Reading user posts was shown to be a cause of worry and distress for a few users, and analysis highlighted several instances of depressogenic and emotional contagion as well as some limited evidence of behavioral contagion (46/197, 23.4%). Very limited evidence of co-rumination (1/197, 0.5%) and no evidence of collusion were identified.

Conclusions: Evidence of adverse events was identified at low levels in the sample of respondents, although we have no comparison data to indicate if levels are low compared with comparable platforms. Not all users of online peer support networks find them wholly beneficial. Research must explore what works for whom. The next stage of service development should consider which users may be likely to receive no benefit, or even deteriorate, as a result of using the service.

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KEYWORDS

digital technology; mental health; online peer support; adverse events; online survey

Introduction

Online Peer Support

Online peer support is an example of a technology-supported mental health self-management approach. Peer support has been defined as “people drawing on shared personal experience to provide knowledge, social interaction, emotional assistance, or practical help to each other, often in a way that is mutually beneficial” [1]. Peer support is often considered a helpful contribution to a wider mental health support and recovery plan. The approach works on the principles of using mutuality and reciprocity, which in turn facilitate the generation of social capital, known to be associated with well-being and resilience in mental health [2].

Evidence for the benefits of online peer support is mixed due in large part to the heterogeneous outcome measures adopted in research [3-8]. When using validated, clinical outcome measures based on a biomedical model to measure effectiveness, online peer support generally appears to have little effect [3,5,6]. When outcomes such as social connectedness, personal empowerment, and quality of life are assessed, research demonstrates evidence of benefits to users [4,7,8]. These are outcomes that are given a higher priority by people taking part in peer support [9].

Adverse Events

The potential for adverse events when using peer support requires attention. Research has identified the presence of adverse events in online peer support including negative perceptions of moderation [8,10,11], emotional and behavioral contagion [11-15], negative debate [8,14], co-rumination [16], collusion [13], and negative interactions with other users [8,11]. Other potentials for harm included unanswered posts and sharing of incorrect or misleading information about mental health [8]. The literature surrounding potential for harm on online peer networks is limited with a focus on depression. It is important

to explore the user-perceived adverse events of using a national online peer support network for people with a range of mental health problems. In identifying the potential for adverse events on such platforms, the user experience may be improved, increasing safety and opportunity for beneficial outcomes.

Methods

A qualitative analysis was conducted using a deductive framework approach [17] with data from 5 online service evaluation surveys posted on the Elefriends peer support platform sponsored by the UK mental health charity Mind from October 2013 to October 2016. Elefriends is a moderated online community with over 50,000 users. Moderation of the site is overseen by Ele handlers, who remove posts containing personal details, swearing, personal attacks, harassment, and potentially triggering content.

All open-ended questions on the online survey were screened for evidence of adverse events. Items included: What could Ele (the moderator) do to make you feel safer? Tell us about being an elefriend (user). What usually brings you to Elefriends? What effect has being an Elefriend had on you? Has being part of this community changed the way you access support? Has being part of this community encouraged you to try anything new? How do you feel about the moderation? Is there anything else you would like to tell us? How does Ele make you feel?

After investigating evidence of harm and negative outcomes of peer support in the literature, a framework was developed to classify the qualitative data. Initially, there were 7 broad categories: negative experiences of moderation, social exclusion, contagion, negative interactions with other users, online relationships, co-rumination and collusion, and other (Table 1). Responses to items on the surveys including those asking about personal safety, moderation, experiences on the site, and how the site could be improved were examined independently by 2 raters and verified by a third to identify evidence of the themes.

Table 1. Themes of adverse events and responses identified in user feedback.

Theme	n
Negative experiences of moderation or site management	73
Social exclusion	50
Contagion or trigger words	46
Negative interactions with other users	38
Online relationships	19
Co-rumination and collusion	1
Other	3

Results

Sample Characteristics

In total, 2353 survey responses were logged across the 5 surveys. Of the 1574 respondents, 79.01% were female (1258/1574) and 1.08% (17/1574) identified as transgender or other. A total of 29.86% (470/1574) of the sample was aged 18 to 25 years, and 28.84% (454/1574) was aged 25 to 35 years. Users were

experiencing depression (384/1574, 24.39%), anxiety (157/1574, 9.97%), or both (587/1574, 37.29%); in addition, 10.42% (164/1574) reported personality disorders and 5.97% (94/1574) reported a diagnosis of posttraumatic stress disorder. A total of 8.37% (197/2353) of responses documented an adverse event of negative experience with 1.15% (27/2353) identifying multiple adverse events, which have been listed under multiple themes.

Themes

The dominant theme of adverse events was moderation, commonly relating to censoring (73/2353).

...getting a post taken off for talking about what's been upsetting me makes the matter even worse for myself...I feel even more alone than before...it just adds an extra weight on top of my bad time. [Response #6, Question 23, October 2015]

Some users of the site experienced social exclusion or found it difficult to identify with others (50/2353).

...I find that my posts often receive little to no response, that in turn causes feelings of being ignored and invisible or unimportant and unpopular...even something as small as somebody not clicking the 'hear you or thinking of you' buttons can be so discouraging and disheartening; it feels as though nobody is reading our posts and instead looking for the more popular, regular posters and users. [Response #68, Question 20, May 2015]

Evidence of distress, depressogenic, emotional, or behavioral contagion was also reported (46/2353).

I don't like seeing people making suicide threats on the page. It's scary for them and frustrating for me as I feel I am putting a lot of energy into positive thinking and that brings me down. [Response #82, Question 17, February 2015]

I had to stop for a while because I felt mentally too fragile to listen to other people's struggles. Somehow their depression exacerbated my own. [Response #103, Question 18, February 2015]

No evidence of collusion was found. Very limited evidence was found of co-rumination (1/2353).

I also get worried that sometimes it's an echo chamber...It can sometimes reinforce negative or unhelpful behaviour...I don't know if I'd have wanted to be an Elefriend when I was really bad. Surrounding myself with other people who agreed with me that life was basically awful may not have been very helpful. [Response #46, Question 18, February 2015]

Discussion

Principal Findings

Evidence of adverse events was identified but appears to be at low levels in the sample of respondents. Moderation, social

exclusion, and emotional contagion were identified in user responses although there is little data to indicate whether the rates we identified are comparable to other available platforms. People taking part in online peer support should feel able to express themselves, but the adverse events of removing posts must be weighed against the risks of leaving them in place, such as the increased contagion and collusion observed on unmoderated platforms [18,19]. Evidence suggests that depression, emotions, and behaviors can pass from one person to another [20]. However, we do not yet know at what rate such interactions need to occur for contagion to have a negative impact on other users. In terms of moderation, it is clear that a balance must be struck between reducing risk of contagion and allowing users in distress to express themselves and receive peer support.

Co-rumination and collusion can reinforce or encourage negative thoughts, perceptions, and behaviors, and this can facilitate contagion [19,20]. No evidence of collusion and very limited evidence of co-rumination was found in our study. This, as well as the lack of evidence of online stalking and sharing of health misinformation, can likely be attributed to the thorough nature of moderation on Elefriends.

Social exclusion and isolation are associated with depressive symptoms and have a detrimental impact on mental health [21,22]. Posts on Elefriends receive an average of 2.5 comments. Innovative ways to encourage users to interact with other posts and offer support, as well as writing their own posts, could be trialed.

Findings should be considered in light of the small self-selected sample and the sample characteristic. Individuals experiencing symptoms of depression or anxiety such as negative thought cycles are prone to catastrophizing, overgeneralization, and discounting positives, which may have influenced reporting of adverse events [23].

Conclusions

Examination of online peer support user feedback indicates that adverse events are uncommon compared with concerns relating to moderation and social exclusion. Not all users of online peer support networks find them wholly beneficial. Research must explore what works for whom. The next stage of service development should consider which users may be likely to receive no benefit, or even deteriorate, as a result of using the service.

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Conflicts of Interest

JD is the Research and Evaluation Manager at Mind, the mental health charity which hosts Elefriends.

References

1. NESTA. Peer support: what is it and does it work?. URL: https://www.nationalvoices.org.uk/sites/default/files/public/publications/peer_support_-_what_is_it_and_does_it_work.pdf [accessed 2017-09-14] [WebCite Cache ID 6tTatkMvY]
2. McKenzie K. Social risk, mental health and social capital. In: McKenzie K, Harpham T, editors. Social Capital and Mental Health. London: Jessica Kingsley Publishers; 2006.
3. Llyod-Evans B, Mayo-Wilson E, Harrison B. A systematic review and meta-analysis of randomised controlled trials of peer support for people with severe mental illness. BMC Psychiatry 2014;14:39. [doi: [10.1186/1471-244X-14-39](https://doi.org/10.1186/1471-244X-14-39)]
4. Naslund JA, Aschbrenner KA, Marsch LA, Bartels SJ. The future of mental health care: peer-to-peer support and social media. Epidemiol Psychiatr Sci 2016 Apr;25(2):113-122 [FREE Full text] [doi: [10.1017/S2045796015001067](https://doi.org/10.1017/S2045796015001067)] [Medline: [26744309](https://pubmed.ncbi.nlm.nih.gov/26744309/)]
5. Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. BMJ 2004 May 15;328(7449):1166 [FREE Full text] [doi: [10.1136/bmj.328.7449.1166](https://doi.org/10.1136/bmj.328.7449.1166)] [Medline: [15142921](https://pubmed.ncbi.nlm.nih.gov/15142921/)]
6. Ali K, Farrer L, Gulliver A, Griffiths KM. Online peer-to-peer support for young people with mental health problems: a systematic review. JMIR Ment Health 2015;2(2):e19 [FREE Full text] [doi: [10.2196/mental.4418](https://doi.org/10.2196/mental.4418)] [Medline: [26543923](https://pubmed.ncbi.nlm.nih.gov/26543923/)]
7. Välimäki M, Athanasopoulou C, Lahti M, Adams CE. Effectiveness of social media interventions for people with schizophrenia: a systematic review and meta-analysis. J Med Internet Res 2016 Apr 22;18(4):e92 [FREE Full text] [doi: [10.2196/jmir.5385](https://doi.org/10.2196/jmir.5385)] [Medline: [27105939](https://pubmed.ncbi.nlm.nih.gov/27105939/)]
8. Griffiths K, Reynolds J, Vassallo S. An online moderated peer-to-peer support bulletin board for depression: user perceived advantages and disadvantages. JMIR Ment Health 2015;2(2):e14 [FREE Full text] [doi: [10.2196/mental.4266](https://doi.org/10.2196/mental.4266)] [Medline: [26543919](https://pubmed.ncbi.nlm.nih.gov/26543919/)]
9. Side by side: early research findings. 2017. URL: <https://www.mind.org.uk/media/6121312/side-by-side-early-research-findings-report.pdf> [accessed 2017-09-14] [WebCite Cache ID 6tTbVW8U4]
10. Takahashi Y, Uchida C, Miyaki K, Sakai M, Shimbo T, Nakayama T. Potential benefits and harms of a peer support social network service on the internet for people with depressive tendencies: qualitative content analysis and social network analysis. J Med Internet Res 2009 Jul 23;11(3):e29 [FREE Full text] [doi: [10.2196/jmir.1142](https://doi.org/10.2196/jmir.1142)] [Medline: [19632979](https://pubmed.ncbi.nlm.nih.gov/19632979/)]
11. Naslund JA, Aschbrenner KA, Marsch LA, Bartels SJ. The future of mental health care: peer-to-peer support and social media. Epidemiol Psychiatr Sci 2016 Apr;25(2):113-122 [FREE Full text] [doi: [10.1017/S2045796015001067](https://doi.org/10.1017/S2045796015001067)] [Medline: [26744309](https://pubmed.ncbi.nlm.nih.gov/26744309/)]
12. Stevens EA, Prinstein MJ. Peer contagion of depressogenic attributional styles among adolescents: a longitudinal study. J Abnorm Child Psychol 2005 Feb;33(1):25-37. [Medline: [15759589](https://pubmed.ncbi.nlm.nih.gov/15759589/)]
13. Mueller AS. Suicidal disclosures among friends: using social network data to understand suicide contagion. J Health Soc Behav 2015;56(1):148.
14. Powel J, McCarthy N, Eysenbach G. Cross-sectional survey of users of Internet depression communities. BioMed Cent Psychiat 2003;3:19.
15. Hill AL, Rand DG, Nowak MA, Christakis NA. Emotions as infectious diseases in a large social network: the SISa model. Proc Biol Sci 2010 Dec 22;277(1701):3827-3835 [FREE Full text] [doi: [10.1098/rspb.2010.1217](https://doi.org/10.1098/rspb.2010.1217)] [Medline: [20610424](https://pubmed.ncbi.nlm.nih.gov/20610424/)]
16. Hankin B, Stone L, Wright P. Corumination, interpersonal stress generation, and internalizing symptoms: accumulating effects and transactional influences in a multiwave study of adolescents. Dev Psychopathol 2010;22(1):217-235 [FREE Full text] [doi: [10.1017/S0954579409990368](https://doi.org/10.1017/S0954579409990368)] [Medline: [20102657](https://pubmed.ncbi.nlm.nih.gov/20102657/)]
17. Gale N, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol 2013;13.
18. Kendal S, Kirk S, Elvey R, Catchpole R, Prymachuk S. How a moderated online discussion forum facilitates support for young people with eating disorders. Health Expect 2017 Feb;20(1):98-111 [FREE Full text] [doi: [10.1111/hex.12439](https://doi.org/10.1111/hex.12439)] [Medline: [26725547](https://pubmed.ncbi.nlm.nih.gov/26725547/)]
19. Lewis S, Heath N, Michal N, Duggan J. Non-suicidal self-injury, youth, and the Internet: what mental health professionals need to know. Child Adolesc Psychiatry Ment Health 2012 Mar 30;6(1):13 [FREE Full text] [doi: [10.1186/1753-2000-6-13](https://doi.org/10.1186/1753-2000-6-13)] [Medline: [22463379](https://pubmed.ncbi.nlm.nih.gov/22463379/)]
20. Schwartz-Mette RA, Smith RL. When does co-rumination facilitate depression contagion in adolescent friendships? Investigating intrapersonal and interpersonal factors. J Clin Child Adolesc Psychol 2016 Sep 01:1-13. [doi: [10.1080/15374416.2016.1197837](https://doi.org/10.1080/15374416.2016.1197837)] [Medline: [27586501](https://pubmed.ncbi.nlm.nih.gov/27586501/)]
21. Hefner J, Eisenberg D. Social support and mental health among college students. Am J Orthopsychiatry 2009 Oct;79(4):491-499. [doi: [10.1037/a0016918](https://doi.org/10.1037/a0016918)] [Medline: [20099940](https://pubmed.ncbi.nlm.nih.gov/20099940/)]
22. Cornwell EY, Waite LJ. Social disconnectedness, perceived isolation, and health among older adults. J Health Soc Behav 2009 Mar;50(1):31-48 [FREE Full text] [doi: [10.1177/002214650905000103](https://doi.org/10.1177/002214650905000103)] [Medline: [19413133](https://pubmed.ncbi.nlm.nih.gov/19413133/)]
23. All About Depression. Thinking styles. 2010. URL: http://www.allaboutdepression.com/workshops/CBT_Workshop/CBT_Thinking_Styles.pdf [accessed 2017-09-14] [WebCite Cache ID 6tTcW2LVs]

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Original Paper

Exploring Working Relationships in Mental Health Care via an E-Recovery Portal: Qualitative Study on the Experiences of Service Users and Health Providers

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Abstract

Background: The quality of working relationships between service users and health providers is fundamental in the processes of recovery in mental health. How Internet-based interventions will influence these relationships for persons with long-term care needs, and the measures that can be taken to maintain and enhance working relationships through Internet, is still not well understood.

Objective: The aim of this study was to gain insights into how service users and health providers experience their working relationships when they are offered the option of supplementing ongoing collaboration with an e-recovery portal.

Methods: In this exploratory and descriptive study, an e-recovery portal was used by service users and their health providers in 2 mental health communities in Norway for at least 6 months and at most 12 months (2015-2016). The portal consists of secure messaging, a peer support forum, and a toolbox of resources for working with life domains including status, goals and activities, network map, crisis plan, and exercises. The portal was owned and managed by the service user while health providers could remotely access parts of the service user-generated content. The participants could use the portal in whatever way they wished, to suit their collaboration. Data from 6 focus groups, 17 individual interviews, and an interview with 1 dyad about their experiences of use of the portal over the study period were inductively coded and thematically analyzed.

Results: The thematic analysis resulted in 2 main themes: (1) new relational avenues and (2) out of alignment, illustrated by 8 subthemes. The first main theme is about dyads who reported new and enriching ways of working together through the portal, particularly related to written communication and use of the goal module. Illustrative subthemes are ownership, common ground, goals and direction, and sense of presence and availability. The second main theme illuminates the difficulties that arose when service users' and health providers' expectations for portal use were not aligned, and the consequences of not addressing these difficulties. Illustrative subthemes are initiative and responsibility, waiting for the other, feeling overwhelmed, and clarifications and agreements.

Conclusions: The degree to which dyads benefited from using the e-recovery portal appeared to be mainly associated with the degree to which the dyads' relations were open and flexible before the portal was introduced. For those who experienced frustrations, the portal may have both exposed and added to suboptimal working relationships. Use of the goal module appeared to strengthen the person-centered nature of collaboration. A key question is how health providers balance between enabling service users' greater control over their care, without relinquishing responsibility for the quality of the working relationship, also when using an e-recovery portal. Implications for implementation are discussed.

KEYWORDS

eHealth; recovery; mental health; psychiatry; user involvement; empowerment; working relationship; secure email; e-recovery; participatory research

Introduction

Therapeutic alliances, or therapeutic relationships, between service users and health providers in mental health care have repeatedly been found to be of significance for outcomes [1] across a range of diagnoses and treatment settings [2]. Moreover, service users report that their relationship with their health provider is the most important component of care [3] along with their own engagement [4,5]. The study reported here builds on a recovery-oriented approach that uses concepts such as working relationship and partnership to underline the collaboration between health providers and persons in need of long-term mental health treatment and support [6]. The aim of mental health care, and the focus of helping relationships, is to help individuals to live meaningful lives with or without the presence of symptoms [7-9]. Personal recovery is conceptualized as personal processes comprising five dimensions: connectedness to others and the community; hope and optimism about the future; identity building beyond being a patient and toward a positive sense of identity without stigma; meaning in life; and empowerment [10]. Health providers contribute with their professional expertise, whereas service users contribute as the experts in their own lives (eg, their personal values, own needs, and goals) [8]. Accordingly, people are referred to as service users, rather than patients, thus underlining the equality of the roles and expertise (ibid). In recovery-oriented approaches, working relationships focus on fostering service users' own strengths and resources while developing mutually shared goals, action plans, and outcomes that service users are in charge of, or, through recovery, ultimately take charge of [11,12]. Knowledge about what service users find to be helpful and nonhelpful relationships with service providers is increasing [13,14].

Internet-based interventions are increasingly incorporated into mental health services in ways that can be expected to influence the quality of working relationships [15]. Studies have shown similar or even enhanced working relationships when compared with face-to-face therapies [16,17]. Reported benefits of Internet-based working relationships include facilitation of therapeutic engagement, greater self-disclosure and therapeutic writing, and extensions of the working relationship beyond the active therapy period [18]. Among challenges reported are difficulties in articulation and lack of nonverbal cues, thereby increasing possibilities for misunderstandings [19], as well as a lack of possibilities to respond in real time [20]. Also described is a lack of guidance about how service users and health providers can appropriately engage with each other through the Internet [21]. There is a need for in-depth insights into how such relationships unfold when supported by the Internet [16,20,22], especially when such support is introduced into ongoing care relationships [23,24].

This study examines the use of an Internet-based portal designed to support recovery processes for service users and their ongoing collaboration with their health providers (here referred to as an e-recovery portal). Although research on traditional patient portals has mostly focused on factors such as patient demographics, use and nonuse, and patient engagement and satisfaction [25], attention is increasingly turning to how portals may affect care practices [26]. In this study, we ask: *How do service users and health providers in ongoing mental health care describe their experiences of using an e-recovery portal relative to their working relationships?*

Methods

The E-Recovery Portal: ReConnect

ReConnect was designed with service users involved and is described in more depth elsewhere [27]. The portal consists of secure messaging, a peer support forum, and a toolbox of diverse resources that support service users in articulating and working with various aspects of their lives (ie, life domains and associated goals and activities; network map; crisis plan; different exercises related to mindfulness, coping, and symptom management; medication overview; information about user involvement, working relationship, personal recovery, and how to use ReConnect; and links to local activities and service users' organizations). The portal is owned and managed by the service user while health providers can remotely access parts of the service user-generated content (eg, goals and activities). The portal enables collaboration between the service user and their health provider (here referred to as the dyad) in between or during consultations. Two-hour group and/or individual training sessions were offered in both communities where the study was conducted, so as to accommodate participants' various schedules and preferences for format. On the basis of the participants' personal preferences, some dyads participated in a training session together, others participated in group sessions for service users and health providers separately, and a few requested individual training sessions. Local in-real-life ReConnect cafés were held monthly in both communities, at which service users could meet and discuss issues related to their own recovery processes, including the working relationship with their health provider, and portal use. The ReConnect cafés were facilitated by a service user consultant with lived experience of mental health problems.

Study Methodology and Design

This explorative and descriptive study with a qualitative and participatory design [28-30] studied the use of an e-recovery portal used by service user and health provider dyads in 2 mental health communities in Norway (see the Setting section below). Participants used the portal for at least 6 and at most 12 months (2015-2016). The dyads were told they could use the portal in whatever way they thought might benefit their working

relationships and were encouraged to clarify and agree on uses beforehand. The service user consultant was part of the research team throughout all phases of the research process, and participants from the study were invited to give feedback about both the implementation of the portal and the study's findings as they unfolded (further elaborated below).

Setting

Norway has universal health care that is publicly funded as part of the national budget through general and earmarked grants. The municipalities are responsible for providing primary health care and social services, while the Regional Health Authorities provide specialist services (eg, hospital wards and district psychiatric centers). As used in this paper, the word "communities" refers to care at primary and specialist levels provided to residents of 2 municipalities in Norway: 1 small community in the North with about 5500 inhabitants within an area of 1493 km² and 1 large community on the outskirts of the capital with about 52,000 inhabitants within an area of 100 km². These were selected for participation to obtain desired contrasts in terms of rural/urban dimensions and access to care. Service users in Norway have at least one specific health provider responsible for the follow-up at each level of care, often a registered nurse, psychologist, and/or psychiatrist. Both communities had expressed commitments to policies promoting eHealth, user involvement, and collaborative practices. The largest community expressed commitments to recovery principles in policy and strategy documents. Local steering committees were established in both communities to ensure that the study and its implementation had local organizational backing.

Recruitment and Participant Inclusion

Written information about the study, along with verbal presentations individually and in groups, was provided by the research team to multiple health services at both levels of care and to local service user organizations. Interested health providers conveyed the information to service users who they believed might be interested and relevant to the study. In addition, some service users who had heard about the study from other sources requested that their health providers participated with them. Participating service users had to fulfill the following criteria: over 18 years of age, had received mental health services for at least 6 months before inclusion, and had expectations of needing services at least 6 months forward, Internet access with a public key solution for secure electronic identification, and at least one health provider willing to participate in the study. For the health providers, employment in the participating communities and a willingness to participate in the study for at least 6 months with at least one service user were inclusion criteria. Efforts were made to recruit a wide range of participants in terms of age, gender, mental health problems or professional background, and types of ongoing support or workplace. Service users and health providers were invited by the research team, administrators, and/or health providers to take part in focus groups and/or individual interviews about their experiences with use of the portal. For focus groups, participation in the study was the only inclusion criteria. For the individual interviews and interviews with dyads,

we intentionally sought participants who had experience of using the e-recovery portal, defined as having logged on to ReConnect >15 times.

Focus Groups and Interviews

Data were collected using focus groups [31,32] and individual interviews [33], as well as one interview with a dyad who requested that format. Focus groups are suitable for exploring experiences and attitudes among people who cooperate, or have a common frame of reference, and can complement other methods [31]. The focus groups were held at an early stage of implementation so that discussions among participants could also serve to stimulate use and collaboration, a recognized objective of focus groups [34]. The individual interviews were used to facilitate collection of more personal and detailed information (ibid) and were held at a later stage when participants had gained more experience with collaborating through the portal over time. The individual interviews enabled us to explore understandings, perceptions, and constructions of issues that participants have some personal stake in, in line with the objectives of individual interviews (ibid).

The focus groups were conducted with service users and health providers separately to facilitate free-flowing conversations [32]. The interview guide consisted of questions about ReConnect relative to working relationships and recovery processes (see [Multimedia Appendix 1](#)). A first draft of the interview guide was discussed with 2 service user consultants who were not part of the research team. In line with the explorative nature of the study, the questions were few and open-ended to stimulate group dialogue [31,32] about the overall study's 2 main topics: experiences with portal use relative to working relationships and experiences with the role that ReConnect might play in recovery processes. The first of these topics is reported here; the second will be reported in a subsequent paper. Participants were given the opportunity to elaborate on subjects they considered relevant and important. Prompts that could encourage openness, examples, and detail (eg, "That is interesting, can you tell us more about that?") were used frequently. The focus groups were conducted by MS, who is a trained nurse with clinical experience from the field, and LSE, who was the study's service user consultant and who had first-hand experience of mental health problems and recovery on both primary and specialist levels of mental health care. The focus groups were conducted after approximately 3 months of participation in the study and lasted for approximately 90 min for the service users and 50 min for the providers.

In the individual interviews and in the 1 dyad interview, we sought more in-depth personal experiences relative to the same topics as the focus groups, also based on semistructured interview guides with open-ended questions (see [Multimedia Appendix 2](#)). The individual and the dyad interviews were conducted by MS, with the exception of one individual interview conducted by LSE. These interviews were conducted after 6 to 8 months of participation in the study and lasted for approximately 60 min.

Thematic Analysis

The focus groups, individual interviews, and the 1 dyad interview were audio-recorded and transcribed verbatim and constitute the entire dataset for this study. Data analysis was aided by use of NVivo software version 11. The data were analyzed by applying a 6-phase thematic analysis for identifying, analyzing, and reporting patterns within the data [35]. The main goal during the analysis was to inductively sort the material into overarching themes and subthemes across the entire dataset, guided by the research question (ibid): *How do service users and health providers in ongoing mental health care describe their experiences of use of an e-recovery portal relative to their working relationships?* MS led the analysis process that entailed the first 3 authors meeting routinely throughout all 6 phases to identify, discuss, and resolve potential differences in, for example, coding and interpretive practices (eg, detail and level of abstraction), thus facilitating multiple perspectives in the process of interpreting the data. In the first phase, authors familiarized themselves with the data, noted initial ideas, and made and discussed preliminary descriptive codes. In the second phase, conducted primarily by MS, relevant extracts of the data (ie, part or all of a sentence, or a small paragraph about 1 particular subject identified in the data related to the research question) were systematically identified and entered into NVivo software version 11 nodes (codes) across the entire dataset. The third phase consisted of collating related codes into preliminary themes and gathering all data relevant to each potential theme. In the fourth phase, the themes were reviewed and adjusted relative to overlaps or inconsistencies both to the coded extracts and the entire dataset. With the goal of generating clear definitions and names for each theme, the fifth phase refined the wording of each theme and the overall story of the analysis. Finally, in the sixth phase, we produced the report by selecting vivid and compelling quotes and to produce a final analysis relating back to the research question. These phases are described sequentially, but in practice, they were conducted as a recursive process (ibid), moving back and forth as needed. Thus, in line with inductive qualitative analysis, the codebook evolved continuously during the analysis [34].

In line with participatory approaches [28-30], participants were invited to give feedback on written and oral tentative summaries of the data through secure messaging, in ReConnect-café, or in the individual interviews. This not only facilitated the participants' contribution to understanding the data but also how to use the e-recovery portal.

The quotes that illuminate identified themes were initially translated from Norwegian to English by DG, a native northern American who is fluent in Norwegian. To minimize the known threats to validity when translating culturally bound expressions [36], the original quotes were kept alongside the translations throughout the development of the manuscript. This enabled all authors to assess the validity of translations, as well as to

backtrack to the dataset when context was needed to ensure that the translation captured the quotes' meaning.

Ethics

This study was approved by the Regional Committees for Medical and Health Research Ethics in Norway and the Privacy Protection Committees at the participating sites. Participants signed a Web-based consent form with information about the study, which was repeated verbally at the time of the interviews. Service users consented to use ReConnect exclusively for nonemergency purposes and that ordinary channels had to be used for acute needs. Moreover, the participants were given information about security procedures and recommendations for ensuring privacy.

Results

A total of 14 service users and 17 health providers from both primary and specialist levels of mental health care participated in 6 focus groups, 17 individual interviews, and 1 interview with a dyad.

The participants

The service users were from 22 to 63 years of age, reporting various mental health diagnoses. The health providers had 1 year to 35 years of clinical experience and represented various professions. Further description of the characteristics of the participants in the different types of interviews is given in [Tables 1 and 2](#).

The thematic analysis resulted in 2 main themes: (1) new relational avenues and (2) out of alignment. These and the 8 identified subthemes are presented below.

New Relational Avenues

This theme encompasses the ways in which dyads used the options offered by ReConnect to enrich their working relationship and is illustrated through the following subthemes: ownership, common ground, goals and direction, and sense of presence and availability. The process of writing, and uses of the service users' writings in consultations, is fundamental to this theme and is common to the 4 subthemes.

Ownership

In ReConnect, the service users had control over the self-generated content and who had access to it (in contrast to, eg, traditional health records). This shift in locus of control from health providers to service users was described as closely linked to the process of writing that was facilitated by the portal, particularly related to goals, activities, and crisis plans. Health providers, in particular, described how the portal enabled service users to set the agenda for collaboration by describing, in their own words, their situation, priorities, and goals. This in turn strengthened service users' ownership, or sense of engagement and responsibility, of their recovery processes.

Table 1. Characteristics of participants in focus groups.

Characteristics	Service users, N=11	Health providers, N=14
Age in years, median (range)	45 (22-63)	47 (24-63)
Gender, n (%)		
Female	11 (100%)	13 (93%)
Male	0 (0%)	1 (7%)
Site, n (%)		
Large community (52,000 inhabitants)	6 (55%)	8 (57%)
Small community (5500 inhabitants)	5 (45%)	6 (43%)
Primary level	5 (45%)	6 (43%)
Specialist level	4 (37%)	8 (57%)
Both levels	2 (18%)	
Diagnosis, n (%)		
Depression	6 (55%)	
Bipolar disorder	2 (18%)	
Generalized anxiety	2 (18%)	
Post-traumatic stress disorder	2 (18%)	
Schizophrenia	1 (9%)	
Schizoaffective disorder	1 (9%)	
Phobic anxiety	1 (9%)	
Panic anxiety	1 (9%)	
Others	2 (18%)	
Number of diagnosis, median (range)	1 (1-5)	
Profession, n (%)		
Registered nurse		6 (43%)
Social worker		3 (21%)
Occupational therapist		1 (7%)
Interdisciplinary specialist		1 (7%)
Priest		1 (7%)
Psychologist (clinical)		1 (7%)
Psychiatrist		1 (7%)
Years of clinical experience, median (range)		15 (1-20)

Table 2. Characteristics of participants in individual and dyad interviews.

Characteristics	Service users, N=11	Health providers, N=8
Age in years, median (range)	45 (24-67)	47 (27-61)
Gender, n (%)		
Female	11 (100%)	7 (88%)
Male	0 (0%)	1 (12%)
Site, n (%)		
Large community (52,000 inhabitants)	6 (55%)	5 (63%)
Small community (5500 inhabitants)	5 (45%)	3 (37%)
Primary level	7 (64%)	7 (88%)
Specialist level	3 (27%)	1 (12%)
Both levels	1 (9%)	
Diagnosis, n (%)		
Depression	8 (73%)	
Generalized anxiety	2 (18%)	
Post-traumatic stress disorder	4 (36%)	
Schizophrenia	1 (9%)	
Schizoaffective disorder	1 (9%)	
Phobic anxiety	1 (9%)	
Panic anxiety	4 (36%)	
Drug addiction	1 (9%)	
Mania	1 (9%)	
Others	3 (27%)	
Number of diagnosis, median (range)	1 (1-7)	
Profession, n (%)		
Registered nurse		4 (50%)
Occupational therapist		1 (13%)
Psychologist (bachelor)		1 (13%)
Psychiatrist		1 (13%)
Physician		1 (13%)
Years of clinical experience, median (range)		11.5 (3-20)

In addition to the processes of writing itself, the use of the service users' own writings in consultations was described by 1 health provider in a focus group as "enabler of ownership and essential for their [service users'] recovery processes." Another put it this way:

My client and I have written several crisis plans earlier. And she's said things about "what are my symptoms" [...] But it's just recently that she has worked independently with her issues. And put her thoughts into her own words to a much greater degree than before. She's also done so earlier, but now she has greater ownership to her crisis plan. And that's important. [Health provider, focus group]

Health providers also described how writing appeared to entice service users into taking on a more active role in the relationship

and providers could stay more in the background. This is illustrated through the following exchange in a focus group:

A: When it comes to goals...because I've been interested in that. I was going to write the action plan. So, it became a kind of win-win situation. The same with the crisis plan which has been very valuable for the service users. And it's really nice, because they formulate it and write it themselves. So we can kind of sit on the side-lines and...

B: Be lazy...[group laughter]

A: Yes and no. It's that they work more with it themselves. Their role is a little different when they...

B: Have greater ownership to it. [Health providers, focus group]

The opportunity to share what was important and perhaps difficult to share face-to-face further helped service users set the agenda for consultations. It also helped dyads stay focused on what mattered, rather than sliding into conversational habits about nonimportant issues. Health providers reported that receiving messages before consultations helped them prepare and know more of what was expected of them, as shown in the quote below:

It's sort of nice to have in front of you. To include it in the consultation, if there is something one wants to expand on. Yes, I think it's good. Just to have an overview of the things the service user had thought about. [Health provider, focus group]

Another put it this way:

It's been...I think a well-ordered way of working on things...A good way of handling our collaboration. In a way, it's clearer what's being requested of me. [Health provider, individual interview]

Common Ground

The secure and asynchronous nature of ReConnect facilitated transferral of clinically relevant information from service users that strengthened the common basis for collaboration in ways not available in ordinary face-to-face consultations. Service users could now describe thoughts and emotions whenever issues arose in real life, rather than having to wait for the next meeting. Because some found it difficult to share thoughts face-to-face, writing helped health providers gain relevant insights.

One service user portrayed the portal as kind of vault where valuables (eg, ruminations) could be safely transferred to the health provider, stored, and dealt with in time. This functioned as a remedy for sleeplessness, as evident from the quote below:

I often write the messages after [health provider] has gone home from work. So, I don't expect to get an answer until the next day. But for me it's a way of transferring it to [health provider], thus allowing me to sleep. Instead of ruminating about all this stuff and not getting to sleep. [Service user, dyad interview]

The health providers who remotely accessed the service users' modules (eg, goals and activities) reported that ReConnect yielded qualitatively new and different information than that typically talked about in consultations. In addition, it allowed health providers to monitor progress and tailor their help in a more timely manner, as echoed in the quote below:

It's much easier to see where my service users are. If some support is needed, if I need to meet with them in-person, or if it's sufficient to have the appointment that's already booked, if I need less...sort of knowing how my service user's everyday life is. I get a grip on this through ReConnect, compared with having a consultation every other week. Then I don't get so much perspective on the person. [Health provider, individual interview]

Despite service users consenting to not using ReConnect for emergency needs, some of their messages could be alarming.

One health provider described allowing such messages from 1 service user whom the health provider had worked with over time, before ReConnect. Acceptance of whatever messages came from the service user was described as important to their relationship and common basis for collaboration, despite the dilemmas that this entailed, as shown in the quote below:

I don't know if I would have been so courageous with others, the way I've been with [service user]. To receive and take in what has come [in messages], and dare to let it run its course. Because it's been a question of living, or not living. It has. But I have also been very clear that this is your choice. I can help you, if you choose to live, but I can't help you if you choose to die. That's the way it is. [Health provider, dyad interview]

Goals and Direction

The mere availability of the goal module appeared to introduce and promote the topic of goals in working relationships, even though actual use of the module itself could vary considerably. Health providers reported working with goals before ReConnect, whereas service users reported that working with goals was new or different after starting with ReConnect. Service users' descriptions of status in their different life domains, and the formulation of goals from this overview, gave the dyad a greater sense of direction and a basis for monitoring progress. It also helped facilitate insights that service users could experience as more relevant. This is evident from the following quote by a health provider:

She [service user] has most likely come into a new stage in her recovery process, to use it [portal] together with other things that have happened in her life. It [ReConnect] helped her to gain greater insight...she understands herself better. Why she reacts like she does in different situations and what she can do to avoid it. It's a topic we discuss all the time, but now it's more like...“Oh, so this is why things are as they are right now.” [Health provider, focus group]

An important aspect of working with the modules was that communication in the dyad about issues became more concrete and substantial in ways service users found relevant, as stated by 1 service user below:

So, I feel that I could make things more specific. And have gotten a good start with my providers in ReConnect. That's probably the most important. That things are more concrete. With my earlier provider, things were really scattered and diffuse [...] Now I'm more receptive to working on things and this tool [portal] has helped, it's encouraged me to get a grip on things. To get specific. To get an overview. To put things into words, in writing. [Service user, individual interview]

In addition to a shift in ownership of the priorities and goals in the working relationship, service users' resources and knowledge of what helps in everyday life came more into focus.

Such topics ranged from exercising and making friends to getting through the many activities and tasks during Christmas. One of the service users stated:

I think it has actually changed the way we work together. Earlier it's always been that [health provider] asked me if I'd taken my medications, and then what openings there were in our calendars for my next consultation. Those two issues were what [health provider] seemed mainly preoccupied with. Now with ReConnect we work more on my resources and goals—it can be as simple as managing to get through Christmas. How do I do it? Sub-goals and activities can be: buy the steak, avoid stress, get everything in the house, that type of thing—it was actually very useful to get ideas from another perspective—how to break down the problem...It really helps to break down the problem into smaller pieces. [Service user, focus group]

Sense of Presence and Availability

Both service users and health providers reported that the portal's 24/7 availability gave service users a sense of flexibility, extra time, and support in their daily lives. One service user said:

She [health provider] has been really good at giving me feedback [...] like when I can't sleep, she answers me when she comes to work at 8 o'clock [in the morning], but then it doesn't wake me up. [Service user, individual interview]

Both persons in the dyad described that the opportunities for written communication between consultations facilitated a sense of availability. One service user explained that it was like the health provider was with her in her own living room and that the opportunity to send messages prevented long waiting hours through the night. One of the health providers underlined the importance of having a sense of presence and availability as follows:

It's sort of that they feel that they are part of something greater, maybe. That there is a connection somewhere out there. Either through the forum, or...maybe their health provider, or someone they can be in touch with. To know someone is there. [Health provider, individual interview]

For another health provider, the portal enabled greater flexibility in that the health provider could respond promptly to the needs of service users outside consultations. Although this did not necessarily require more time, service users might experience it that way, as described in the quote below:

To be completely honest, I really think they feel like they get more time with me and feel more appreciated. [Health provider, individual interview]

Out of Alignment

This theme illustrates difficulties that participants described about working together through ReConnect and contains 4 subthemes: initiative and responsibility, waiting for the other, feeling overwhelmed, and clarifications and agreements.

Initiative and Responsibility

Service users reported difficulties in taking the initiative and responsibility to work with their health provider through ReConnect. Some did not know exactly what they needed or how to ask for help and reported that they did not want to disturb the health provider, who had an already heavy workload. Although service users acknowledged their own responsibility to take action and to set the agenda in the collaboration through ReConnect, they also described how this could be difficult as follows:

When you're struggling, at least I find it very difficult to sit down and write things to my helper. I would prefer that my helper would write to me first. [Service user, focus group]

Health providers explained their lack of initiative by referring to characteristics of the portal, which was intended to be owned and managed by service users. They also argued that the initiative and responsibility should be with the service users as part of their recovery process. Health providers also expressed concerns that encouraging use might be an added burden for the service users. However, health providers also stated that they did not consider the portal suitable for everyone. One of the health providers said:

Yes, I've read some things about user involvement. How it should be. And then you think that maybe it doesn't work for everyone [...]. I've maybe thought of this as being user-controlled, so you [service user] can do more for yourself. [Health provider, individual interview]

Mainly, it was the service users' initiatives that determined the health providers' activity in the portal, mostly for reading and/or responding to messages. However, some health providers described that they encouraged activities in ReConnect such as working with different modules in the portal, initiating messages, and following up work with goals and activities both online and in consultations. The health providers' initiatives toward use of ReConnect were highly appreciated and considered essential for successful use by some of the service users. For other health providers, the service users' expectations to take initiative and responsibility for use were difficult to fulfill, as described below:

I have a feeling that she had somewhat higher expectations on my...that I should have been more active. But...it's not really the way we work. [Health provider, individual interview]

Waiting for the Other

For service users, the lack of response from their health providers to their initiatives through ReConnect resulted in feelings of mistrust and not being appreciated. As one service user said,

Just feeling that one is not believed. Feeling not being taken seriously. [Service user, individual interview]

Some service users described the work in ReConnect without the support of the health provider as meaningless. One service

user reported needing support especially in working with goals, but that the health provider had not responded, as follows:

But then it's really important that you have your helper on the other end. That you work together in ReConnect with goals for example. I haven't had that. [Service user, focus group]

Health providers expressed awareness of how unmet initiatives and expectations could potentially be harmful for service users. However, difficulties in expressing oneself in writing about complex issues was one health provider's explanation for not responding to service users' messages:

I find it difficult to answer in writing, sort of...in some ways...when there are a lot of questions. And she wanted me to say what I think. It gets very difficult. Because it's the kind of thing that's best discussed in a dialogue. Verbally. It gets so...when there isn't any wrong and right, sort of, in what we're working on. And I can't do it in writing. This is something that she experienced as a disappointment, and thought, yeah, we should have clarified that ahead of time. [Health provider, individual interview]

Some health providers also described frustration over a lack of response to their initiatives to use ReConnect. For one health provider, a lack of response from the other decreased her motivation to take new initiatives:

So...you know I feel that...when that after that long response, and [service user] doesn't answer. Then the gas sort of goes out of my balloon. [Health provider, focus group]

Feeling Overwhelmed

Several health providers described different experiences of being overwhelmed when using ReConnect. Frequent messages, ambiguities in how to respond, and a call for being more proactive in the use of ReConnect were found difficult. One health provider elaborates,

...if there are three A4 pages with dense text that I have to go through, then it's sort of...then I can feel that I don't measure up sort of. And she might have experienced that she didn't get the response that she was hoping for. [Health provider, individual interview]

Furthermore, therapeutic responses to messages from the service users were found time-consuming, in addition to causing concerns with how the text could be interpreted by the receiver. As one health provider stated:

You've got to watch what you write. Many patients can be easily offended. Some patients are really obsessed with details. And it's not your intention to hurt feeling, or...right. But it can be perceived like that. So that's why you have to be very careful with how you express yourself. Where the commas, and the periods are. And I experience that as demanding. [Health provider, individual interview]

The work with ReConnect came on top of what health providers described as a heavy workload and was difficult for some to

balance. During a group interview with health providers, the interviewer conveyed a wish expressed by a service user who would have liked it if the health provider could send a message asking "How are you doing?" now and then. This prompted 1 health provider to burst out that she regretted participating in ReConnect, as shown in the quote below:

So, when I hear that kind of thing I get...I don't have a problem being nagged at, that doesn't upset me. But having to go around with other peoples' issues in my head all the time, I just don't have the capacity. So, when you said that...you know what? [...]I need to get out of this. That was exactly what I felt. [Health provider, focus group]

Clarifications and Agreements

As was evident throughout the above 3 subthemes, few dyads reported explicitly addressing expectations or making agreements about how they would use ReConnect. In hindsight, most of the health providers expressed that such discussions would have made the collaboration easier and reduced uncertainties. One health provider stated:

Yes, I think it would have been best to set aside time at the beginning and do things, test it out together. That would probably have contributed to a safer basis for using the portal in a better way. [Health provider, focus group]

However, a lack of clarifications and agreements was not necessarily experienced as a problem, as reported by 1 service user below:

No, we have never really had any agreement about how we would work. [...] ReConnect has in a way been an extended arm for me. It's very seldom [health provider] writes anything on her own initiative. So, it's me who opens communication. [Service user, individual interview]

One health provider underlined a need for recurrent discussions about use and expectations as collaboration progressed and needed adaptations, as shown in the quote below:

Back to the issue of expectations. I think there are, in a way, several layers to the issue. The first is to clarify expectations about response times and such. That's one thing, but then if a service user is active, that they use exercises, or are working on new goals that you need to be involved in, then it's important to make new clarifications. What type...where are we now? How do we do this together? So, that you have to take a new round each time. [Health provider, individual interview]

Discussion

Principal Findings

This study describes service user and health provider experiences in ongoing mental health care with an e-recovery portal as a basis for exploring the potential role it may play in working relationships. The 2 main themes that emerged from our data depict 2 contrasting roles.

Exploiting New Relational Avenues

The main theme *new relational avenues* describes how dyads used the e-recovery portal to enrich their working relationship. Mainly described by the health providers, ReConnect strengthened service users' sense of ownership in their care, largely through the goal module and writing process. The writings from service users also offered health providers broader and more nuanced insights from the service users' perspectives, and thus a more person-centered basis for working together, also during in-person consultations. ReConnect was described as helping to focus collaboration on the needs and goals that service users considered relevant to their daily lives; for example, a positive Christmas for one's family. Service users' 24/7 access to the portal promoted a sense of providers' presence and availability despite asynchronous, and sometimes lengthy, response times.

In addition to coinciding with other studies showing the potential of e-health technologies in fostering engagement in treatment and care, self-disclosure, and therapeutic writing [18], our study found that use of the goal module, in particular, appeared to boost the person-centered nature of collaboration. Setting the agenda and doing things for oneself is central to recovery-oriented practices [37,38]. However, findings from a review study of care plans indicate that goals and actions are mostly formulated in terms of actions to be taken by providers on behalf of service users [39]. Incorporating support for goal formulation and follow-up into service users' own portal for collaboration with providers, as done in this study, appears to be a promising way of counterbalancing this. Moreover, the examples of successful uses of the goal module illustrate how service users' values, preferences, strengths, and resources relevant to their everyday lives came more to the forefront of collaboration. This coincides with recovery-oriented approaches [39] and descriptions of helpful relationships [13]. However, such benefits are not given. Common among dyads reporting positive portal use was that they had health providers who elicited and were responsive to service users' initiatives and needs.

Aligning Expectations and Responsibilities

The main theme *out of alignment* highlights the difficulties that arose when service users' and health providers' expectations were not aligned and when the resulting difficulties were not addressed. Nonhelping relationships have earlier been described as impersonal and lacking space for negotiation of the relationship, and the support and treatment provided through it [14]. Although participants were encouraged during the training sessions to discuss beforehand how they would use the portal, few did so explicitly. Those who expressed frustrations, both among service users and health providers, reported expecting initiatives or responses via the portal that the other party failed to fulfill. Service users experienced this as not being taken seriously, whereas some health providers reported losing motivation to use the portal.

Some health providers who neglected to initiate contact with service users via the portal explained this by referring to the information about the study underlining that ReConnect was mainly the service users' portal that they owned and managed.

When service users were uncertain about use, or needed encouragement from their health providers to use the tool, a lack of initiative from health providers brought use to a standstill, which service users described as frustrating. This raises the issue of how health providers can balance between enabling service users' greater engagement, responsibility, and control of their recovery process, without relinquishing responsibility for the quality of the working relationship in care processes when using e-recovery portals.

The factors collectively grouped under the subtheme *feeling overwhelmed* refer to the experiences of health providers, especially related to well-known difficulties with the use of written communication in a working relationship [19]. Such factors include discomfort in receiving frequent and long messages, service users' expectations about frequency and content of responses, difficulties in articulating oneself in writing, fear of misunderstandings due to lack of nonverbal cues, and heavy workload. It should be noted that none of the service users reported expecting immediate or therapeutic responses to their messages. Interestingly, health providers' frustrations over not being able to respond in real time [20] were not reported by service users. Instead, nonsynchronicity was described as enabling them to rest after transferring difficult issues over to the provider, knowing it would be addressed in time.

Although some dyads clarified their understandings about how to use the portal and adjusted accordingly, others did not. Dyads that were enriched by use of ReConnect, despite not explicitly agreeing on how to use the system, appeared to have relationships that were open and adaptable at the outset. For some of those who experienced frustrations, the portal appeared to expose and sometimes reinforce suboptimal working relationships. An earlier study of portal use reported that service users and health providers seek guidance for how to appropriately engage with each other through the portal [21]. Although such guidelines may have helped reduce some of the difficulties the participants experienced in reaching a common understanding in our study, it is not clear that relationships that are nonhelping at the outset will be improved by such guidelines.

Limitations

Our own involvement in the design of ReConnect, as well as participants' knowledge of our involvement, poses known risks to the trustworthiness of our findings [40]. We have sought to limit these risks by addressing them repeatedly in the research team throughout the study and by providing thorough and transparent descriptions of context and method. Discussions with participants about our preliminary findings (see Methods section) helped us critique and nuance our evolving interpretations of the data. The conduct of the study as part of ongoing community practices and the inclusion of participants with diverse ages, mental health problems, and professional backgrounds should strengthen the transferability of findings, at least in a Norwegian context. However, the study's dependability, that is, awareness of the degree to which the data changed over time, could have been discussed by the research team in further detail (ibid). The gender bias toward women,

despite concerted efforts to recruit men, is also a limitation to this study.

Implications for Practice and Further Research

In efforts to ensure that e-recovery portals such as ReConnect enhance rather than undermine the quality of working relationships, some suggestions can be derived from our findings.

Instead of introducing a portal to dyads by saying “use it as you see fit,” as done in this study, more detailed information and recommendations would likely have benefited dyads. Such information would include the advantages and disadvantages that others have experienced with portal use, recommendations for how to clarify mutual expectations (eg, response times, type of content, and how to resolve disagreements about preferences for use), and that agreements for use need to be revisited as parties gain experience with use.

Furthermore, implementation of an e-recovery portal into organizations is probably more likely to be successful if coupled with organizational commitments to recovery principles as described in the literature [6]. This includes training providers in how to foster good working relationships (eg, responsiveness to service users’ initiatives). Although we have yet to test this, we believe such training might be more effective if feedback-informed methods [41] were incorporated into the portal. Without the above dyad clarifications and organizational support, our findings suggest that health providers who are skeptical to using a portal for collaborating with service users should probably refrain from use regardless of the wishes of service users.

Our hypothesis that the quality of preexisting working relationships is the primary determinant of the benefits of an

e-recovery portal (rather than the portal itself) needs closer study. If such portals can play an independent role in benefiting or undermining working relationships, then we need to know more about how and by which mechanisms, some of which are suggested by our findings. A key question is how health providers can balance between enabling service users’ greater engagement, responsibility, and control in their own care, without relinquishing responsibility for the quality of the working relationship, also when using e-recovery portals.

Furthermore, we propose that the goal module in particular strengthens person-centered collaboration and is worthy of further study. For example, how does collaboration through the goal module affect providers’ engagement in the service users’ priorities and goals? More knowledge is also needed about gender preferences to ensure that tool and intervention design is inclusive of both genders. Finally, more knowledge is needed about how to optimally leverage the expertise of service user consultants in promoting positive working relationships both online and in real life.

Conclusions

The degree to which service user-health provider dyads benefited from portal use appeared to be mainly associated with the degree to which the dyads’ relations were open and flexible before the portal was introduced. For those who experienced frustrations, the portal may have both exposed and added to suboptimal working relationships. Use of the goal module, in particular, appeared to strengthen the person-centered nature of collaboration. A key question is how providers balance between enabling service users’ greater control over their own treatment and care, without relinquishing responsibility for the quality of the working relationship, also when using an e-recovery portal.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Interview guide for focus groups.

[[JPG File, 69KB](#) - [mental_v4i4e54_app1.JPG](#)]

Multimedia Appendix 2

Interview guide for individual and dyad interviews.

[[JPG File, 99KB](#) - [mental_v4i4e54_app2.JPG](#)]

References

1. Martin DJ, Garske JP, Davis MK. Relation of the therapeutic alliance with outcome and other variables: a meta-analytic review. *J Consult Clin Psychol* 2000 Jun;68(3):438-450. [Medline: [10883561](#)]

2. Priebe S, McCabe R. Therapeutic relationships in psychiatry: the basis of therapy or therapy in itself? *Int Rev Psychiatry* 2008 Dec;20(6):521-526. [doi: [10.1080/09540260802565257](https://doi.org/10.1080/09540260802565257)] [Medline: [19085408](#)]
3. Johansson H, Eklund M. Patients' opinion on what constitutes good psychiatric care. *Scand J Caring Sci* 2003 Dec;17(4):339-346. [Medline: [14629636](#)]
4. Kirsh B, Tate E. Developing a comprehensive understanding of the working alliance in community mental health. *Qual Health Res* 2006 Oct;16(8):1054-1074. [doi: [10.1177/1049732306292100](https://doi.org/10.1177/1049732306292100)] [Medline: [16954525](#)]
5. Dixon LB, Holoshitz Y, Nossel I. Treatment engagement of individuals experiencing mental illness: review and update. *World Psychiatry* 2016 Feb;15(1):13-20 [FREE Full text] [doi: [10.1002/wps.20306](https://doi.org/10.1002/wps.20306)] [Medline: [26833597](#)]
6. Le Boutillier C, Leamy M, Bird VJ, Davidson L, Williams J, Slade M. What does recovery mean in practice? A qualitative analysis of international recovery-oriented practice guidance. *Psychiatr Serv* 2011 Dec;62(12):1470-1476. [doi: [10.1176/appi.ps.001312011](https://doi.org/10.1176/appi.ps.001312011)] [Medline: [22193795](#)]
7. Anthony WA. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychiatr Rehabil J* 1993;16(4):11-23. [doi: [10.1037/h0095655](https://doi.org/10.1037/h0095655)]
8. Slade M. *Personal Recovery and Mental Illness: A Guide for Mental Health Professionals (Values-Based Medicine)*. Cambridge: Cambridge University Press; 2009.
9. Davidson L, Roe D. Recovery from versus recovery in serious mental illness: one strategy for lessening confusion plaguing recovery. *J Ment Health* 2009;16(4):459-470. [doi: [10.1080/09638230701482394](https://doi.org/10.1080/09638230701482394)]
10. Leamy M, Bird V, Le Boutillier C, Williams J, Slade M. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *Br J Psychiatry* 2011 Dec;199(6):445-452 [FREE Full text] [doi: [10.1192/bjp.bp.110.083733](https://doi.org/10.1192/bjp.bp.110.083733)] [Medline: [22130746](#)]
11. Slade M, Amering M, Farkas M, Hamilton B, O'Hagan M, Panther G, et al. Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems. *World Psychiatry* 2014 Feb;13(1):12-20 [FREE Full text] [doi: [10.1002/wps.20084](https://doi.org/10.1002/wps.20084)] [Medline: [24497237](#)]
12. Farkas M, Gagne C, Anthony W, Chamberlin J. Implementing recovery oriented evidence based programs: identifying the critical dimensions. *Community Ment Health J* 2005 Apr;41(2):141-158. [Medline: [15974495](#)]
13. Ljungberg A, Denhov A, Topor A. The art of helpful relationships with professionals: a meta-ethnography of the perspective of persons with severe mental illness. *Psychiatr Q* 2015 Dec;86(4):471-495. [doi: [10.1007/s1126-015-9347-5](https://doi.org/10.1007/s1126-015-9347-5)] [Medline: [25631156](#)]
14. Ljungberg A, Denhov A, Topor A. Non-helpful relationships with professionals - a literature review of the perspective of persons with severe mental illness. *J Ment Health* 2016 Jun;25(3):267-277. [doi: [10.3109/09638237.2015.1101427](https://doi.org/10.3109/09638237.2015.1101427)] [Medline: [27150468](#)]
15. Akesson KM, Saveman BI, Nilsson G. Health care consumers' experiences of information communication technology-a summary of literature. *Int J Med Inform* 2007 Sep;76(9):633-645. [doi: [10.1016/j.ijmedinf.2006.07.001](https://doi.org/10.1016/j.ijmedinf.2006.07.001)] [Medline: [16931133](#)]
16. Sucala M, Schnur JB, Constantino MJ, Miller SJ, Brackman EH, Montgomery GH. The therapeutic relationship in e-therapy for mental health: a systematic review. *J Med Internet Res* 2012 Aug 2;14(4):e110 [FREE Full text] [doi: [10.2196/jmir.2084](https://doi.org/10.2196/jmir.2084)] [Medline: [22858538](#)]
17. Hanley T, Reynolds Jr DJ. Counselling psychology and the internet: a review of the quantitative research into online outcomes and alliances within text-based therapy. *Counselling Psychology Review* 2009;24(2):4-13 [FREE Full text]
18. Clough BA, Casey LM. Technological adjuncts to increase adherence to therapy: a review. *Clin Psychol Rev* 2011 Jul;31(5):697-710. [doi: [10.1016/j.cpr.2011.03.006](https://doi.org/10.1016/j.cpr.2011.03.006)] [Medline: [21497153](#)]
19. Rochlen AB, Zack JS, Speyer C. Online therapy: review of relevant definitions, debates, and current empirical support. *J Clin Psychol* 2004 Mar;60(3):269-283. [doi: [10.1002/jclp.10263](https://doi.org/10.1002/jclp.10263)] [Medline: [14981791](#)]
20. Cavanagh K, Millings A. (Inter)personal computing: the role of the therapeutic relationship in e-mental health. *J Contemp Psychother* 2013;43(4):197-206. [doi: [10.1007/s10879-013-9242-z](https://doi.org/10.1007/s10879-013-9242-z)]
21. Sieck CJ, Hefner JL, Schnierle J, Florian H, Agarwal A, Rundell K, et al. The rules of engagement: perspectives on secure messaging from experienced ambulatory patient portal users. *JMIR Med Inform* 2017 Jul 4;5(3):e13 [FREE Full text] [doi: [10.2196/medinform.7516](https://doi.org/10.2196/medinform.7516)] [Medline: [28676467](#)]
22. Denneson LM, Cromer R, Williams HB, Pisciotto M, Dobscha SK. A qualitative analysis of how online access to mental health notes is changing clinician perceptions of power and the therapeutic relationship. *J Med Internet Res* 2017 Jun 14;19(6):e208 [FREE Full text] [doi: [10.2196/jmir.6915](https://doi.org/10.2196/jmir.6915)] [Medline: [28615152](#)]
23. Berger T. The therapeutic alliance in internet interventions: a narrative review and suggestions for future research. *Psychother Res* 2017 Sep;27(5):511-524. [doi: [10.1080/10503307.2015.1119908](https://doi.org/10.1080/10503307.2015.1119908)] [Medline: [26732852](#)]
24. Strand M, Gammon D, Ruland CM. Transitions from biomedical to recovery-oriented practices in mental health: a scoping review to explore the role of Internet-based interventions. *BMC Health Serv Res* 2017 Apr 7;17(1):257 [FREE Full text] [doi: [10.1186/s12913-017-2176-5](https://doi.org/10.1186/s12913-017-2176-5)] [Medline: [28388907](#)]
25. Emont S. 2011. Measuring the impact of patient portals: what the literature tells us URL: <https://www.mnhospitals.org/Portals/0/Documents/patientsafety/Perinatal/PDF%20MeasuringImpactPatientPortals.pdf> [accessed 2017-10-30] [WebCite Cache ID 6ubDUuKm]

26. Gammon D, Strand M, Eng LS, Børøsund E, Varsi C, Ruland C. Shifting practices toward recovery-oriented care through an e-recovery portal in community mental health care: a mixed-methods exploratory study. *J Med Internet Res* 2017 May 2;19(5):e145 [FREE Full text] [doi: [10.2196/jmir.7524](https://doi.org/10.2196/jmir.7524)] [Medline: [28465277](https://pubmed.ncbi.nlm.nih.gov/28465277/)]
27. Gammon D, Strand M, Eng LS. Service users' perspectives in the design of an online tool for assisted self-help in mental health: a case study of implications. *Int J Ment Health Syst* 2014 Jan 9;8(1):2 [FREE Full text] [doi: [10.1186/1752-4458-8-2](https://doi.org/10.1186/1752-4458-8-2)] [Medline: [24405765](https://pubmed.ncbi.nlm.nih.gov/24405765/)]
28. Beresford P. From 'other' to involved: user involvement in research: an emerging paradigm. *Nord Soc Work Res* 2013;3(2):139-148. [doi: [10.1080/2156857X.2013.835138](https://doi.org/10.1080/2156857X.2013.835138)]
29. Beresford P. User involvement, research and health inequalities: developing new directions. *Health Soc Care Community* 2007 Jul;15(4):306-312. [doi: [10.1111/j.1365-2524.2007.00688.x](https://doi.org/10.1111/j.1365-2524.2007.00688.x)] [Medline: [17578391](https://pubmed.ncbi.nlm.nih.gov/17578391/)]
30. Davidson L, Bellamy C, Flanagan E, Guy K, O'Connell M. A participatory approach to person-centred research: maximising opportunities for recovery. In: McCormack B, van Dulmen S, Eide H, Skovdahl K, Eide T, editors. *Person-Centred Healthcare Research*. West Sussex: WILEY Blackwell; 2017:69-83.
31. Malterud K. Fokusgrupper som forskningsmetode for medisin og helsefag [Norwegian]. Oslo: Universitetsforlaget Oslo; 2012.
32. Morgan DL. *Focus Groups as Qualitative Research*. Thousand Oaks, California: Sage Publications; 1996.
33. Malterud K. Kvalitative metoder i medisinsk forskning - en innføring [Norwegian]. Oslo: Universitetsforlaget; 2011.
34. Clarke V, Braun V. *Successful qualitative research - a practical guide for beginners*. Thousand Oaks, California: Sage; 2013.
35. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006 Jan;3(2):77-101. [doi: [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)]
36. van Nes F, Abma T, Jonsson H, Deeg D. Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing* 2010 Dec;7(4):313-316 [FREE Full text] [doi: [10.1007/s10433-010-0168-y](https://doi.org/10.1007/s10433-010-0168-y)] [Medline: [21212820](https://pubmed.ncbi.nlm.nih.gov/21212820/)]
37. Slade M, Bird V, Le Boutillier C, Farkas M, Grey B, Larsen J, et al. Development of the REFOCUS intervention to increase mental health team support for personal recovery. *Br J Psychiatry* 2015 Dec;207(6):544-550 [FREE Full text] [doi: [10.1192/bjp.bp.114.155978](https://doi.org/10.1192/bjp.bp.114.155978)] [Medline: [26450586](https://pubmed.ncbi.nlm.nih.gov/26450586/)]
38. Tondora J, Davidson L, Miller R, Slade M. *Partnering for Recovery in Mental Health: Practical Guide to Person-Centered Planning*. Chichester, West Sussex: Wiley; 2014.
39. Gilburd H, Slade M, Bird V, Oduola S, Craig TK. Promoting recovery-oriented practice in mental health services: a quasi-experimental mixed-methods study. *BMC Psychiatry* 2013 Jun 13;13:167 [FREE Full text] [doi: [10.1186/1471-244X-13-167](https://doi.org/10.1186/1471-244X-13-167)] [Medline: [23764121](https://pubmed.ncbi.nlm.nih.gov/23764121/)]
40. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004 Feb;24(2):105-112. [doi: [10.1016/j.nedt.2003.10.001](https://doi.org/10.1016/j.nedt.2003.10.001)] [Medline: [14769454](https://pubmed.ncbi.nlm.nih.gov/14769454/)]
41. Miller SD, Hubble MA, Chow D, Seidel J. Beyond measures and monitoring: realizing the potential of feedback-informed treatment. *Psychotherapy (Chic)* 2015 Dec;52(4):449-457. [doi: [10.1037/pst0000031](https://doi.org/10.1037/pst0000031)] [Medline: [26641375](https://pubmed.ncbi.nlm.nih.gov/26641375/)]

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Original Paper

School Counselors' Perspectives of a Web-Based Stepped Care Mental Health Service for Schools: Cross-Sectional Online Survey

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Abstract

Background: Mental health problems are common among youth in high school, and school counselors play a key role in the provision of school-based mental health care. However, school counselors occupy a multispecialist position that makes it difficult for them to provide care to all of those who are in need in a timely manner. A Web-based mental health service that offers screening, psychological therapy, and monitoring may help counselors manage time and provide additional oversight to students. However, for such a model to be implemented successfully, school counselors' attitudes toward Web-based resources and services need to be measured.

Objective: This study aimed to examine the acceptability of a proposed Web-based mental health service, the feasibility of providing this type of service in the school context, and the barriers and facilitators to implementation as perceived by school counselors in New South Wales (NSW), Australia.

Methods: This study utilized an online cross-sectional survey to measure school counselors' perspectives.

Results: A total of 145 school counselors completed the survey. Overall, 82.1% (119/145) thought that the proposed service would be helpful to students. One-third reported that they would recommend the proposed model, with the remaining reporting potential concerns. Years of experience was the only background factor associated with a higher level of comfort with the proposed service ($P=.048$). Personal beliefs, knowledge and awareness, Internet accessibility, privacy, and confidentiality were found to influence, both positively and negatively, the likelihood of school counselors implementing a Web-based school mental health service.

Conclusions: The findings of this study confirmed that greater support and resources are needed to facilitate what is already a challenging and emotionally demanding role for school counselors. Although the school counselors in this study were open to the proposed service model, successful implementation will require that the issues outlined are carefully addressed.

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KEYWORDS

secondary schools; adolescent; counseling; internet; depression

Introduction

Background

Worldwide, mental illness in adolescence is a major public health burden. Up to 50% of all mental disorders emerge before the age of 18 [1] and are associated with poor academic performance, early termination of schooling, elevated suicide risk, and comorbidities such as substance misuse and self-harm [2-4]. Despite the substantial impact, professional help-seeking is low [5-8]. When help is sought, adolescents prefer informal sources who are familiar and trusted [9]. Barriers to formal help-seeking include poor mental health literacy, perceived negative stigma [10,11], and service inaccessibility [12]. Current youth services are overburdened, fragmented, and unable to provide preventative care for the wide spectrum of youth presentations [13]. Given that up to 70% of those who experience mental illness in adolescence will relapse within 5 years, prevention and early intervention is key [14,15]. There is a demonstrated need to improve the ability to screen, initiate prevention, and respond to youth at all levels of severity of mental ill health [13].

Schools play a vital role in fostering the social and emotional well-being of youth [16-18]. Schools have a formalized duty of care, defined as the moral and legal obligation to ensure the well-being of their students. In addition to this, schools are an ideal setting to promote mental health as adolescents spend a significant portion of their time at school; schools are a natural setting for learning skills and strategies; mental health education can be integrated into the curriculum (reducing time, location, and cost barriers); access to parents and families is easily facilitated; and the social context allows for stigma reduction [19]. School staff are well positioned to identify changes in students' behavior and to identify threats to well-being in the school environment [20]. As attendance at school is typically compulsory until the age of 16 years, schools give unparalleled access to youth [21]. Despite this, secondary schools remain underutilized for the prevention and treatment of mental health problems.

In Australia, approaches to mental health in secondary schools are varied and multifaceted. In the state of New South Wales (NSW), student mental health is mainly supported by a school counselor who is employed to offer counseling [17]. All NSW students can expect to have access to a school counselor, although recent figures have shown that the student-to-counselor ratio is double the recommendation of 500:1 [17,22]. This disparity is also common in the United States [23], which may reduce the school counselors' capacity to proactively identify students in need [12]. Australian school counselors also occupy a multispecialist role as they conduct psychometric assessments, deliver training to staff, and liaise with parents, teachers, and external services [24]. These demands can lead to a sense of role ambiguity [24]. Despite the emotional impacts of the role, school counselors can feel isolated because of confidentiality issues [25,26] and a perceived lack of clinical supervision [26]. Studies in the United States have found school counselors experience high levels of stress and burnout due to role conflict, professional overload, and lack of autonomy [27,28]. It is likely

that these factors also affect Australian school counselors and their capacity to provide care, although comprehensive studies among this population are lacking. Although school counselors are often supported by a broader range of school programs, there is substantial variability in the type, extent, quality, and evidence base of these [29-31]. Competing responsibilities, parent disengagement, lack of support from school staff [31], limited resources, and significant variations in staff training [32] have hindered implementation. As a result, many schools have a highly reactive, disjointed, and piecemeal approach to mental health [33] that lacks a universal and preventative focus [34].

Web-based mental health resources, also known as e-mental health, may overcome many of the challenges faced by school counselors [35]. Young people are very willing to seek help for mental health via the Internet [36,37], and Web resources provide convenient access to information and support. However, school counselors have been found to be reluctant to use some types of Web resources, specifically online counseling [36,38]. Lack of training, misbeliefs about quality and efficacy, confidentiality, and dishonesty concerns have been found to affect the use of online counseling in school settings [36,39]. It is likely that these barriers influence the uptake of other Web-based programs and resources, although there is little research examining school counselors' perspectives toward more recent developments such as mobile technology, e-monitoring tools, automated feedback, stepped care, and interventions delivered to entire student populations at once. One such advance is *Smooth Sailing*—a Web-based mental health service developed by the Black Dog Institute, which is based on the principles of stepped care [35]. Delivered in the classroom using a mobile or desktop device, this service utilizes the Internet to triage students' mental health and assist school counselors in identifying and attending to those in need. On the basis of their responses to clinically validated measures, students are allocated to one of five sequential treatment steps. The service offers low-intensity interventions (eg, Web-based psychoeducation and cognitive behavioral therapy) to youth with mild to moderate symptoms (ie, steps 0, 1, 2), whereas more costly, intensive face-to-face interventions (eg, school counseling) are reserved for those who are more severe (ie, steps 3, 4). Students who report suicidal ideation trigger an automatic email alert to the school counselor who responds within 48 hours, conducting the risk assessment and external referral. Although complex, this novel service may improve school counselors efficiency and capacity to prevent mental illness in students by detecting symptoms early [33]. Web-based programs are easily integrated into the service, as they are fully automated, acceptable to youth, preserve fidelity of care, and allow for ongoing monitoring and automated feedback [40,41]. This service is yet to be implemented in NSW schools, as the attitudes of school counselors toward this new type of care are not yet known.

Objectives

Using an online survey, this study aimed to examine the acceptability of the proposed Web-based mental health service, the feasibility of providing this type of service in the school context, and the barriers and facilitators to implementation as perceived by school counselors in NSW, Australia. This study

was guided by the Stage Based Implementation Framework [42] and the Medical Research Council's Guide for Complex Interventions [43], which outline the need for stakeholder engagement in measuring the barriers and facilitators to implementation. Using these frameworks, this study aimed to bridge the research-to-practice gap that currently exists within school-based mental health care by consulting closely with school counselors as to their needs and capacity, context characteristics, and their willingness to integrate novel interventions into their practice. These findings will assist health service researchers who wish to leverage the Web to deliver efficient mental health services, at scale, and within the school setting.

Methods

Study Design

This study utilizes a cross-sectional online survey. Ethics approval was obtained from the University of New South Wales (approval: HC15456) and the NSW Department of Education (SERAP approval: 2015369).

Sample Size

The NSW Department of Education estimates that there are 790 school counselors across NSW [17]. On the basis of this figure, and adopting a CI of 95% and margin of error of 7%, the sample size necessary for representativeness was calculated to be 157.

Participants, Procedure, and Recruitment

Participants were aged over 18 years, fluent in English, and currently working as a school counselor in an NSW secondary school. Recruitment took place between July and October 2016 (108 days) via the Black Dog Institute website, social media channels, word of mouth, and an electronic direct mail-out to professional networks. The online survey link was included in all recruitment material such that participants were automatically directed to the study website. Online consent was provided before answering the survey questions, in which participants were required to confirm their status as a secondary school counselor in NSW. The survey was voluntary and could be completed on either a mobile or a computer device. Participants did not receive any financial benefit for their participation.

Survey

The online survey is included as [Multimedia Appendix 1](#). The questions were taken from a semistructured interview schedule and adapted for online delivery. The survey consisted of 91 questions, displayed over 17 pages, and took approximately 45 minutes to complete. Participants were not able to change their answers once saved and submitted. Participants' Internet Protocol addresses were collected and checked for duplicates. The quantitative data consisted of all nominal and interval questions, whereas the qualitative data consisted of the free-text response options.

Demographics

A total of 12 questions assessed participant demographics and background factors, including age, gender, Aboriginal or Torres Strait Islander (ATSI) identification, place of birth, relationship

status, highest level of education, registration status (registered or unregistered psychologist), years working as a school counselor, and number of schools currently working in.

Current Role

A total of six questions assessed the current school counselor role, including the type of school (funding: public or private, gender: single sex or coeducational), employment (part-time or full-time), school size (number of students enrolled), and school location (metropolitan or regional and rural). Using multiple-choice responses, participants were asked about the common referral pathways for students (self-referral, school counselors, teacher, year advisor, parent, and other), perceived barriers to care among students (stigma, low mental health literacy, personal embarrassment or shame, distrust in school, cultural perceptions, personal characteristics of counselor, confidentiality concerns, and other), and perceived prevalence of mental health issues. Workload questions related to average number of session per day, number of sessions related to mental health, mental health issues most prevalent, and a breakdown of daily tasks. Using a 5-point Likert scale ranging from not at all (1) to entirely (5), participants were asked how manageable their workload was and to what extent work stress impacted on their health and well-being. Participants were also asked whether they had ever experienced burnout (yes, no, unsure, rather not say). Frequency of providing personal contact details, frequency of providing care outside of school hours, frequency of deliberate self-care, and frequency of external service referral and parent engagement were also assessed (answered never, rarely, sometimes, often, always). Also using a 5-point Likert scale ranging from not at all (1) to entirely (5), participants were asked to rate how supported they felt by external services, parents, and other teachers. Participants were also asked how satisfied they were with the way their current school addressed the mental health of students, ranging from not at all (1) to entirely (5).

Openness to Practice

This was assessed using the Openness to Practice subscale from the Evidence-Based Practice Attitude Scale (EBPAS) [44,45]. This subscale is designed for mental health service providers and consists of four items in which respondents are asked to rate how likely they are to use or try different types of therapies and interventions. Answers are given using a 5-point Likert scale ranging from not at all (0) to a very great extent (4). Computing the overall mean creates the total score. Total scores range from 0 to 4, with higher scores indicating more favorable attitudes. In a comparative sample of mental health service providers working with children and adolescents, the mean openness score was found to be 2.49 (standard deviation [SD] 0.75). The internal consistency and reliability of this subscale was high for this sample ($\alpha=.78-.81$).

Use of Web-Based Programs and Resources

Participants were asked to indicate how often they used, recommended, or referred students to (1) information websites, (2) online peer support, (3) mobile phone apps, (4) symptom-focused programs, (5) online counseling, and (6) telepsychiatry/ videoconferencing (answered never, sometimes,

often, always). Responses were then dichotomized into “frequently recommended” (often and always) and “rarely recommended” (sometimes and never).

Attitudes Toward Smooth Sailing Service

The survey included short descriptions of the Smooth Sailing service to familiarize participants with the core components. As Smooth Sailing has not yet been publicly released, no school counselors were using this service at the time of the study. Participants were asked 13 questions about their level of comfort with certain features of the service (eg, referral pathways, provision of personal information, data access, computer-assisted decision making, risk management, feasibility of responding in 48 hours, short message service (SMS), and email monitoring). These were answered on a 5-point Likert scale ranging from not at all comfortable (1) to entirely comfortable (5). Short answer responses allowed participants to elaborate on reasons why or why not. Lastly, participants were asked whether they thought the service would be helpful to students (yes, no, unsure) and whether they would prefer that the service was offered outside of the school setting (yes, no, unsure).

Data Analysis

Data were exported from Key Survey version 8.13, an online survey tool developed by WorldAPP, and analyzed using IBM SPSS Statistics version 22. Only those participants who completed the entire survey were included in the analyses. Basic descriptions were calculated and reported for demographics and role characteristics. To examine the factors associated with the level of comfort recommending the Smooth Sailing service, a series of chi-square tests and simple point-biserial correlations were computed. The aim of these analyses was to determine whether age, gender, years of experience, number of students within the school, registration as a psychologist, openness to practice, or manageability of workload were associated with acceptability. The free-text data were analyzed using Braun and Clarke's [46] thematic analysis guidelines. This was an iterative process of reading and coding response to extract key themes and meanings. The answers were analyzed and classified into main themes using an initial coding framework established by one researcher (BOD). A second researcher (MSK) then used this framework to independently code the responses. Initial coder agreement was 88%, with final themes decided upon by consensus.

Results

Participants

A total of 145 (145/166, 87.3%) school counselors completed the survey in its entirety. Of these participants, the mean age was 43 years (SD 12.0, range: 24-71), 85.5% (124/145) were female, 1.4% (2/145) reported to be ATSI, and 84.1% (122/145) were born in Australia. The majority (77.2%, 112/145) were married or partnered. In terms of their education, 77.2% (112/145) had received postgraduate training and 61.4% (89/145) were registered as a psychologist with 15.9% (23/145) currently undertaking their registration process. A total of 75.9% (110/145) were working full-time. On average, participants

reported that they had been a school counselor for 10 years (SD 13.0, range: 1-38 years) and in their career lifetime, had worked at 11 different schools (SD 13.0, range: 1-12). At the time of survey completion, 31.7% (46/145) were working at only one school, with the remainder based at two or more schools. The average school size was 790 students (SD 396.0, range: 21-2015), and 49.7% (72/145) of participants were working in a metropolitan area. A total of 56.6% (82/145) were working in a coeducational, publicly funded school.

Current Role

On average, participants conducted 5 individual student sessions per day (SD 1.60, range: 2-18). When asked to select what proportion of their workload was dominated by various activities, individual therapy (45.1%), administration (19.3%), and psychometric assessments (13.9%) were the three highest responses. Crisis management (7.3%), risk assessments (6.9%), personal or group supervision (5.1%), and professional development (5.4%) occupied less of the participants' workload. A total of 67.6% (98/145) reported that most of their sessions were related to mental health issues. The prevalent mental health issues were anxiety (92.4%, 134/145), depression (85.5%, 124/145), family (77.2%, 112/145), self-harm (55.1%, 80/145), and relationships (54.5%, 79/145).

The most common methods of gaining access to the school counselor were referrals from students themselves (36.6%, 53/145), year advisors (26.9%, 39/145), teachers (21.4%, 31/145), and other school staff (9.6%, 14/145). Direct initiation from the school counselor accounted for only 2.8% (4/145) of students' access. When asked how comfortable they thought students were in approaching them about mental health, only 1 participant reported not at all, with 96.6% (140/145) feeling that students were somewhat to entirely comfortable seeking their help. “Perceived stigma from others” (64.8%, 94/145), “a lack of understanding or knowledge about school counseling” (62.8%, 91/145), “personal embarrassment or shame” (55.9%, 81/145), “wanting to remain anonymous” (38.6%, 56/145), “concerns about confidentiality” (37.2%, 54/145), “cultural perceptions about mental illness” (35.9%, 52/145), and “distrust in the school” (21.4%, 31/145) were identified as the main barriers inhibiting students from seeking school counselors' help.

A total of 2.8% (4/145) reported that they had, at some point, provided their personal contact details to students, and one-third (32.4%, 47/145) had found themselves providing care to students outside of school hours. A total of 68.3% (99/145) often referred students to external services, with 30.3% (44/145) feeling entirely or moderately supported by these services. A total of 50.3% (73/145) often engaged with parents, with 37.2% (54/145) feeling entirely or moderately supported by them. Two-thirds of the sample (61.4%, 89/145) felt supported by other teachers. One-third (44/145) reported that their current workload was not at all (11.0%) or only slightly (19.3%) manageable. Two-thirds (66.9%, 97/145) reported that work stress impacted on their health and well-being, and 44.8% (65/145) reported that they had experienced burnout. Overall, less than half (47.6%, n=69/145) were moderately or entirely satisfied with the way their current school addressed mental health.

Table 1. Openness to practice scores.

Item	Mean (SD)	Those who answered great or very great extent (N=145) n (%)
I like to use new types of therapies/interventions to help my clients.	2.18 (0.70)	41 (28.3)
I am willing to try new types of therapies/interventions even if I have to follow a treatment manual.	2.42 (0.81)	64 (44.1)
I am willing to use new and different types of therapies/interventions developed by researchers.	2.70 (0.80)	88 (60.7)
I would try a new therapy/intervention even if it were different to what I am used to doing.	2.63 (0.85)	78 (53.8)

Table 2. Participants' level of comfort with the features of the Web-based mental health service.

Feature	Mean (SD)
Students being sent emails and SMS to monitor their mental health	3.79 (1.04)
Students answering questions about their mental health over the Web	3.50 (0.99)
Students' receiving additional psychological support from an external psychologist over the phone	3.44 (0.98)
Students receiving treatment for mental health via a Web-based service	3.39 (0.89)
Students providing personal details over the Web	3.06 (1.11)
Students' mental health being assessed and classified by an automated Web-based service	3.04 (0.98)

Openness to Practice

Overall, the sample yielded a mean openness score of 2.50 (SD 0.67), with 28% being open to trying new therapies or interventions to a great or very great extent. Table 1 outlines the mean scores for each item and the percentage who reported being open to a great or very great extent.

Use of Web-Based Mental Health Resources

A total of 77.2% (112/145) of the sample used, recommended, or referred students to at least one type of Web-based resource or program, with these participants using an average of 2.24 different Web resources with students (SD 1.22). Among this group, psychoeducation websites (77.7%, 87/112) and mobile phone apps (75.0%, 84/112) were the most frequently used. The least frequently used were online counseling (31.3%, 35/112), automated symptom-reduction/ psychological therapy programs (21.4%, 24/112), peer support sites (16.1%, 18/112), and telepsychiatry/ videoconferencing (2.7%, 3/112).

Level of Acceptability of the Proposed Service

Overall, one-third of the sample (n=44/145) reported that they were entirely comfortable recommending a student try a Web-based service for their mental health (mean 3.90, SD 0.95), with only 1 participant reporting not at all. Table 2 outlines participants' mean levels of comfort with the different features of the proposed service.

Overall, a total of 82.1% (119/145) reported that the proposed service would be helpful to high school students, although 14.5% (21/145) preferred that this type of service was not offered in the school setting. A total of 26.9% (39/145) believed that responding to automated at-risk alerts (ie, initiating contact and conducting a face-to-face session for those at higher steps or with suicidality) within 48 hours would not currently be feasible. Only 7.6% (11/145) were entirely comfortable with teachers

being involved in referring or recommending a Web-based mental health service to students.

Factors Influencing Acceptability

Level of comfort with referring a student to a Web-based service was found to be significantly associated with years of experience ($r=.17$, $P=.048$). Participants' age, school size, workload manageability, and openness to practice were not significantly associated with their level of comfort referring to a Web-based service ($r=.09$ to $.17$, $P=.17$ -.88). Gender was also not significantly associated with level of comfort ($t_{1,143}=-1.50$, $P=.14$), and nor was registration as a psychologist ($t_{1,143}=1.36$, $P=.18$).

Level of comfort was found to be influenced by the following:

Knowledge, Familiarity and Confidence With Online Services

This theme encompassed school counselors' knowledge and awareness of Web-based mental health services, their familiarity with service content, their overall confidence in the service, and their personal preferences for providing care. A total of 34% (n=50) reported that these aspects influenced their likelihood of referral or recommendation. One participant reported:

I need to have knowledge of and feel comfortable with a service prior to my recommending it. [Participant 31]

Another participant stated:

...some hesitation in referring to new things due to lack of knowledge...I would really need to use it myself before recommending it. [Participant 90]

One participant said:

I would only refer if I had a full understanding of it. [Participant 106]

A portion of respondents (9%, n=13) also revealed that they simply had a personal preference for face-to-face care:

I don't see it being engaging and worthwhile, the relationship is not the same. [Participant 103]

It's just not part of my practice. [Participant 109]

Internet Accessibility

This theme related to school counselors' perceptions that the Internet can generally lead to greater access to care, with 30% (n=44) reporting that accessibility issues influenced their likelihood of recommending or referring. Within this, 18% (n=26) felt the Internet improved access to care as it defied time and spatial barriers.

One participant stated:

Accessibility, cost effective, suits the student in regard to time and commitments, the right fit can provide a more timely response. [Participant 98]

Another participant reported:

Rural and remote location—often there are no other options. [Participant 114]

A subset (12%, n=18) said that they were unlikely to refer or recommend a Web-based service because some students might not have Internet access at home (n=15) or that the literacy levels of their students was not adequate (n=3). For example, one participant 14 stated:

I work in a low SES area and some of the families do not have Internet or can't afford to keep the Internet for long periods of time. [Participant 14]

Another participant reported:

My most disadvantaged youth don't have sufficient credit on their phone or on home computer to access...they don't like to use these services in a public section of the school where they may be observed. [Participant 47]

Beliefs About the Effectiveness and Accuracy of Web-Based Services

This theme referred to the beliefs, both positive and negative, that school counselors have about the effectiveness and clinical accuracy of Web-based mental health care. A total of 29% (n=43) reported that their beliefs about clinical effectiveness influenced the likelihood of referring or recommending a Web-based service. An example of one negative belief was "I believe face-to-face interventions are more effective," whereas examples of positive beliefs were "it can monitor their health and provide support when I am not there" (n=20), "it complements the work I do with students" (n=17), and "it can help students feel that they are taking control" (n=6). Some respondents were concerned with the reliability and validity of the automated decision-making processes within the Web-based service, mainly concerned that young people will not be honest in their disclosure of symptoms. For example, one participant stated:

...a computer cannot decide when a young person is being truthful. [Participant 19]

Participant 144 described the clinical classification system as "too binary." A total of 38% (n=56) identified that personal beliefs about effectiveness and accuracy were likely to be a risk to successful service implementation.

Duty of Care

This theme related to school counselors' concerns that a Web-based mental health service would complicate their duty of care, with 46% (n=66) feeling their capacity was diminished when students were engaged in a Web-based service. Some reported hesitation about referral. For example, one of the participants stated:

I feel that it is my job to see them. [Participant 44]

Others were concerned with risk management:

There needs to be more than one person who knows the student is at-risk...the counselor might not get the message. [Participant 4]

Another participant stated:

...the biggest risk is promising access to a school counselor within such a short time...my referral list is so long I just don't know how I could do it. [Participant 9]

When asked what should happen when a student was not improving in a Web-based service, 56% (n=81) said the student should be referred to an external mental health professional, and 26% (n=37) felt that parents should be informed. When asked what should happen when a student is suicidal, 48% (n=70) said the student should be contacted by an external mental health professional, 33% (n=48) said the student's parents should be contacted, and 26% (n=37) said emergency services should be contacted. Other suggestions included informing the school, offering e-crisis support services, and referring to the general practitioner (GP). However, participants expressed concerns with multiple caregivers:

...it needs to be very clear who is responsible for following up with each child. [Participant 10]

...if collaboration between school and external provider does not work well, there are risks to client safety. [Participant 12]

...things get more difficult with online treatment and monitoring when a student is found to be at risk as the process of contacting people that can keep them safe is more convoluted. [Participant 78]

Student Preferences

This theme related to school counselors' perceptions that young people like digital technology and, for various reasons, prefer doing activities and spending time on the Web. School counselors felt young people were more likely to engage with a Web-based service as it was delivered using a preferred medium. A total of 21% (n=30) school counselors reported that student preferences influenced their likelihood of referring, with most expressing this to be a positive effect (n=20). For example, as expressed by one of the participants :

...kids love online stuff, it's their world. [Participant 6]

Interestingly, however, a subset (7%, n=10) reported that some students had low levels of motivation to engage and complete online programs and that an online service would be unhelpful for these types of students. Further, a subset (7%, n=10) reported that student adherence to the service would be a risk to successful implementation.

Privacy and Confidentiality

This theme related to the primary concerns of privacy, anonymity, and confidentiality, such that school counselors were concerned that data provided over the Web may be mishandled or be accessed without authorization. A total of 7% (n=10) of the sample reported that issues relating to privacy and confidentiality influenced how comfortable they were with recommending or referring to a Web-based service. As one participant reported:

...potential for information to be lost or not given to right people. [Participant 22]

A total of 8% (n=12) were uncomfortable with school counselors accessing students' mental health data via the Web, and 78% (n=113) were also uncomfortable with teachers accessing students' mental health data via the Web. For example, one participant stated:

Teachers have very different understandings of mental health concerns and levels of competence in managing them. [Participant 118]

On the contrary, this theme also encompassed the advantages of Web-based interaction. Some participants reported positively:

E-MH [E-Mental Health] programs also provide confidentiality and students don't have to engage on a personal level when typing on a computer. [Participant 28]

Overall, 14% (n=21) felt that issues relating to privacy and confidentiality posed a risk to the successful implementation of the service.

Informed Consent and Parental Contact

This theme related to school counselors' concerns about collecting informed consent from students and how best to involve their parents. Although gaining informed consent was not expressed as a factor influencing school counselors' referral or recommendation of a Web-based service, a small number of participants did identify it as a possible risk to successful implementation (4%, n=6). Participants' responses confirmed that there are mixed feelings about students giving informed consent via the Internet and the need to inform others. For example, one of the participants responded:

The student would have to be well informed at the beginning of the process, so they are fully aware that some of their information may be passed on to others if required. [Participant 86]

Nearly the entire sample (n=142) felt that parents should be involved at some point, with almost half (49%, n=72) reporting that parents should be informed when their child's mental health scores were of clinical severity. Two-thirds (61%, n=89) felt that a phone call was the most ideal way to contact a parent,

with only 25% (n=36) preferring an in-person consultation. Email (6%, n=9) and SMS (2%, n=3) were not popular methods of contacting parents. However, some expressed concerns with parental contact, as outlined by one participant:

...sometimes students don't want parents to know they are seeking help. [Participant 20]

Discussion

Principal Findings

This study aimed to understand school counselors' roles in NSW secondary high schools, their level of comfort with Web-based resources and the proposed service, and to identify key barriers and facilitators to implementing such a service in the school setting. It was expected that this study would reveal key insights into the current context of school counseling, including the capacity of school counselors, as well as their likelihood of integrating a Web-based mental health service into their practice. On the basis of the study results, the average school counselor is a 43-year-old female, who is married or partnered, registered or completing registration as a psychologist, and has been practicing as a school counselor for more than 10 years. They are likely to be working full-time, but across two schools, with student populations of approximately 800 youth per school. The most common referral pathway to the school counselor was via student and teacher referrals, with only a minority occurring from initiation by school counselors themselves. School counselors reported undertaking a wide range of daily tasks with one-fifth of their time spent on administration. This confirms the multispecialist role of the school counselor [24].

The results of this study suggest that school counselors would benefit from additional mental health support in the school setting. One-third of school counselors reported that their workload was unmanageable. Work stress was reported to impact their health and well-being, and almost half had experienced burnout. Furthermore, one-third were providing care outside of school hours. Although this is consistent with previous results [22,27,47], it signifies that school counseling remains a demanding profession. Mental health issues, primarily anxiety and depression, were prominent among students, and despite the need, school counselors spent less than half of their time providing individual therapy. More support is necessary to reduce the personal burden of school counseling but also to increase school counselors' capacity to service their students. Taken together, these findings provide evidence that clinical systems that increase efficiency would be highly favorable among school counselors. The levels of acceptability of the proposed Web-based service indicates that the stepped care model may provide the structured framework needed for improving the delivery of care, allowing greater detection of problems and more efficient allocation of resources.

Overall, one-third of the sample was entirely comfortable recommending the proposed Web-based service, and only 1 participant was not at all comfortable. Most of the school counselors believed that Web-based stepped care would be helpful to high school students, which is likely to be influenced by the fact that more than two-thirds of the sample already recommended Web resources to students. This is an important

finding as it signifies support for the stepped care framework. It also indicates that school counselors are open to referring to Web-based interventions but have concerns that need to be alleviated before they will recommend or integrate the proposed service into their practice. This is not surprising, given the significant legal and moral obligations associated with providing mental health care to youth. The results show that some features of the proposed service, such as SMS or email monitoring, were more acceptable than others, such as mental health being classified by an automated process or the sharing of personal details. There was concern that responding in a timely manner to at-risk students would not be feasible. This is likely to reflect the high workload and low manageability within the sample. Future trials of the proposed service would need to monitor and measure the time taken to respond to at-risk students to quantify the feasibility of responding to real-time alerts.

Two-thirds of the sample reported that they often referred to external services and were mostly supported by these services. An external referral process is a key feature of the proposed Web-based service which is likely to be heavily utilized if widely implemented. Future trials of the service would need to ensure that external service providers are easily accessible for school counselors and that they have mechanisms of keeping in contact with the external providers. Background factors did not appear to influence the level of comfort. The qualitative results provide a significant level of insight into the issues that may need to be targeted and resolved for successful implementation. As already discussed, some of these relate to feasibility, but others, such as beliefs and level of knowledge, are specific to the individual counselor. These factors indicate that a significant amount of groundwork would need to take place, including training and demonstrations of the Web-based service, alongside case studies and evaluation data to increase the likelihood of school counselors recommending and referring to the service.

Finally, the results of this study outlined strengths of the proposed model. School counselors perceived that stigma, personal embarrassment/shame, and wanting to remain anonymous were significant barriers preventing students from

seeking their help. This is consistent with other help-seeking literature [10], although only 5% of the current sample perceived that their own personal characteristics were a barrier to students seeking their help. Conversely, in their review, Gulliver et al [10] found that over one-third of studies reported that young people do not seek help because of concerns about characteristics of the provider. Despite the current sample not acknowledging this, students' help-seeking is likely to be impacted by provider characteristics. The proposed service may circumvent this issue, as students are able to self-refer. In addition, allowing teacher-referrals may increase uptake of the service, as some students report more trusting and responsive relationships with teachers [48]. Future trials of the proposed service would benefit from measuring changes in student attitudes toward seeking help from different sources, as well as actual help-seeking behavior, specifically from the school counselor. This would help to confirm whether the service is effective for increasing access to and uptake of mental health care.

Limitations

Despite the depth of insight, the current sample was drawn exclusively from one state within Australia (NSW). Views may differ among international samples, where the role of school counseling may be different. In addition, the self-report data are subjective and subject to misrepresentation [49]. The volunteer sample was not representative, and it was not possible to estimate bias resulting from this and the questions asked may have precluded factors that influence school counselors' views.

Conclusions

Overall, this study confirms that greater support and resources are needed to facilitate what is already a challenging and emotionally demanding role for school counselors. The school counselors surveyed were supportive of the proposed stepped care service, and their insight has informed the service development in several ways. Key next steps would be a demonstration and trial of the service in the school environment, alongside a formal evaluation of its usefulness and effectiveness, with outcomes assessed for both students and school counselors.

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Authors' Contributions

BOD and CK contributed to all aspects of study design including project inception, as well as research operations including recruitment, data collection, and analyses, and authorship of the manuscript. KOM and CK were also involved in study design, data collection, and manuscript preparation, with MSK involved in data analysis, interpretation, project management, and manuscript preparation.

Conflicts of Interest

BOD is a Section Editor for *JMIR Mental Health*.

Multimedia Appendix 1

Online survey.

[[PDF File \(Adobe PDF File\), 53KB - mental_v4i4e55_app1.pdf](#)]

References

1. Kessler RC, Berglund P, Demler O, Jin R, Merikangas KR, Walters EE. Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry* 2005 Jun;62(6):593-602. [doi: [10.1001/archpsyc.62.6.593](#)] [Medline: [15939837](#)]
2. Avenevoli S, Knight E, Kessler R, Merikangas K. Epidemiology of depression in children and adolescents. In: *Handbook of depression in children and adolescents*. New York: Guilford; 2008:6-32.
3. Leach LS, Butterworth P. The effect of early onset common mental disorders on educational attainment in Australia. *Psychiatry Res* 2012 Aug 30;199(1):51-57. [doi: [10.1016/j.psychres.2012.03.040](#)] [Medline: [22507527](#)]
4. Merikangas KR, He JP, Burstein M, Swanson SA, Avenevoli S, Cui L, et al. Lifetime prevalence of mental disorders in U.S. adolescents: results from the National Comorbidity Survey Replication--Adolescent Supplement (NCS-A). *J Am Acad Child Adolesc Psychiatry* 2010 Oct;49(10):980-989 [FREE Full text] [doi: [10.1016/j.jaac.2010.05.017](#)] [Medline: [20855043](#)]
5. Sawyer MG, Arney FM, Baghurst PA, Clark JJ, Graetz BW, Kosky RJ, et al. The mental health of young people in Australia: key findings from the child and adolescent component of the national survey of mental health and well-being. *Aust N Z J Psychiatry* 2001 Dec;35(6):806-814. [Medline: [11990891](#)]
6. Rickwood DJ, Deane FP, Wilson CJ. When and how do young people seek professional help for mental health problems? *Med J Aust* 2007 Oct 1;187(7 Suppl):S35-S39. [Medline: [17908023](#)]
7. Reavley NJ, Cvetkovski S, Jorm AF, Lubman DI. Help-seeking for substance use, anxiety and affective disorders among young people: results from the 2007 Australian National Survey of Mental Health and Wellbeing. *Aust N Z J Psychiatry* 2010 Aug;44(8):729-735. [doi: [10.3109/00048671003705458](#)] [Medline: [20636194](#)]
8. Merikangas KR, He JP, Burstein M, Swendsen J, Avenevoli S, Case B, et al. Service utilization for lifetime mental disorders in U.S. adolescents: results of the National Comorbidity Survey-Adolescent Supplement (NCS-A). *J Am Acad Child Adolesc Psychiatry* 2011 Jan;50(1):32-45 [FREE Full text] [doi: [10.1016/j.jaac.2010.10.006](#)] [Medline: [21156268](#)]
9. Rickwood D, Deane FP, Wilson CJ, Ciarrochi J. Young people's help-seeking for mental health problems. *AeJAMH* 2005;4(3):218-251. [doi: [10.5172/jamh.4.3.218](#)]
10. Gulliver A, Griffiths KM, Christensen H. Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry* 2010;10:113 [FREE Full text] [doi: [10.1186/1471-244X-10-113](#)] [Medline: [21192795](#)]
11. Huggins A, Weist MD, McCall M, Kloos B, Miller E, George MW. Qualitative analysis of key informant interviews about adolescent stigma surrounding use of school mental health services. *Int J Ment Health Promot* 2016 Feb 05;18(1):21-32. [doi: [10.1080/14623730.2015.1079424](#)]
12. Lawrence D, Johnson SE, Hafekost J, de Haan KB, Sawyer MG, Ainley J, et al. Health.gov. 2015. The Mental Health of Children and Adolescents: Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing URL: <https://www.health.gov.au/internet/main/publishing.nsf/Content/9DA8CA21306FE6EDCA257E2700016945/%24File/child2.pdf> [accessed 2017-11-01] [WebCite Cache ID 6udXRLmzC]
13. McGorry P, Bates T, Birchwood M. Designing youth mental health services for the 21st century: examples from Australia, Ireland and the UK. *Br J Psychiatry Suppl* 2013 Jan;54:s30-s35. [doi: [10.1192/bjp.bp.112.119214](#)] [Medline: [23288499](#)]
14. Dunn V, Goodyer IM. Longitudinal investigation into childhood- and adolescence-onset depression: psychiatric outcome in early adulthood. *Br J Psychiatry* 2006 Mar;188:216-222 [FREE Full text] [doi: [10.1192/bjp.188.3.216](#)] [Medline: [16507961](#)]
15. Lewinsohn PM, Rohde P, Seeley JR, Klein DN, Gotlib IH. Natural course of adolescent major depressive disorder in a community sample: predictors of recurrence in young adults. *Am J Psychiatry* 2000 Oct;157(10):1584-1591. [doi: [10.1176/appi.ajp.157.10.1584](#)] [Medline: [11007711](#)]
16. Wyn J, Cahill H, Holdsworth R, Rowling L, Carson S. MindMatters, a whole-school approach promoting mental health and wellbeing. *Aust N Z J Psychiatry* 2000 Aug;34(4):594-601. [doi: [10.1080/j.1440-1614.2000.00748.x](#)] [Medline: [10954390](#)]
17. New South Wales Government. Sydney, Australia; 2011. Paper 1. The School Counselling Workforce in NSW Government Schools URL: <https://www.det.nsw.edu.au/media/downloads/about-us/statistics-and-research/public-reviews-and-enquiries/school-counselling-services-review/paper1-tscwings.pdf> [accessed 2016-07-21] [WebCite Cache ID 6riVXPpay]
18. Rickwood D. Supporting young people at school with high mental health needs. *Aust J Guid Couns* 2012 Feb 23;15(02):137-155. [doi: [10.1375/ajgc.15.2.137](#)]
19. Fazel M, Hoagwood K, Stephan S, Ford T. Mental health interventions in schools in high-income countries. *Lancet Psychiatry* 2014 Oct;1(5):377-387 [FREE Full text] [doi: [10.1016/S2215-0366\(14\)70312-8](#)] [Medline: [26114092](#)]
20. Clayton S, Chin T, Blackburn S, Echeverria C. Different setting, different care: integrating prevention and clinical care in school-based health centers. *Am J Public Health* 2010 Sep;100(9):1592-1596. [doi: [10.2105/AJPH.2009.186668](#)] [Medline: [20634447](#)]

21. Australian Bureau of Statistics. ABS. Canberra, ACT; 2015. Summary of findings URL: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4221.0> [accessed 2017-07-05] [WebCite Cache ID 6riTzj7gU]
22. Australian Psychological Society. Framework for the effective delivery of school psychological services. Melbourne, Australia: Australian Psychological Society; 2013.
23. Gagnon DJ, Mattingly MJ. scholars.unh.edu.: University of New Hampshire; 2016. Most U.S. School Districts Have Low Access to School Counselors: Poor, Diverse, and City School Districts Exhibit Particularly High Student-to-Counselor Ratios URL: <http://scholars.unh.edu/cgi/viewcontent.cgi?article=1285&context=carsey> [accessed 2017-07-01] [WebCite Cache ID 6riW80nbx]
24. Thielking M, Jimerson S. Perspectives Regarding the Role of School Psychologists: Perceptions of Teachers, Principals, and School Psychologists in Victoria, Australia. *Aust J Guid Couns* 2006;16(2):211-223. [doi: [10.1375/ajgc.16.2.21](https://doi.org/10.1375/ajgc.16.2.21)]
25. Mara P. Who supports the counsellor? *Journal of Psychologists and Counsellors in Schools* 1991;1:1-2. [doi: [10.1017/S1037291100002326](https://doi.org/10.1017/S1037291100002326)]
26. McMahon M, Patton W. Conversations on clinical supervision: benefits perceived by school counsellors. *Br J Guid Couns* 2000;28:339-351. [doi: [10.1080/713652301](https://doi.org/10.1080/713652301)]
27. Wilkerson K, Bellini J. Intrapersonal and organizational factors associated with burnout among school counselors. *J Couns Dev* 2006;84(4):440-450. [doi: [10.1002/j.1556-6678.2006.tb00428.x](https://doi.org/10.1002/j.1556-6678.2006.tb00428.x)]
28. Butler SK, Constantine MG. Collective Self-Esteem and Burnout in Professional School Counselors. *Professional School Counseling* 2005 Oct;9(1):55-62. [doi: [10.5330/prsc.9.1.17n44151163720u5](https://doi.org/10.5330/prsc.9.1.17n44151163720u5)]
29. Askill-Williams H, Lawson MJ, Slee PT. Venturing into schools: locating mental health initiatives in complex environments. *Int J Emot Educ* 2009;1(2):14-33.
30. Taras HL, American Academy of Pediatrics Committee on School Health. School-based mental health services. *Pediatrics* 2004 Jun;113(6):1839-1845. [Medline: [15173522](https://pubmed.ncbi.nlm.nih.gov/15173522/)]
31. Langley AK, Nadeem E, Kataoka SH, Stein BD, Jaycox LH. Evidence-based mental health programs in schools: barriers and facilitators of successful implementation. *School Ment Health* 2010;2(3):105-113 [FREE Full text] [doi: [10.1007/s12310-010-9038-1](https://doi.org/10.1007/s12310-010-9038-1)] [Medline: [20694034](https://pubmed.ncbi.nlm.nih.gov/20694034/)]
32. Weist MD, Mellin EA, Chambers KL, Lever NA, Haber D, Blaber C. Challenges to collaboration in school mental health and strategies for overcoming them. *J Sch Health* 2012;82(2):97-105. [doi: [10.1111/j.1746-1561.2011.00672.x](https://doi.org/10.1111/j.1746-1561.2011.00672.x)] [Medline: [22239135](https://pubmed.ncbi.nlm.nih.gov/22239135/)]
33. Hopkins L. Schools and adolescent mental health: education providers or health care providers? *J Public Ment Health* 2014;13(1):20-24. [doi: [10.1108/jpmh-07-2013-0050](https://doi.org/10.1108/jpmh-07-2013-0050)]
34. Furey AW. Northeastern University. 2015. Adolescent mental health: Exploring the school counselor experience URL: <https://repository.library.northeastern.edu/files/neu:336577/fulltext.pdf> [accessed 2017-11-01] [WebCite Cache ID 6ue7mMsv7]
35. van Straten A, Hill J, Richards DA, Cuijpers P. Stepped care treatment delivery for depression: a systematic review and meta-analysis. *Psychol Med* 2014 Mar 26;45(2):231-246. [doi: [10.1017/S0033291714000701](https://doi.org/10.1017/S0033291714000701)] [Medline: [25065653](https://pubmed.ncbi.nlm.nih.gov/25065653/)]
36. Glasheen K, Campbell M, Shochet I. School counsellors' and students' attitudes to online counselling: a qualitative study. *Journal of Relationships Research* 2015;6:e12. [doi: [10.1017/jrr.2015.8](https://doi.org/10.1017/jrr.2015.8)]
37. Glasheen KJ, Shochet I, Campbell MA. Online counselling in secondary schools: who would students seek help by this medium? *Br J Guid Couns* 2016;108-122. [doi: [10.1080/03069885.2015.1017805](https://doi.org/10.1080/03069885.2015.1017805)]
38. Glasheen K, Campbell MA. The use of online counselling within an Australian secondary school setting: a practitioner's viewpoint. *Counselling Psychology Review* 2009;24:42-51.
39. Glasheen K, Campbell MA, Shochet I. Opportunities and challenges: school guidance counsellors' perceptions of counselling students online. *Aust J Guid Couns* 2013 Sep 4;23(2):222-235. [doi: [10.1017/jgc.2013.15](https://doi.org/10.1017/jgc.2013.15)]
40. Christensen H, Griffiths KM. The prevention of depression using the Internet. *Med J Aust* 2002;177 Suppl:S122-S125. [Medline: [12358571](https://pubmed.ncbi.nlm.nih.gov/12358571/)]
41. Robinson J, Hetrick S, Cox G, Bendall S, Yung A, Pirkis J. The safety and acceptability of delivering an online intervention to secondary students at risk of suicide: findings from a pilot study. *Early Interv Psychiatry* 2015;9(6):498-506. [doi: [10.1111/eip.12136](https://doi.org/10.1111/eip.12136)] [Medline: [24684927](https://pubmed.ncbi.nlm.nih.gov/24684927/)]
42. Metz A, Naom S, Halle T, Bartley L. Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services. 2015. An Integrated Stage-Based Framework for Implementation of Early Childhood Programs and Systems URL: https://www.acf.hhs.gov/sites/default/files/opre/es_ccepra_stage_based_framework_brief_508.pdf [accessed 2017-11-01] [WebCite Cache ID 6udZsgqle]
43. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *Int J Nurs Stud* 2013 May;50(5):587-592. [doi: [10.1016/j.ijnurstu.2012.09.010](https://doi.org/10.1016/j.ijnurstu.2012.09.010)] [Medline: [23159157](https://pubmed.ncbi.nlm.nih.gov/23159157/)]
44. Aarons GA. Mental health provider attitudes toward adoption of evidence-based practice: the Evidence-Based Practice Attitude Scale (EBPAS). *Ment Health Serv Res* 2004;6(2):61-74 [FREE Full text] [Medline: [15224451](https://pubmed.ncbi.nlm.nih.gov/15224451/)]

45. Aarons GA, McDonald EJ, Sheehan AK, Walrath-Greene CM. Confirmatory factor analysis of the Evidence-Based Practice Attitude Scale in a geographically diverse sample of community mental health providers. *Adm Policy Ment Health* 2007;34(5):465-469. [doi: [10.1007/s10488-007-0127-x](https://doi.org/10.1007/s10488-007-0127-x)] [Medline: [17619137](https://pubmed.ncbi.nlm.nih.gov/17619137/)]
46. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77-101. [doi: [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)]
47. Campbell M, Colmar S. Current status and future trends of school counseling in Australia. *J Asia Pac Couns* 2014;4(2):181-197. [doi: [10.18401/2014.4.2.9](https://doi.org/10.18401/2014.4.2.9)]
48. Anderson S, Kerr-Roubicek H, Rowling L. Staff voices: what helps students with high mental health support needs connect to school? *Journal of Psychologists and Counsellors in Schools* 2006;16(1):1-13. [doi: [10.1375/ajgc.16.1.1](https://doi.org/10.1375/ajgc.16.1.1)]
49. Wright KB. Researching internet-based populations: advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. *J Comput Mediat Commun* 2005(10). [doi: [10.1111/j.1083-6101.2005.tb00259.x](https://doi.org/10.1111/j.1083-6101.2005.tb00259.x)]

Abbreviations

ATSI: Aboriginal or Torres Strait Islander

EBPAS: evidence-based practice attitude scale

GP: general practitioner

NSW: New South Wales

SD: standard deviation

SMS: short message service

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Original Paper

Assessing Therapist Competence: Development of a Performance-Based Measure and Its Comparison With a Web-Based Measure

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Abstract

Background: Recent research interest in how best to train therapists to deliver psychological treatments has highlighted the need for rigorous, but scalable, means of measuring therapist competence. There are at least two components involved in assessing therapist competence: the assessment of their knowledge of the treatment concerned, including how and when to use its strategies and procedures, and an evaluation of their ability to apply such knowledge skillfully in practice. While the assessment of therapists' knowledge has the potential to be completed efficiently on the Web, the assessment of skill has generally involved a labor-intensive process carried out by clinicians, and as such, may not be suitable for assessing training outcome in certain circumstances.

Objectives: The aims of this study were to develop and evaluate a role-play-based measure of skill suitable for assessing training outcome and to compare its performance with a highly scalable Web-based measure of applied knowledge.

Methods: Using enhanced cognitive behavioral therapy (CBT-E) for eating disorders as an exemplar, clinical scenarios for role-play assessment were developed and piloted together with a rating scheme for assessing trainee therapists' performance. These scenarios were evaluated by examining the performance of 93 therapists from different professional backgrounds and at different levels of training in implementing CBT-E. These therapists also completed a previously developed Web-based measure of applied knowledge, and the ability of the Web-based measure to efficiently predict competence on the role-play measure was investigated.

Results: The role-play measure assessed performance at implementing a range of CBT-E procedures. The majority of the therapists rated their performance as moderately or closely resembling their usual clinical performance. Trained raters were able to achieve good-to-excellent reliability for averaged competence, with intraclass correlation coefficients ranging from .653 to .909. The measure was also sensitive to change, with scores being significantly higher after training than before as might be expected (mean difference 0.758, $P < .001$) even when taking account of repeated data (mean difference 0.667, $P < .001$). The major shortcoming of the role-play measure was that it required considerable time and resources. This shortcoming is inherent in the method. Given this, of most interest for assessing training outcome, scores on the Web-based measure efficiently predicted therapist competence, as judged by the role-play measure (with the Web-based measure having a positive predictive value of 77% and specificity of 78%).

Conclusions: The results of this study suggest that while it was feasible and acceptable to assess performance using the newly developed role-play measure, the highly scalable Web-based measure could be used in certain circumstances as a substitute for the more labor-intensive, and hence, more costly role-play method.

KEYWORDS

therapist competence; Web-based knowledge assessment; skill assessment; therapist training outcome; scalable assessment; eating disorders; cognitive-behavioral treatment

Introduction

Recent research interest in the training of therapists in psychological treatments has highlighted the need for rigorous measures of training outcome, with measures of therapist competence being regarded as of particular importance [1-3]. Competence in this context refers to what has been described as “limited-domain intervention competence” [4], that is, the therapist’s capacity to implement a specific form of treatment to the standard needed for it to achieve its expected effects [5]. Generally, it has been agreed that achieving such competence requires knowledge of the treatment, including how and when to use its strategies and procedures, as well as an ability to apply such knowledge skillfully in practice [6,7]. The assessment of knowledge has generally been regarded as relatively straightforward, because there is a well-studied and documented method for assessing this aspect of competence, usually involving the use of some form of multiple-choice testing [8]. Nevertheless, there are, as yet, few standardized measures for assessing knowledge of the type required to establish therapist competence.

On the other hand, the assessment of skill in delivering a psychological treatment is more complex. A widely used method for assessing the skill of therapists involves the evaluation of the quality of their treatment sessions (ie, therapy quality is being used as an index of therapist competence). Assessing therapy quality requires that treatment sessions be evaluated using a standard procedure [9]. In the field of cognitive behavioral therapy (CBT), for example, treatment sessions are generally rated using the Cognitive Therapy Scale (CTS) [10,11] or its revised version (CTS-R) [12]. Treatment sessions, or usually recordings of them, are evaluated by highly trained raters (usually therapists) with respect to the presence and quality of certain features displayed by the therapist (eg, the eliciting of key cognitions, the use of guided discovery, the setting of homework). Those who score above a prespecified threshold are judged to have performed sufficiently skillfully to be judged competent. This method has the advantage of directly assessing therapists’ skill at implementing the treatment, and thus, has clear ecological validity. In practice, the method poses a number of problems. It is labor-intensive, with the result that few sessions tend to be rated. Consequently, generalizations about the therapist’s overall competence are made on the basis of rating a limited number of the treatment’s procedures. The issue of patient variability is an additional problem. It has been documented that therapists are less likely to adhere to a treatment protocol with some patients rather than others, for example, when comorbidity is present or when they perceive patients’ difficulties to be particularly severe. [13]. Thus, with this method, it is difficult to sample the full range of a treatment’s procedures with patients of varying levels of difficulty [5,6,14]. A related issue is that the CTS and CTS-R,

for example, focus largely on aspects of treatment that are common to most forms of CBT and, of necessity, ones that are expected to be present in most treatment sessions. Thus, they assess generic skills but do not assess disorder-specific strategies. In the area of social anxiety disorder, for example, this has led to the development of a disorder-specific measure [15,16].

A potential solution to these problems lies in role-play-based assessments using simulated standardized patients. This method offers the possibility of assessing therapists’ skills on a wide range of procedures or interventions while controlling the variability of the patient. For many years, this type of assessment has formed part of the objective structured clinical examinations used in evaluating medical training [17] and has been described as one of the most effective “substitutes for reality” [6]. The method also lends itself to the evaluation of psychological treatment training, a situation in which the assessment of a range of patient sessions before and after training would otherwise be difficult to achieve. Indeed, this method has just begun to be used to assess skill acquisition following psychological treatment training [18-21].

This study was part of a program of work designed to develop scalable methods for training therapists to deliver evidence-based psychological treatments. It used enhanced cognitive behavior therapy (CBT-E) for eating disorders [22-24] as the exemplar treatment. This treatment is described in detail in a comprehensive treatment guide [25], and an outline of its main stages and procedures is shown in Table 1.

As an essential first step in our work to develop a scalable method of training, we planned to develop methods of assessing training outcome that would also be scalable. Consistent with the view outlined above, we aimed to develop a measure of applied knowledge of CBT-E and a measure of skill at implementing it. We first developed and validated a Web-based measure of applied knowledge of CBT-E [26]. The eMeasure is a brief, scalable, 22-item, Web-based measure for testing applied knowledge of CBT-E, taking about 30 min to complete. It was tested on a relatively large, heterogeneous sample of clinicians at different levels of training. It meets the stringent requirements of the Rasch model and has 3 equivalent versions making it suitable for repeat testing of trainees in outcome studies. Best cut points have been established empirically to distinguish between those judged competent by experts and those who were not.

In this paper, we describe the second stage of the work. This involved developing a performance-based role-play measure of skill at delivering CBT-E to complement the applied knowledge measure. The performance-based measure was designed as a structured role play with therapists being asked to implement a range of CBT-E procedures with a simulated *patient* that would be recorded and subsequently rated for competence. To

provide evidence to support the use of this measure, we have described its content and the steps involved in its development. Its performance in assessing clinicians at various stages of training was investigated by examining the feasibility and acceptability of the measure, its sensitivity to change after training, and its interrater reliability. In addition, given our interest in scalability, we also investigated its performance in relation to the previously validated scalable measure of applied knowledge to ascertain whether under certain circumstances it might be possible to use the Web-based measure alone to efficiently assess the outcome of training.

Methods

Design

This study was conducted in 3 phases. In the first, clinical scenarios for the role plays were developed and piloted together with a rating scheme for assessing trainees' performance. In the second, the scenarios were evaluated by examining the performance of a range of trainee therapists from different professional backgrounds and with differing levels of experience in implementing CBT-E. In the third, the relationship between the role-play method of assessing competence and the previously developed Web-based measure of applied knowledge was investigated. Ethical approval was obtained from the Oxford University Central Research Ethics committee.

Phase One—The Development of the Clinical Scenarios and Rating Scheme

It was decided in advance that the role-play scenarios should focus on all the main CBT-E procedures and that they should not be inordinately difficult. Each scenario would involve the trainee therapist "treating" a "patient" who would be role-played by an actor (acting as a patient). The scenarios would last no longer than 12 min and 3 different scenarios would be administered in sequence within 1 session, thus enabling the implementation of 3 different procedures to be tested in a 45-min assessment session. We also decided to use 2 different "patients," each representing a type of patient commonly encountered when helping those with an eating disorder. Patient A was reticent and anxious with an eating style that was generally rigidly controlled, whereas Patient B was talkative and easily distracted and had a more chaotic eating pattern.

The next step was to identify the skills needed to implement CBT-E. To ensure adequate sampling of the potential content, we developed a *blueprint*. When developing assessment measures, blueprints are commonly used to match the elements of the assessment measure to the content to be mastered [27,28]. Using the CBT-E treatment manual [25] as our source, we obtained agreement between the CBT-E treatment developers (CF and ZC) and 3 experienced trial therapists (SBS, KB, and RM) that the role-play measure should focus on the implementation of 10 key procedures. We then developed a *scenario* for each procedure (see Table 1), the goal being to create a partially standardized interaction, that is, one that was focused on the implementation of a particular procedure but not so scripted as to be unrealistic. To this end, we prepared, for the actors, a written account for each scenario describing how

the patient should respond in general and the particular patient's manner of responding, depending upon whether she was Patient A or Patient B. For the person being assessed (ie, the trainee therapist), we prepared for each scenario a written description of the clinical situation to be addressed using CBT-E, a summary of the patient's progress in treatment so far and some information about her circumstances, personality, and history. To create realistic encounters, we modeled these descriptions on actual patient-therapist interactions. Pilot work led to the 10 clinical scenarios being standardized to 8-min therapist-patient interactions, with each being preceded by 5 min of preparation time for the trainee being assessed.

We decided to use a global scale for rating trainees' performance rather than a checklist, as global measures have been shown to have greater validity in discriminating levels of expertise in complex interactions [29-31]. Two rating scales were developed, one to assess the quality of implementation of the procedure in terms of its content and the other to assess whether the trainee's style was consistent with CBT-E. We developed detailed scenario-specific guidelines specifying both core and desirable features to guide the former ratings and a description of CBT style that included details about therapist behavior that would be both appropriate and inappropriate to guide the latter ratings. These guidelines formed the raters' manual that guided rater training and was available to raters when making their ratings of trainees' performance.

To rate the quality of implementation of participants' performance in terms of content, a 7-point scale was developed with defined anchor points. The scale ranged from a complete absence of the relevant CBT-E procedures as specified in the scenario-specific guidelines (score=0) to the consistent and complete application of all these procedures (score=6), with a score of 2 indicating limited or inconsistent application of the core features and a score of 4 indicating moderate application of these features (most of the main features present). Remaining scores were used to indicate performance falling between the defined anchor points. On the basis of our extensive experience in training therapists to implement CBT-E, a rating of 4 or more on this scale (defined as at least moderate application of CBT-E procedures) was taken to represent the cut point for "competent" performance at implementing each procedure. With regard to rating the trainee therapist's style, raters were provided with a detailed description of generic aspects of CBT style (such as being warm, empathic, collaborative, asking open-ended questions, focusing on and encouraging change) as well as a description of those features that would be inappropriate (such as being insensitive to the patient's feelings, not attending to the patient's distress, being critical, lacking professional boundaries, personal disclosures demonstrating behavior inconsistent with the advice given to the patient, being controlling). A yes or no rating assessed whether the trainee therapist adopted a CBT-consistent style.

In practice, the rater first made a procedural rating on the 7-point scale to reflect the quality of implementation of the relevant CBT-E scenario-specific procedure (ie, doing the right thing well). Then if a therapist received a rating of 4 or more (indicating a competent performance on the procedural rating), the rater was required to consider whether an otherwise

competent performance was potentially undermined by answering the yes or no categorical question regarding the trainee therapist's CBT-E style. If this was answered in the affirmative, the rater was required to re-rate the therapists'

performance on the 7-point scale using only a restricted 0 to 3 rating, reflecting the decision that the therapist could not obtain an overall score of 4 or more in the presence of a CBT-E inconsistent style.

Table 1. Blueprint showing scenarios for enhanced cognitive behavioral therapy (CBT-E) procedures.

CBT-E treatment stage	Scenario number	Scenario content
Stage 1	1	Creating a case formulation
	2	Reviewing self-monitoring
	3	Implementing and reviewing regular eating
	4 ^a	Motivation—encouraging and maintaining engagement in treatment
	5	Collaborative weighing and interpreting weight change
Stage 2 ^b		Reviewing progress and planning stage 3
Stage 3	6	Addressing body checking
	7	Addressing residual binges
	8	Addressing avoided foods and dietary rules
	9	Addressing feeling fat
Stage 4	10	Recognizing and manipulating mindsets and preparing for the future

^aThis scenario focuses on a topic relevant to all stages of treatment. The particular situation in the case of Scenario 4 is of a patient in stage 1 of treatment.

^bStage 2 in treatment is a transitional stage and does not have an associated scenario.

Phase Two—Evaluation of the Clinical Scenarios

To examine the performance of the clinical scenarios, we recruited a sample of 93 therapists who wished to be trained in CBT-E by our group. They were recruited (and participated) at various stages in the training process. Before training, therapists were recruited from the following sources: those registered to attend a conventional 2-day CBT-E training workshop and those about to begin a Web-based training in CBT-E. After training, therapists were recruited from those who had just completed a 2-day workshop, those who had completed a course of expert-led supervision in CBT-E, and those who had completed Web-based training.

Each trainee therapist completed 3 clinical scenarios on any 1 testing occasion selected from the 20 possible scenarios (10 scenarios each with Patient A or B). Two therapists (SBS and KB) role-played the patients. The encounters were audiorecorded for subsequent rating by at least 2 trained raters (see Table 2) who were blind to the identity and training status of the trainee therapists. The trainees were also asked to rate the extent to which they thought their performance in the role plays resembled their usual everyday clinical performance. To do this, a simple 4-point scale (from no resemblance=0 to close resemblance=3) was used. In addition, after completing the role-play assessment, the trainees were asked to complete the Web-based measure of applied knowledge of CBT-E [26] within 2 weeks. The trainees were not provided with any feedback after completing these summative assessments.

Four raters, research assistants with psychology degrees, were trained to assess the trainees' performance in the role plays. After didactic training in the use of the rating scale provided by 2 experts, the raters were then required to rate 40 prerecorded

calibration [32] role plays covering the 10 scenarios and both patients. These had been previously rated by 2 expert clinicians (ZC and RM). Training ratings were compared with the experts' calibration ratings and any discrepancies discussed and clarified to obtain consensus with the expert calibration ratings before beginning to rate the trainees' performance on the role-play assessments [15,33].

Phase Three—Relationship Between the Web-Based Measure and the Role-Play Measure

The trainee therapists' scores on the Web-based eMeasure completed at the same time point as their role-play performance (ie, time-matched) were compared with their ratings on the role-play measure to determine whether competence on the former (a scalable measure of applied knowledge of the treatment) predicted competence on the role-play measure (performance skill at applying the treatment).

Data Analysis

Data were analyzed using SPSS version 19.0 (IBM Corp) and Stata version 12.0, (StataCorp). Both individual performance scores (categorical scores) and scores averaged over all 3 clinical scenarios in any one assessment (continuous scores) were used in the analyses. Average performance scores on the clinical scenarios were approximately normally distributed. Values of *n* (%), mean (SD), and median (range) were used as appropriate to describe the data, with chi-square tests (with linear trend where appropriate) used to compare categorical scores between groups and *t* tests and ANOVAs (analyses of variance) and linear mixed models to compare continuous scores.

Agreement between categorical individual performance scores given by each of the raters was assessed using kappa statistics with Cohen kappa statistics used to assess agreement between

pairs of raters and Fleiss kappas to calculate agreement across all 4 raters. Analyses were conducted first using all possible rating scores (ie, scores 0-6) and then on binary variables defined as scores over the threshold for competence (ie, 4 or more). Values of kappa <0 were taken to indicate no agreement, 0 to 0.20 slight, 0.21 to 0.40 fair, 0.41 to 0.60 moderate, 0.61 to 0.80 substantial, and 0.81 to 1 almost perfect agreement over that expected by chance [34].

Agreement between continuous scores was assessed with intraclass correlation coefficients (ICCs). With the average performance scores, ICCs (2-way random effects model, ie, ICC2,1 for single measures and ICC2,k for average measures) were calculated between raters in pairs, in triplets, and over all 4 raters, with values of <0.4 indicating poor agreement, 0.4 to 0.75 fair-to-good agreement, and >0.75 excellent agreement [35].

To assess the impact of time (before or after training), rater, simulated patient type, and particular scenario on performance scores, data were first analyzed using ANOVA to compare performance scores between groups. An interaction term between rater and time was also fitted. Values of eta-squared (η^2) were used to express the percentage of variance explained by each factor, with 0.02 considered to be small, 0.13 medium, and 0.26 large [36]. To take account of the repeated nature of the data and the specific correlation structure of nonindependent (repeated) data, linear mixed models with variance components were used. This is a form of Generalizability theory (G-theory) in which the sources of measurement error are identified, estimated, and disentangled [37]. Models were fitted with fixed and random effects as appropriate for time, rater, time \times rater, patient type, and scenario. The relative contribution of these factors to the variability in the model was estimated using the ICC, calculated as the variance of each individual effect divided by the overall variance.

To determine whether competence on the Web-based eMeasure predicted competence on the role-play measure, the competence scores of each trainee therapist (average performance score over all raters on each occasion on the clinical scenarios [averaged over 3 scenarios] rated as >4) and their competence score on the Web-based eMeasure (using the previously reported cut points for competence [26]) were matched. Values for the sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV) of the Web-based measure were calculated.

Results

Characteristics of the Trainee Therapists

The mean age of the 93 trainee therapists who took part in the role-play based assessment was 42.7 (SD 9.6) years, and the majority (77 trainees) were female (83%). Their mean number of years of clinical experience was 15.0 (SD 9.65) with their professional backgrounds being as follows: 33 clinical psychologists (35%); 26 psychiatric nurses or nurse therapists (28%); 7 eating disorder therapists (8%); and 4 occupational therapists (4%). The remaining 23 trainee therapists (25%) came from a variety of other professional groups, including social

workers, psychiatrists, and dietitians. Eighty-seven trainees (94%) encountered patients with eating disorders in their clinical practice, with 65 (75%) doing so regularly. A substantial majority of the trainees (78/93, 90%) also treated patients with eating disorders.

Scenario and eMeasure Completion

Of the 93 trainee therapists, there were 27 in the workshop-only training group, 36 in the workshop plus clinical supervision group, and 30 in the Web-based training. All the trainees completed at least one set of (3 different) scenarios, either before or after receiving training, with 24 therapists completing them before training only, 29 after training only, and 40 therapists completing scenarios both before and after training. Before training, 64 (24+40) trainees completed a set of scenarios and an accompanying eMeasure (both completed at the same time point, ie, time-matched), whereas after training 68 had a complete set of time-matched role-play and accompanying eMeasure score (1 eMeasure score was lost because of technical failure: 29+40-1). Results are reported separately for groups before training and after training.

Of those who treated patients, 60 trainees (77%) rated that their performance moderately, or closely (a rating of 2 or 3 on the 0-3 scale), resembled their usual clinical performance.

Agreement Between the Raters

Overall, ratings of the mean Cohen kappa statistic for the binary ratings of competence (averaged over the 3 scenarios) were moderate, with a kappa of 0.51 over pairs of raters and with a Fleiss combined kappa of 0.52.

ICCs assessing the reliability of the raters' scores, assuming a single rater or average scores for more than 1 rater (as was the case for all competence ratings in this study), are shown in Table 2 (data include ratings given both before and after training). The mean (standard error, SE) scenario scores for each rater (rated on the 7-point rating scale) are shown along with the ICCs for each combination of raters, indicating fair-to-good agreement in all cases and excellent agreement in the majority of cases of the average ratings.

Factors Contributing to Variance in Performance Scores

Performance scores increased significantly from before to after training (mean difference 0.758, $P<.001$; effect size 0.51). After taking the repeated nature of the data into account, the adjusted mean difference remained highly significant (mean difference 0.667, $P<.001$) but with a smaller effect size at 0.33 (see Table 3).

Before training, there was no significant difference in the mean rating scores of the 4 raters ($P=.56$, $\eta^2=0.005$). Although there was a significant difference after training ($P=.01$), the value of η^2 was small (0.020). Although the main effect of rater was nonsignificant ($P=.65$), there was an overall effect of time (mean difference: 0.80, SE=0.091, $P<.001$) and a significant interaction between rater and time ($P=.02$). In the mixed model analyses adjusting for repeated data, the significant effect of time remained (mean difference: 0.79, SE=0.117, $P<.001$), and there

was a significant interaction between time and rater ($P=.03$) but no significant overall effect of rater ($P=.16$).

Using mixed model (variance components) analyses with fixed effects for time, patient type, and scenario, and random effects for trainee and rater, there was no significant effect of patient type (Patient A or B; $P=.41$), but there was a significant effect

for scenario ($P<.001$), with 5 scenarios (scenarios 1, 2, 5, 9, and 10) given significantly lower ratings than the other 5 (mean difference: -0.48 , $SE=0.088$), thus suggesting that they were more challenging than the others. Trainee therapists were, however, just as likely to receive these scenarios as the other potentially easier scenarios (with 505/984, 51.3% of scenario scores derived from the 5 less challenging ones).

Table 2. Mean scenario scores and values of intraclass correlation coefficient (ICC) for agreement between groups of raters.

Raters	N	Mean (SE ^a)				Single ICC _{2,1} ^b	Average ICC _{2,k} ^b
		Rater 1	Rater 2	Rater 3	Rater 4		
1, 2, 3, 4	15	4.03 (0.35)	4.01 (0.27)	3.31 (0.33)	3.88 (0.43)	0.653	0.883
1, 3, 4	15	4.03 (0.35)	-	3.31 (0.33)	3.88 (0.43)	0.694	0.872
1, 2, 3	28	3.90 (0.23)	3.87 (0.18)	3.58 (0.22)	-	0.616	0.828
1, 2, 4	22	3.64 (0.29)	3.67 (0.23)	-	3.85 (0.34)	0.619	0.830
2, 3, 4	15	-	4.01 (0.27)	3.31 (0.33)	3.88 (0.43)	0.620	0.830
1, 2	54	3.48 (0.16)	3.47 (0.13)	-	-	0.833	0.909
1, 3	28	3.90 (0.23)	-	3.58 (0.22)	-	0.517	0.682
1, 4	22	3.64 (0.29)	-	-	3.85 (0.34)	0.604	0.753
2, 3	28	-	3.87 (0.18)	3.58 (0.22)	-	0.542	0.703
2, 4	22	-	3.67 (0.23)	-	3.85 (0.34)	0.485	0.653
3, 4	96	-	-	3.50 (0.11)	3.67 (0.12)	0.690	0.816

^aSE: standard error.

^bICC: intraclass correlation coefficient.

Table 3. Mean (standard error) and median scores of trainee therapists before and after training.

Scenario scores	Mean (SE) ^a	Median	Mean difference (SE)	Effect size	P value (η^2)
Scenario scores unadjusted for repeated data					
Before training (N=411)	3.15 (0.073)	3.0			
After training (N=573)	3.90 (0.056)	4.0	0.758 (0.090)	0.51	<.001 (0.067)
Scenario scores adjusted for repeated data^b					
Before training (N=411)	3.22 (0.10)				
After training (N=573)	3.89 (0.10)		0.667 (0.10)	0.33	<.001

^aSE: standard error.

^bFixed effects=time; random effects=therapist trainee.

Table 4. Number of trainee therapists achieving competence as assessed by the skill (role-play) measure and the eMeasure.

Competence	Before training			After training		
	Skill (role-play) measure					
eMeasure	Competent, n	Not competent, n	Total, N	Competent, n	Not competent, n	Total, N
Competent, n	2	0	2	24	7	31
Not competent, n	19	43	62	12	25	37
Total, N	21	43	64	36	32	68

Relationship Between the Web-Based Measure and the Role-Play Measure

The ability of the Web-based measure (eMeasure), with an effect size of 0.46 for change following training, to predict competence on the role-play measure was assessed. The findings are shown in Table 4. Before training (64 trainee therapists), the sensitivity of the Web-based measure was 10% (2/21), whereas after training (68 trainee therapists) it was 67% (24/36). The figures for specificity were 100% (43/43) and 78% (25/32), respectively. NPV of the Web-based measure was 69% (43/62) before training and 68% (25/37) after training, and PPVs were 100% (2/2) and 77% (24/31), respectively. Thus, the majority of trainee therapists who were judged competent on the Web-based measure were also judged competent on the role-play measure.

Discussion

Principal Findings

There are at least two components involved in assessing therapist competence: the assessment of their knowledge of the treatment concerned, including how and when to use its strategies and procedures, and an evaluation of their ability to apply such knowledge skillfully in practice. Using CBT-E as an exemplar, this paper describes the development and the evaluation of the performance of a role-play based measure of skill at delivering CBT-E designed as a complement to the previously developed and validated Web-based measure of applied knowledge [26]. It also reports results of a comparison of the performance of these measures at assessing therapist competence with particular emphasis on whether the more scalable Web-based measure was able to predict performance on the more time-consuming and complex role-play measure.

The role-play based measure had a number of strengths. It assessed actual performance skill rather than mere knowledge and understanding; it was possible to test trainee therapists' performance on a range of key CBT-E procedures; and it did this within an hour. Furthermore, it was found that trained raters could rate trainees' performance with moderate-to-good agreement for binary ratings of competence between pairs of raters, and more importantly, good-to-excellent reliability for averaged competence. The measure was also sensitive to change, with scores being significantly higher after training than before, as might be expected. Of note, as well, the majority of the trainee therapists thought that their role-play performance resembled their everyday clinical practice. A further potential advantage is that the role-play measure could be used as a formative assessment to assess and improve performance during training. In the present context, it was used purely as a summative assessment measure, but it is clear that its design does not preclude its use as a formative assessment tool.

The major shortcoming of the role-play-based measure was that it required considerable time and resources. This shortcoming is inherent in the method. Although the medical literature has long recognized that standardized patient evaluations are a good substitute for reality [6], they have also been recognized as complex to devise and expensive to

implement [17], especially when the need to devise relatively long and comprehensive assessments is taken into account [14].

The relationship between the scores on the Web-based measure of applied knowledge and those on the role-play measure is therefore of importance, given the ease of use and scalability of the former. It was found that the Web-based measure had a PPV of 77% after training. Thus, the majority of those judged competent on the Web-based measure were also found to be competent on the role-play measure. As role-play tasks are generally accepted as simulating reality well and the therapists regarded their performance as being representative of their clinical practice, it seems reasonable to take estimates of competence on the Web-based measure as a good substitute for a skill-based measure.

Limitations

Some limitations of this work need to be recognized. First, despite recruiting almost 100 trainee therapists to help evaluate the performance-based measure, a larger sample might have allowed further refinement of the role-play measure by allowing reassessment of its performance after modifications. Ideally, all scenarios would be of equal difficulty or the difficulty level of the scenarios could be better ranked for use in further competence testing. Larger numbers of trainees tested would also have potentially strengthened confidence in the results of the comparison of trainees' performance on the 2 measures. Second, although cut points for competence by their very nature require expert judgments, it would have been preferable to validate these against treatment outcome. However, obtaining such data presents considerable practical obstacles. Third, we have used just one treatment as an exemplar. It cannot be assumed that similar findings would be obtained with all psychological treatments. Fourth, while establishing competence at a given time (eg, passing a driving test) may make ongoing high-quality performance both feasible and more likely, it does not ensure it (consistent high-quality driving). Thus, there is a need to complement the assessment of competence, required for training outcome, with the assessment of the quality of therapists' performance over time. This is especially important to combat the well-documented phenomenon of "therapist drift" [38,13]. Finally, whereas the cost of an easily administered Web-based measure that can be scored automatically is likely to be less than more traditional and labor-intensive method of assessing competence, a formal study of cost-effectiveness was unfortunately beyond the scope of this work.

Conclusions

In summary, this study describes the development and testing of a performance-based measure of skill at delivering CBT-E. Although the measure performed reasonably well, it had inherent disadvantages in terms of scalability. It is therefore of considerable interest that the Web-based measure of applied knowledge of CBT-E was relatively efficient at predicting competence as assessed by the role-play measure. This indicates that the scalable Web-based measure could be used in certain circumstances to assess the outcome of training in CBT-E.

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Conflicts of Interest

None declared.

References

1. Beidas RS, Kendall PC. Training therapists in evidence-based practice: a critical review of studies from a systems-contextual perspective. *Clin Psychol (New York)* 2010 Mar;17(1):1-30 [FREE Full text] [doi: [10.1111/j.1468-2850.2009.01187.x](https://doi.org/10.1111/j.1468-2850.2009.01187.x)] [Medline: [20877441](#)]
2. Muse K, McManus F. A systematic review of methods for assessing competence in cognitive-behavioural therapy. *Clin Psychol Rev* 2013 Apr;33(3):484-499. [doi: [10.1016/j.cpr.2013.01.010](https://doi.org/10.1016/j.cpr.2013.01.010)] [Medline: [23454222](#)]
3. McHugh RK, Barlow DH. The dissemination and implementation of evidence-based psychological treatments. A review of current efforts. *Am Psychol* 2010;65(2):73-84. [doi: [10.1037/a0018121](https://doi.org/10.1037/a0018121)] [Medline: [20141263](#)]
4. Barber JP, Sharpless BA, Klostermann S, McCarthy KS. Assessing intervention competence and its relation to therapy outcome: a selected review derived from the outcome literature. *Prof Psychol Res Pr* 2007;38(5):493-500. [doi: [10.1037/0735-7028.38.5.493](https://doi.org/10.1037/0735-7028.38.5.493)]
5. Fairburn CG, Cooper Z. Therapist competence, therapy quality, and therapist training. *Behav Res Ther* 2011 Jun;49(6-7):373-378 [FREE Full text] [doi: [10.1016/j.brat.2011.03.005](https://doi.org/10.1016/j.brat.2011.03.005)] [Medline: [21492829](#)]
6. Miller GE. The assessment of clinical skills/competence/performance. *Acad Med* 1990 Sep;65(9 Suppl):S63-S67. [Medline: [2400509](#)]
7. McHugh RK, Barlow DH. Training in evidence-based psychological interventions. In: McHugh RK, Barlow DH, editors. *Dissemination and Implementation of Evidence-Based Psychological Interventions*. New York: Oxford University Press; 2012:43-58.
8. Haladyna TM. *Developing and Validating Multiple-choice Test Items*. Mahwah, NJ: Lawrence Erlbaum Associates; 2004.
9. Kazdin AE. Implementation and evaluation of treatments for children and adolescents with conduct problems: findings, challenges, and future directions. *Psychother Res* 2016;1-15. [doi: [10.1080/10503307.2016.1208374](https://doi.org/10.1080/10503307.2016.1208374)] [Medline: [27449266](#)]
10. Young J, Beck AT. *Members Academy of CT*. 1980. Cognitive therapy scale rating manual URL: https://members.academyofct.org/files/documentlibrary/CTRS_Manual.pdf [accessed 2017-10-25] [WebCite Cache ID 6uUQPPLVT]
11. Young J, Beck A. *Cognitive Therapy Scale: Rating Manual*. Philadelphia: Unpubl Manuscr; 1988.
12. Blackburn IM, James IA, Milne DL, Baker C, Standart S, Garland A, et al. The Revised Cognitive Therapy Scale (CTS-R): psychometric properties. *Behav Cogn Psychother* 2001 Oct;29(4):431-446. [doi: [10.1017/S1352465801004040](https://doi.org/10.1017/S1352465801004040)]
13. Waller G, Turner H. Therapist drift redux: why well-meaning clinicians fail to deliver evidence-based therapy, and how to get back on track. *Behav Res Ther* 2016 Feb;77:129-137. [doi: [10.1016/j.brat.2015.12.005](https://doi.org/10.1016/j.brat.2015.12.005)] [Medline: [26752326](#)]
14. van der Vleuten CP, Schuwirth LW, Scheele F, Driessen EW, Hodges B. The assessment of professional competence: building blocks for theory development. *Best Pract Res Clin Obstet Gynaecol* 2010 Dec;24(6):703-719. [doi: [10.1016/j.bpobgyn.2010.04.001](https://doi.org/10.1016/j.bpobgyn.2010.04.001)] [Medline: [20510653](#)]
15. Ginzburg DM, Bohn C, Höfling V, Weck F, Clark DM, Stangier U. Treatment specific competence predicts outcome in cognitive therapy for social anxiety disorder. *Behav Res Ther* 2012 Dec;50(12):747-752 [FREE Full text] [doi: [10.1016/j.brat.2012.09.001](https://doi.org/10.1016/j.brat.2012.09.001)] [Medline: [23072975](#)]
16. von Consbruch K, Clark DM, Stangier U. Assessing therapeutic competence in cognitive therapy for social phobia: psychometric properties of the cognitive therapy competence scale for social phobia (CTCS-SP). *Behav Cogn Psychother* 2012 Mar;40(2):149-161. [doi: [10.1017/S1352465811000622](https://doi.org/10.1017/S1352465811000622)] [Medline: [22047669](#)]
17. Hodges BD, Hollenberg E, McNaughton N, Hanson MD, Regehr G. The Psychiatry OSCE: a 20-year retrospective. *Acad Psychiatry* 2014 Feb;38(1):26-34. [doi: [10.1007/s40596-013-0012-8](https://doi.org/10.1007/s40596-013-0012-8)] [Medline: [24449223](#)]
18. Ruzek JI, Rosen RC, Garvert DW, Smith LD, Sears KC, Marceau L, et al. Online self-administered training of PTSD treatment providers in cognitive-behavioral intervention skills: results of a randomized controlled trial. *J Trauma Stress* 2014 Dec;27(6):703-711. [doi: [10.1002/jts.21977](https://doi.org/10.1002/jts.21977)] [Medline: [25522731](#)]
19. Beidas RS, Maclean JC, Fishman J, Dorsey S, Schoenwald SK, Mandell DS, et al. A randomized trial to identify accurate and cost-effective fidelity measurement methods for cognitive-behavioral therapy: project FACTS study protocol. *BMC Psychiatry* 2016 Sep 15;16(1):323 [FREE Full text] [doi: [10.1186/s12888-016-1034-z](https://doi.org/10.1186/s12888-016-1034-z)] [Medline: [27633780](#)]
20. Beidas RS, Edmunds JM, Marcus SC, Kendall PC. Training and consultation to promote implementation of an empirically supported treatment: a randomized trial. *Psychiatr Serv* 2012 Jul;63(7):660-665 [FREE Full text] [doi: [10.1176/appi.ps.201100401](https://doi.org/10.1176/appi.ps.201100401)] [Medline: [22549401](#)]

21. Dimeff LA, Harned MS, Woodcock EA, Skutch JM, Koerner K, Linehan MM. Investigating bang for your training buck: a randomized controlled trial comparing three methods of training clinicians in two core strategies of dialectical behavior therapy. *Behav Ther* 2015 May;46(3):283-295. [doi: [10.1016/j.beth.2015.01.001](https://doi.org/10.1016/j.beth.2015.01.001)] [Medline: [25892165](#)]
22. Fairburn CG, Cooper Z, Shafran R. Cognitive behaviour therapy for eating disorders: a “transdiagnostic” theory and treatment. *Behav Res Ther* 2003 May;41(5):509-528. [Medline: [12711261](#)]
23. Fairburn CG, Cooper Z, Doll HA, O'Connor ME, Bohn K, Hawker DM, et al. Transdiagnostic cognitive-behavioral therapy for patients with eating disorders: a two-site trial with 60-week follow-up. *Am J Psychiatry* 2009 Mar;166(3):311-319 [FREE Full text] [doi: [10.1176/appi.ajp.2008.08040608](https://doi.org/10.1176/appi.ajp.2008.08040608)] [Medline: [19074978](#)]
24. Fairburn CG, Bailey-Straebl S, Basden S, Doll HA, Jones R, Murphy R, et al. A transdiagnostic comparison of enhanced cognitive behaviour therapy (CBT-E) and interpersonal psychotherapy in the treatment of eating disorders. *Behav Res Ther* 2015 Jul;70:64-71 [FREE Full text] [doi: [10.1016/j.brat.2015.04.010](https://doi.org/10.1016/j.brat.2015.04.010)] [Medline: [26000757](#)]
25. Fairburn CG. *Cognitive Behavior Therapy and Eating Disorders*. New York: The Guilford Press; 2008.
26. Cooper Z, Doll H, Bailey-Straebl S, Klucznik D, Murphy R, O'Connor ME, et al. The development of an online measure of therapist competence. *Behav Res Ther* 2015 Jan;64:43-48 [FREE Full text] [doi: [10.1016/j.brat.2014.11.007](https://doi.org/10.1016/j.brat.2014.11.007)] [Medline: [25528502](#)]
27. Bridge PD, Musial J, Frank R, Roe T, Sawilowsky S. Measurement practices: methods for developing content-valid student examinations. *Med Teach* 2003 Jul;25(4):414-421. [doi: [10.1080/0142159031000100337](https://doi.org/10.1080/0142159031000100337)] [Medline: [12893554](#)]
28. Coderre S, Woloschuk W, McLaughlin K. Twelve tips for blueprinting. *Med Teach* 2009 Apr;31(4):322-324. [doi: [10.1080/01421590802225770](https://doi.org/10.1080/01421590802225770)] [Medline: [18937095](#)]
29. Setyonugroho W, Kennedy KM, Kropmans TJ. Reliability and validity of OSCE checklists used to assess the communication skills of undergraduate medical students: a systematic review. *Patient Educ Couns* 2015 Jun 27;98(12):1482-1491. [doi: [10.1016/j.pec.2015.06.004](https://doi.org/10.1016/j.pec.2015.06.004)] [Medline: [26149966](#)]
30. Hodges B, Regehr G, McNaughton N, Tiberius R, Hanson M. OSCE checklists do not capture increasing levels of expertise. *Acad Med* 1999 Oct;74(10):1129-1134. [Medline: [10536636](#)]
31. Norman G. Editorial--checklists vs. ratings, the illusion of objectivity, the demise of skills and the debasement of evidence. *Adv Health Sci Educ Theory Pract* 2005;10(1):1-3. [doi: [10.1007/s10459-005-4723-9](https://doi.org/10.1007/s10459-005-4723-9)] [Medline: [15912279](#)]
32. Martino S, Paris Jr M, Añez L, Nich C, Canning-Ball M, Hunkele K, et al. The effectiveness and cost of clinical supervision for motivational interviewing: a randomized controlled trial. *J Subst Abuse Treat* 2016 Sep;68:11-23. [doi: [10.1016/j.jsat.2016.04.005](https://doi.org/10.1016/j.jsat.2016.04.005)] [Medline: [27431042](#)]
33. Martino S, Ball SA, Nich C, Frankforter TL, Carroll KM. Community program therapist adherence and competence in motivational enhancement therapy. *Drug Alcohol Depend* 2008 Jul 1;96(1-2):37-48 [FREE Full text] [doi: [10.1016/j.drugalcdep.2008.01.020](https://doi.org/10.1016/j.drugalcdep.2008.01.020)] [Medline: [18328638](#)]
34. Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics* 1977 Mar;33(1):159-174. [Medline: [843571](#)]
35. Fleiss JL. *Design and Analysis of Clinical Experiments*. New York: Wiley Classical Library; 1999.
36. Cohen J. *Statistical Power Analysis for the Behavioural Sciences*. New Jersey: Lawrence Erlbaum Associates; 1988.
37. Webb N, Shavelson R. Generalizability theory: overview. In: Inveritt BS, Howell D, editors. *Encyclopedia of Statistics in Behavioral Science*. Chichester: John Wiley and Sons; 2005:717-719.
38. Rosen RC, Ruzek JI, Karlin BE. Evidence-based training in the era of evidence-based practice: challenges and opportunities for training of PTSD providers. *Behav Res Ther* 2017 Jan;88:37-48. [doi: [10.1016/j.brat.2016.07.009](https://doi.org/10.1016/j.brat.2016.07.009)] [Medline: [28110675](#)]

Abbreviations

ANOVA: analysis of variance
CBT: cognitive behavioral therapy
CBT-E: enhanced cognitive behavioral therapy
CTS: Cognitive Therapy Scale
CTS-R: revised Cognitive Therapy Scale
ICCs: intraclass correlation coefficients
NPV: negative predictive value
PPV: positive predictive value
SD: standard deviation
SE: standard error

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Original Paper

Stopping Antidepressants and Anxiolytics as Major Concerns Reported in Online Health Communities: A Text Mining Approach

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Abstract

Background: Internet is a particularly dynamic way to quickly capture the perceptions of a population in real time. Complementary to traditional face-to-face communication, online social networks help patients to improve self-esteem and self-help.

Objective: The aim of this study was to use text mining on material from an online forum exploring patients' concerns about treatment (antidepressants and anxiolytics).

Methods: Concerns about treatment were collected from discussion titles in patients' online community related to antidepressants and anxiolytics. To examine the content of these titles automatically, we used text mining methods, such as word frequency in a document-term matrix and co-occurrence of words using a network analysis. It was thus possible to identify topics discussed on the forum.

Results: The forum included 2415 discussions on antidepressants and anxiolytics over a period of 3 years. After a preprocessing step, the text mining algorithm identified the 99 most frequently occurring words in titles, among which were escitalopram, withdrawal, antidepressant, venlafaxine, paroxetine, and effect. Patients' concerns were related to antidepressant withdrawal, the need to share experience about symptoms, effects, and questions on weight gain with some drugs.

Conclusions: Patients' expression on the Internet is a potential additional resource in addressing patients' concerns about treatment. Patient profiles are close to that of patients treated in psychiatry.

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KEYWORDS

social media; antidepressant; anxiolytic; text mining; data mining

Introduction

The different Internet resources make it possible to share content quickly and to interact within a large population. The biomedical literature shows a significant increase in studies published in online communities. In 2015, almost 400 publications linking to Facebook, over 300 linking to Twitter, and almost 400 documents linking to blogs and forums were published. Online health communities (OHCs), social media, and blogs are a potential mine of information exchanged daily. Among the applications of text mining, the automatic analysis of data from the Internet is a challenge. In fact, the large amount of data

available on this platform can be processed by the tools of natural language processing. In addition, screening the Internet is almost impossible manually, and it is a very interesting application for automatic data extraction tools [1].

Social networks are a particularly dynamic way to capture the concerns of a population in real time. Blogs, microblogs such as Twitter [2], social networking sites such as Facebook [3], and discussion forums are spaces for exchange of information where people publish their personal stories or their opinions in real time. This dynamic and continuously updated source of information is ideal for the collection of data in a variety of

disciplines, enabling users to tap into the wisdom of crowds. Through the Internet, we could explore the information exchanged, irrespective of its quality. It is important to be aware of information disseminated on the Internet. It is useful to know what concerns people have, as well as to inform, alert, correct, and prevent specific issues.

The online social networks provide a valuable complement to communication face-to-face and help patients to improve their self-esteem and social skills [4-6]. Social networks encourage patients to be more active in their social environment [7]. For example, patients can chat via online media about their private problems without fear of prejudice or discrimination [8]. The impact on patient health of sharing information on the Internet is a topic that has been explored in the literature. Yan and Tan investigated the usefulness of OHC on patient health [9]. The authors found that patients benefit from the experience of others and that their participation in the online community helped to improve their health. Social support exists in various forms and depends on patients' health conditions. However, one factor remains essential whatever the illness: emotional support plays a very important role in helping patients improve their health.

Social Media as a Resource for Mental Health Service

Some studies have focused on the use of the social media and Internet psychiatry forums. OHCs and the social media as a resource for mental health service users are important in reducing stigma and promoting help-seeking behaviors. The analysis of the information shared on the Web is crucial in psychiatry, as public misinformation could negatively affect mood. Research on the social networks has increased and has explored different aspects of people's health status. Several studies have considered the way depression and eating disorders are discussed on Twitter [10], whereas others have focused on the detection of depression via identification of events, emotions, and negative thoughts in Web and Facebook messages [11-13], or on suicide detection on Twitter [14], or again on exploring disorders such as depression by analyzing the behaviors of Facebook users [15]. With the growing popularity of the social media, the impact of support on the Internet is of interest only because it naturally occurs outside the setting of professional guidance.

The influence of the social networks has been studied for the development of attitudes of mutual trust and self-help. In some cases, face-to-face support cannot provide adequate help for patients with mental disorders [16]. The proliferation of OHCs has enabled patients to share information and experiences and to communicate on their illness. Ma X found that social interaction in online communities such as PatientsLikeMe.com was significantly associated with time to recovery in patients with mental disorders [17]. However, online social interactions reveal a more complex picture. Several studies have linked the use of OHCs to decline in mood, well-being, and quality of life [18-21]. For example, the passive consumption of OHCs' content with no active involvement has been linked to a reduction in social interactions in real life and increased solitude [22]. This finding reflects a limitation of online interactions with respect to social activity in real life. The impact of Internet on behavior cannot be ignored. An obvious example is the

impact of the use of Facebook combined with comparisons of physical appearance online, which could lead to more disordered eating habits and associated conditions [23].

Applications of Text Mining to Web Data

Several studies have been published on the applications of text mining to Web data. The exploitation of Internet data has provided early monitoring information on adverse reactions to drugs [24-26]. The study of social interactions on the Web in real or near-real time is also of interest in public health surveillance. In a health crisis, as experienced with the spread of the Ebola or influenza A (H1N1) viruses, it is important to understand the expectations and questions of the population [27-29]. These analyses provide content to inform health authorities to anticipate epidemics such as H1N1 and to respond to the concerns of the public. Other studies have used this source of information to investigate depressive trends from messages posted on the Web [13]. The purpose of the exploration of data from blogs is, in this case, to help bloggers or authors of posted messages by detecting major depressive disorders early. More generally, the objective is to capture patient perceptions through the messages posted on discussion forums. The patient perspective includes views on treatment, on the illness, and on priorities and needs in terms of health [30-32].

Text mining is proving to be a powerful method to exploit large continuous flows of user-generated content on the World Wide Web. This resource has rarely been exploited to understand the perceptions of patients about treatments. We set out to study an online discussion forum dedicated to the use of antidepressants and anxiolytics to explore patient concerns.

Methods

Data Collection

Our dataset is derived from a French online discussion forum about drugs, illness, procedures, and other information relating to general health. As mentioned in the forum charter, discussions can be read and potentially used by all. We focused initially on the titles of discussions from 2013 to 2015. The participants themselves summarize the topic or question they post on the forum. In other words, we focus on a condensed form of the concerns of the participants regarding antidepressants or anxiolytics.

The data extraction step is dependent on the data source and differs according to whether it is data from a website, from patient medical records, or from qualitative interviews. In our study, health information was extracted from Web pages via a program that explores the Web of data using R packages (R Project for Statistical Computing). Our corpus of documents was formed from discussion titles. A page contains 50 topics and each topic consists of a title, an initial message (demand), and potential responses (messages). To create this database, we implemented the following process: first, we extracted pages including lists of discussions. Links to each discussion are found on the website in a specific location. The storage address for a discussion is indicated via a URL link. By capturing all the discussion addresses, we had access to the messages stored there in Hyper Text Markup Language (HTML) format. Second, each

URL and each of the discussions were analyzed to remove unnecessary information (images and advertising) and to extract the date, titles, and discussion of messages in a Microsoft Excel file.

There has been discussion about the ethical concerns of analyzing data retrieved from OHCs [33]. To minimize these concerns, we searched for and included only the title of discussions that were publicly available. We used the dataset solely for statistical analysis and reporting of aggregated information and not for investigation of specific individuals or organizations. We have no prior knowledge of the possible identities of any study participants. We did not submit our study to an ethics committee because no user was interviewed. The identity of users is protected because of the use of alias, and all usernames or potential demographic characteristics in the results were removed from the dataset.

Preprocessing Step

Once the extraction of data is performed, the data preparation stage can begin. The tools need to be adapted to the language (English, French, and Spanish) and to the vocabulary if certain words are used in a specific domain (eg, medical). In addition, words used on the Internet via social networks or blogs are not the same as those used in a newspaper. We, therefore, need to pay special attention to spelling irregularities and to include everyday words used in spoken language.

A morphological analysis is the first part of the process. It consists of analyzing the morphology of the sentences in the text. All messages are reviewed by screening for particular typographic elements such as accents. This step is essential in French because accents are a characteristic of our language. For example, the letter “a” can have several variants and is replaced by its generic form without an accent. Then, there is a harmonization step, consisting of converting all lowercase letters to uppercase. Each sentence is finally cut off using the punctuation that defines it. Punctuation marks are deleted. Finally, the spaces between the words are used to delineate them.

The next step is to parse the text and to remove noninformative elements such as numbers or link words occurring in the database. The words and codes for data extraction from the Internet may also be present, such as XML and HTML tags (<html>, </n>...). Finally, a list of “stop words” is predefined in the software to automatically delete the list of prepositions and articles (what, my, ...) that are not informative and to reduce the list of words that are most relevant to the analysis.

The last step is stemming, which consists of grouping similar words according to a common root. For instance, a verb can have different spellings following conjugation rules. Stemming enables us to group every inflection of the verb into one term, which is the root. For instance, the word “continue” exists in different variants—“continued,” “continuing,” “continuous,” “continuation,” and so on. The three inflected forms will be identified as one relating to “continue.” The same principle is applied for compound words or words with a prefix or suffix. To perform the stemming step, it is necessary to have an exhaustive list of words including all variants and the associated

root. The quality of this processing varies with the software used and from one language to another and depends on the list of words referenced. Finally, to simplify the analysis of the treatments mentioned, we harmonized the names of the different drugs by using their international nonproprietary names.

Initially, every word in every sentence is recognized as unique. At the end of this stage of data preparation, the number of words is reduced following the simplification of word variants. To analyze the occurrence of these words in our corpus, a contingency table is created and called document-term matrix (DTM). In our study, we analyzed only the words used in the titles of discussions. Our DTM table shows the number of times a word was used (column) in a discussion title (online). The majority of words appear only in some titles. Accordingly, if a DTM is still almost empty, it means that there are a large number of 0s in the table. We, therefore, need to adapt the data modeling approach to this type of data.

Analysis

The Most Frequent Words

The easiest and commonest way to visualize textual data is the word cloud. The aim is to display each word and represent its frequency by the size of the font used. First, only words included in the DTM table are used. Then, the frequency of each word is calculated, and the list is ordered in decreasing manner. The word that appears most frequently is represented with the largest font. The second word is most often graphically smaller than the first word but larger than the third word in the list and so on with other words. In the end, the word cloud reflects the word frequency table, maximizing the visibility of the most common terms.

Centrality of Co-occurrences

To analyze the patterns of occurrence of words in the discussion titles, we studied the influence of each word in terms of co-occurrence. Due to the sparsity of the DTM, correlation analysis was not appropriate. The analysis of co-occurrences, via centrality measures using graph theory, is an alternative, which has been proved to be better in quantity and quality [34]. The patterns of word occurrences can be graphically represented in two complementary forms inspired by the graph theory and social network analysis.

The first type identifies a centrality pattern, which highlights some words of importance based on their better positioning in the co-occurrence relationships. These words have a central role in some units in the graph. Centrality can be measured by a local measure using the degree of centralization, considering that words with many connections are the most important words. The degree of centrality measures the importance of a word and is involved in a large number of interactions, measuring by an exposure index to what is flowing through the network. Another way of looking at centrality is by considering how important words are in connecting to other words (betweenness centrality). The idea is to reflect the mediation role of words based on how many words each word would have to go through to reach the others.

Community of Co-occurrences

The second type identifies a modular pattern of occurrence (community), where the words are grouped into classes based on semantic similarities (ie, similar semantic patterns of word occurrences). The aim of this analysis was to identify the thematic structure of the text [35,36]. This analysis yields a division into classes and a hierarchy of words based on co-occurrences. A graph shows words, each being linked by ties of co-occurrence. By construction, words in the same class are interconnected and connected to another class based on co-occurrence links in the titles. We present only results from the fast greedy algorithm based on the high density of internal links of words inside a group [37]. One study indicates more stable and better results with fast greedy algorithms compared with others such as k-means, expectation maximization, and the walktrap algorithm [38]. All analyses were performed using R tm package.

Results

Data Collection

The Health Forum studied is a French-language website, Doctissimo [39], and includes 2415 discussions on antidepressants and anxiolytics from 2013 to 2015. It includes 33,865 messages written by 1257 different authors. On average, a first message posted (a question) received 14 responses. In 7.7% of cases (n=185), questions received no answer on the forum. In other cases, a demand can be widely discussed with up to 50 replies. The average time of discussion is 30 days. A discussion can be maintained over a longer period with interruptions of up to several years.

Preprocessing Step

The preprocessing step is represented in Figure 1, showing how text data are structured. Each step of preprocessing is shown, as well as the impact of each step on reducing the number of words stored in the DTM final table.

The titles of discussions extracted initially contained 3025 different words. After the pretreatment step, only 99 words were

identified as being the most representative, in other words, only the words that appeared most frequently in the titles and considered the most informative (excluding prepositions, articles, and some adverbs).

Finally, the final table reduction step was applied to remove words that appeared infrequently. We did not analyze all the terms in the titles because many words are not informative. To reduce the size of our final DTM table without the risk of losing information, we removed the words occurring in less than 0.05% of the titles. Few words are retained as the most relevant by text mining to define the title content. Content of some of the titles was reduced to one or two words. More than 400 titles did not contain any of the words listed by text mining in the DTM as the most frequent. Several reasons could explain this phenomenon. First, some titles could include some uncommon words. Second, noninformative words are deleted during the preprocessing phase.

Analysis

The Most Frequent Words

Figure 2 is the word cloud that visually represents word frequencies in the data. Letter size is proportional to the frequency of the words in the discussion titles. The more often the word appears in the titles of discussions, the larger the font.

Words related to antidepressants were the most frequent. The words corresponding to information sharing between participants, such as “help,” “testimony,” “advice,” “need,” and “opinion” are also present. Multimedia Appendix 1 lists the 20 most frequent words by decreasing order plotted in the word cloud. The drug names “escitalopram” and “venlafaxine” are words that are frequently used in the titles of discussions and to a lesser extent the drugs fluoxetine, sertraline, alprazolam, paroxetine, and bromazepam. The list of 26 molecules named in the discussions is presented in Multimedia Appendix 2. Other related words such as *stop* and *take treatment* were often used. In Figure 1, we can see that symptoms relative to weight, anxiety, depression, and distress are mentioned. These symptoms are more difficult to identify automatically because several denominations can be used to describe the same condition.

Figure 1. Preprocessing step.

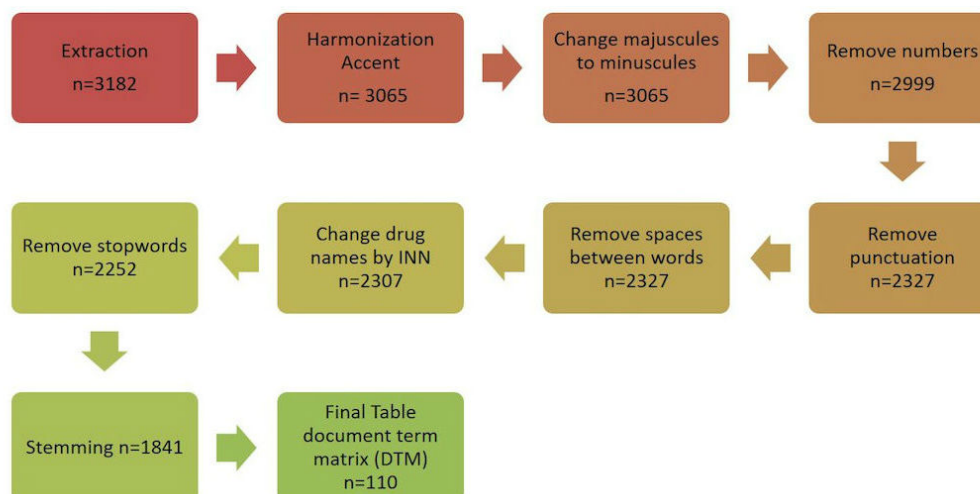


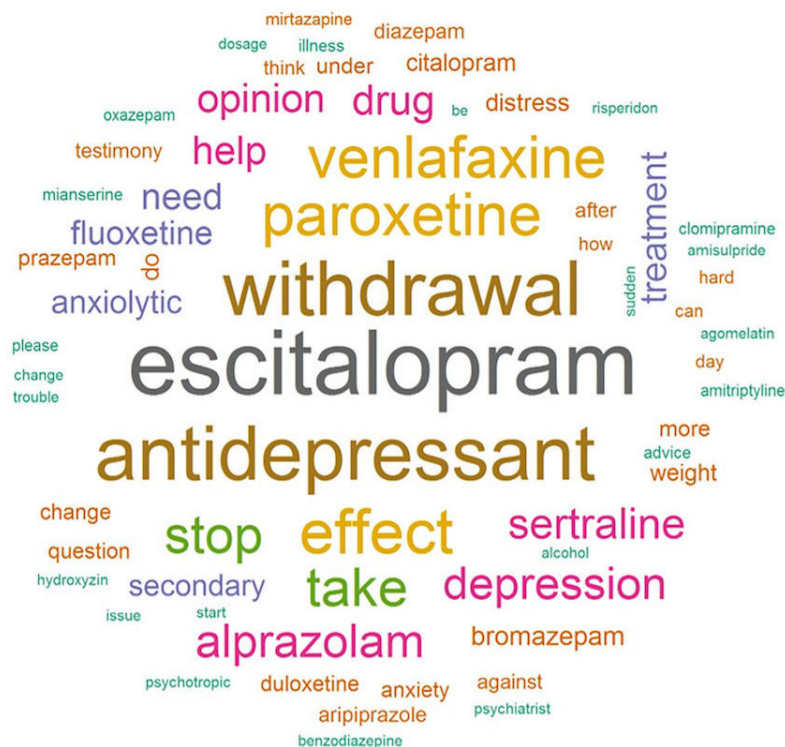
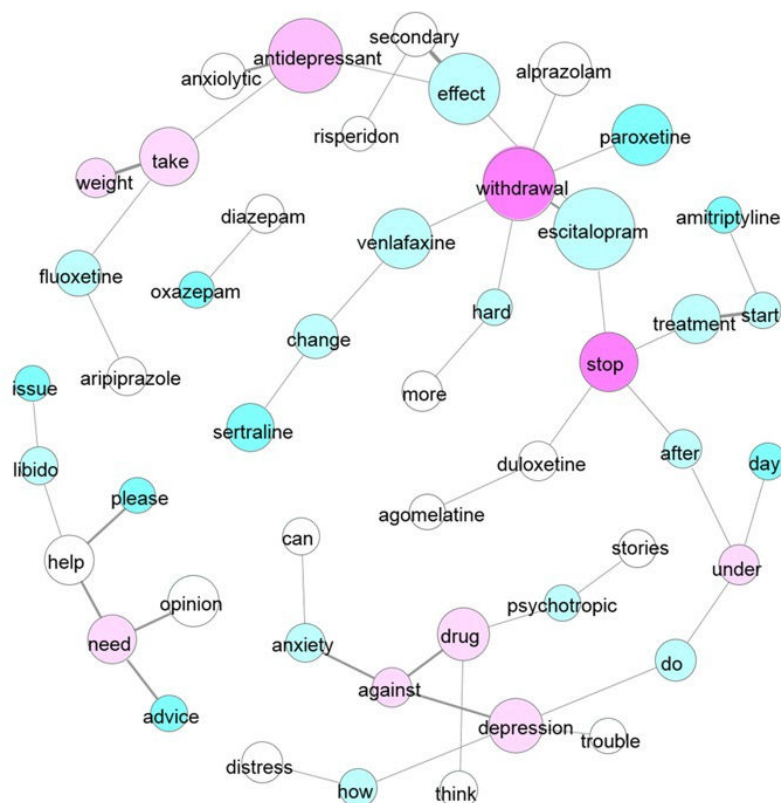
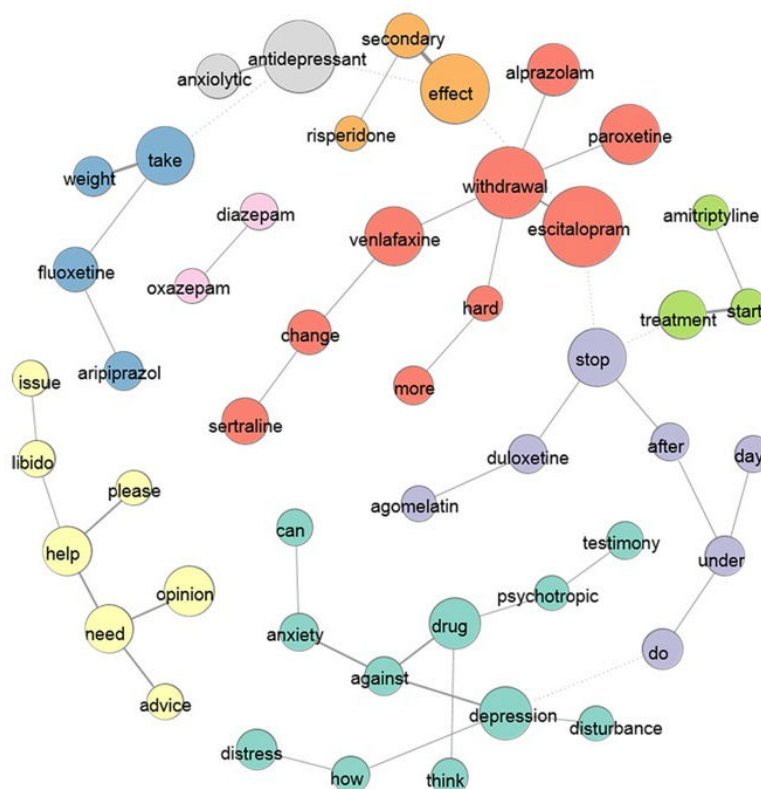
Figure 2. Wordcloud.**Figure 3.** Centrality of co-occurrences based on degree algorithm.

Figure 4. Cluster of co-occurrences-community detection based on modularity (fast greedy algorithm).

Centrality of Co-occurrences

Centrality reflects the relative importance of a word within a corpus (ie, the links between words by measuring the position of a word in the network). The centrality measure based on degree enables visualization of the most frequently used words in the forum. Figure 3 shows the words considered the most central, in the sense that they have numerous links to other words (in pink).

As in the word cloud, the most popular words are “withdrawal,” “stop,” and “antidepressant.” These words reflect major concerns expressed in the forum. Betweenness centrality relates to words with a mediator role, serving as paths linking to other words in the network. It quantifies the control of a word on the communication between other words. Six words are considered as mediator-linking terms relative to the request (“after,” “under,” and “do”) and defining different topics around common terms (“escitalopram,” “withdrawals,” and “antidepressant”).

Community of Co-occurrences

The detection of “communities” makes it possible to highlight patterns of co-occurrences, nonhierarchical but localized. Community detection based on modularity (fast greedy algorithm) is used to visualize different topics in Figure 4.

Nine clusters of words are identified, representing the interconnection of terms on the basis of their co-occurrence in titles:

- Depression, distress, and anxiety, where people ask about the experiences of people who took treatments against these symptoms (11 words in turquoise)

- Withdrawal linked to paroxetine, escitalopram, alprazolam, and changes of treatment especially with venlafaxine and sertraline (9 words in red)
- Effects after stopping medication of duloxetine and agomelatine (7 words in violet)
- Search for advice, assistance, and libido issues (7 words in yellow)
- Weight gain with fluoxetine and aripiprazole (4 blue words)
- Effects of amitriptyline (3 words in green)
- Side effects of risperidone (3 words in orange)
- Changing prescription and switching two antidepressants: duloxetine and agomelatine (2 green words)
- Concerns about the effects and side effects of medications (2 gray words)

Detecting communities is an interesting graphic approach to visualize knowledge of relational data and to bring information to light more quickly when it is hidden in large volumes of data. Similar results were found using the random walk algorithm (walktrap).

Discussion

Principal Findings

The principal concerns in the forum relate to withdrawal and discontinuing certain antidepressants. We can see the central role of withdrawal in patients’ questions. This issue was previously minimized for a long period. In 1997, a survey concluded that many physicians denied being aware of the existence of antidepressant withdrawal symptoms [40]. The incidence of discontinuation reactions is unclear, owing to the lack of research and a clear definition of withdrawal [41].

Conclusions from conventional approaches such as meta-analyses and those from our text mining on an online forum are consistent. Events previously reported with antidepressants after discontinuation of treatment for major depression are nausea, vomiting, diarrhea, headache, dizziness, insomnia, sexual side effects, and weight gain [42]. For instance, 31% of nausea was reported by patients with major depression. Adverse event profiles varied with the drugs. However, only 13% of clinical studies collected adverse events using a standardized scale. The lack of guidance based on evidence available to both practitioners and patients reflects a lack of information on how to deal with discontinuation of antidepressant medication [36].

Interest in Analyzing Online Health Communities

The study of interactions on OHCs provides an additional source of information to better understand the difficulties encountered in real life. Patients may be able to develop skills to overcome the difficulties of communication and recovery. In our study, we identified patients' need to share experiences about illness management and to brighten their lives through social interactions on these online platforms [9]. The online social media thus plays a complementary role to that of the traditional mental health services and helps patients understand their conditions more fully and take better control of their illness and behavior [43]. For example, although many treatment decisions are still based on empirical judgments that might not have solid evidence to support them, sharing health care information on OHCs can enable patients to perceive their illness from another point of view, do their own research online, and make their own informed decisions about how to manage their illness [44-46]. Patients consult various online sources, in particular when they feel that their physician does not meet their information needs during a consultation. Concerns about topics discussed on the forum, such as withdrawal, weight gain, or dosage, need to be asked directly to a professional health care provider. Encouraging communication with a physician would help to clarify what "withdrawals" is referring to. The word "withdrawals" could be used inadequately by a forum and used to define two concepts: (1) the classic antidepressant discontinuation syndrome and (2) withdrawal syndrome relative to benzodiazepines use. In our study, we considered both antidepressants and anxiolytics, and the difference between the two technical words is probably not well established in the forum. However, two terms (withdrawals and stop) relative to the same concern are frequently reported in the title of discussion, reflecting a major preoccupation in the forum. The perceived quality of communication with physicians is one of the factors influencing the use of the Internet as a source of information [47].

Limitations

We focus our analysis on people posting messages via the Internet, meaning that they have Internet access. There are still many people who do not use the Web on a regular basis. In these communities, there may be no easy way to obtain general health information, and we cannot therefore extrapolate our results to the views and behaviors of other population. However, Internet usage is increasing exponentially with technology and

connectivity ever more widely available. There is, therefore, a need to monitor the changing demographics of website users (geographical location, age, and gender). In addition, not all information has the same impact on the Internet, and certain factors can quantify their influence on patient behavior [48]. Information quality, emotional support, and credibility of the source have a significant, positive impact on the adoption of health information. Among these criteria, the quality of information plays an important role in shaping patient decisions.

Ethics

For the moment, no guideline is available to inform how to deal with data ownership. Although there are potential benefits of OHCs' content analysis, it introduces new ethical challenges. The lack of clear guideline to conduct online human subject's research leaves researchers with no clear way to analyze data shared on the Internet [49]. Only two reports provide advice on psychological research online in the American Psychological Association website [50]. In 2002, one report produced by the Board of Scientific Affairs Advisory Group on conducting research on the Internet identified the opportunities and challenges of conducting research on the Internet. However, their suggestions could not be adapted for new way communication tools such as OHCs. In 2012, a second report written presented ethical dilemma of subject research on the Internet. No recommendation of any guidelines beyond the requirement that any research conducted on the Internet has been proposed.

Consequently, this gap discourages social scientists from conducting online research. Several options have been used by researchers to publish their research based on Internet data. Some scientists do not publish any information about ethics consideration. Computer scientists raise fewer concerns because they are often unfamiliar with ethical and social implications. One study using Twitter data asked the advice of an institutional review board. They qualified the project as not human subjects' research because public identification handles are avatars and are not identifiable living individuals according to local and national regulations [51]. In another study, the authors considered it as a post hoc analysis and explained that no ethical approval or informed consent is needed [52]. Website terms and conditions indicate that we should contact the website to obtain an agreement to use data hosting in their platform. In our study, we contacted the forum's owner to present our project and to obtain their agreement to use their data. Different approaches of ethical considerations using Internet content are needed and would implicate discussion to define a clear guideline between OHCs, institutional review boards, and researchers. Few previous studies publishing results based on Internet user analysis report a section ethics statement. In this case, authors mentioned that data collection process has been carried out through the Facebook or Twitter API, which is publicly available, and only public available data were used for the analysis. We recommend reading attentively the conditions of utilization that might be different on each website and contact them to explain the research project avoiding any potential issues.

Despite these limitations, the antidepressants and anxiolytics cited are coherent for the management of patients with depression. Escitalopram, paroxetine, venlafaxine, and sertraline are the main antidepressants used in practice to treat depressed patients in France [53]. The French population is well known to be a major consumer of anxiolytics, but the majority of drugs reported in the forum are antidepressants. Antidepressants are more often mentioned than benzodiazepines in the titles of discussions. Prescriptions of anxiolytics such as Lexomil and Xanax decreased by 1.42% in 2014. The trend of benzodiazepines continued to decrease in 2015 compared with previous years. However, prescriptions of antidepressants increased by 0.67% in the same period and could explain why benzodiazepines are less frequent in discussion titles.

Conclusions

Our analysis focuses on the most frequent words used in 2415 titles on a French online forum about antidepressants and

anxiolytics. Major concerns addressed in the titles are as follows: (1) stopping medications (using the word “withdrawal”) for certain antidepressants, (2) the need to share the experience of symptoms (depression and anxiety), (3) effects, and (4) questions concerning weight gain with some treatments. The analysis of centrality gives a general idea of the words used. In addition, community analysis provides the context of the use of these words, helping to identify questions discussed in the forum. Our findings show that the patient profiles asking questions in the forum is close to that of patients treated in psychiatry. The concerns expressed are coherent with real-life situations and are not outlandish requests and complaints about mental health issues. Our research is based on text mining tools that are more and more used to evaluate drug surveillance. In practice, pharmacovigilance refers almost exclusively to spontaneous reporting systems. As a complement to the standard approach, analyzing what is spontaneously reported by patients could improve investigations in pharmacovigilance.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Top 20 most frequent words in titles.

[PDF File (Adobe PDF File), 244KB - [mental_v4i4e48_app1.pdf](#)]

Multimedia Appendix 2

Frequency of drug names in titles.

[PDF File (Adobe PDF File), 249KB - [mental_v4i4e48_app2.pdf](#)]

References

1. Borrás-Morell JE. Data mining for pulsing the emotion on the web. *Methods Mol Biol* 2015;1246:123-130 [FREE Full text] [Medline: [25417083](#)]
2. Twitter. URL: <http://twitter.com/> [accessed 2017-10-06] [WebCite Cache ID 6u0svVJt9]
3. Facebook. URL: <https://www.facebook.com/unsupportedbrowser> [accessed 2017-10-06] [WebCite Cache ID 6u0uToRik]
4. Kummervold PE, Gammon D, Bergvik S, Johnsen JK, Hasvold T, Rosenvinge JH. Social support in a wired world: use of online mental health forums in Norway. *Nord J Psychiatry* 2002;56(1):59-65. [doi: [10.1080/08039480252803945](#)]
5. Morris RR, Schueller SM, Picard RW. Efficacy of a Web-based, crowdsourced peer-to-peer cognitive reappraisal platform for depression: randomized controlled trial. *J Med Internet Res* 2015 Mar 30;17(3):e72 [FREE Full text] [Medline: [25835472](#)]
6. Myneni S, Cobb NK, Cohen T. Finding meaning in social media: content-based social network analysis of QuitNet to identify new opportunities for health promotion. *Stud Health Technol Inform* 2013;192:807-811 [FREE Full text] [Medline: [23920669](#)]
7. Cothrel J, Williams RL. Online communities: helping them form and grow. *J Knowl Manag* 1999;3(1):54-60 [FREE Full text] [doi: [10.1108/13673279910259394](#)]
8. Hsiung RC. Suggested principles of professional ethics for the online provision of mental health services. *Stud Health Technol Inform* 2001;84(Pt 2):1296-1300 [FREE Full text] [Medline: [11604937](#)]
9. Yan L, Tan Y. Feel blue? Go online: an empirical study of social support among patients. *Inf Syst Res* 2014;25(4):690-709 [FREE Full text] [doi: [10.1287/isre.2014.0538](#)]
10. Prieto VM, Matos S, Álvarez M, Cacheda F, Oliveira JL. Twitter: a good place to detect health conditions. *PLoS ONE* 2014;9(1):e86191 [FREE Full text] [doi: [10.1371/journal.pone.0086191](#)] [Medline: [24489699](#)]

11. Jelenchick L, Eickhoff JC, Moreno MA. "Facebook Depression?" social networking site use and depression in older adolescents. *J Adolesc Health* 2013 Jan;52(1):128-130 [[FREE Full text](#)] [doi: [10.1016/j.jadohealth.2012.05.008](https://doi.org/10.1016/j.jadohealth.2012.05.008)]
12. Pantic I. Online social networking and mental health. *Cyberpsychol Behav Soc Netw* 2014 Oct 1;17(10):652-657 [[FREE Full text](#)] [doi: [10.1089/cyber.2014.0070](https://doi.org/10.1089/cyber.2014.0070)] [Medline: [25192305](#)]
13. Tung C, Lu W. Analyzing depression tendency of web posts using an event-driven depression tendency warning model. *Artif Intell Med* 2016 Jan;66:53-62 [[FREE Full text](#)] [doi: [10.1016/j.artmed.2015.10.003](https://doi.org/10.1016/j.artmed.2015.10.003)] [Medline: [26616420](#)]
14. O'Dea B, Wan S, Batterham PJ, Calear AL, Paris C, Christensen H. Detecting suicidality on Twitter. *Internet Interv* 2015 May;2(2):183-188 [[FREE Full text](#)] [doi: [10.1016/j.invent.2015.03.005](https://doi.org/10.1016/j.invent.2015.03.005)]
15. Csepeli G, Nagyfi R. Facebook diagnostics: detection of mental hygiene problems based on online trace. In: Benkő Z, Modi I, Tarkó K, editors. *Leisure, Health and Well-Being. Leisure Studies in a Global Era*. Cham: Palgrave Macmillan; 2017.
16. Farrell SP, McKinnon CR. Technology and rural mental health. *Arch Psychiatr Nurs* 2003 Feb;17(1):20-26 [[FREE Full text](#)] [Medline: [12642884](#)]
17. Ma X, Sayama H. Mental disorder recovery correlated with centralities and interactions on an online social network. *PeerJ* 2015 Aug 20;3:e1163 [[FREE Full text](#)] [doi: [10.7717/peerj.1163](https://doi.org/10.7717/peerj.1163)] [Medline: [26312174](#)]
18. Caplan SE. Problematic Internet use and psychosocial well-being: development of a theory-based cognitive behavioral measurement instrument. *Comput Human Behav* 2002 Sep;18(5):553-575 [[FREE Full text](#)] [doi: [10.1016/S0747-5632\(02\)00004-3](https://doi.org/10.1016/S0747-5632(02)00004-3)]
19. Chou HT, Edge N. "They are happier and having better lives than I am": the impact of using Facebook on perceptions of others' lives. *Cyberpsychol Behav Soc Netw* 2012 Feb;15(2):117-121 [[FREE Full text](#)] [Medline: [22165917](#)]
20. Kross E, Verduyn P, Demiralp E, Park J, Lee DS, Lin N, et al. Facebook use predicts declines in subjective well-being in young adults. *PLoS One* 2013 Aug 14;8(8):e69841 [[FREE Full text](#)] [doi: [10.1371/journal.pone.0069841](https://doi.org/10.1371/journal.pone.0069841)] [Medline: [23967061](#)]
21. Leung L. Predicting Internet risks: a longitudinal panel study of gratifications-sought, Internet addiction symptoms, and social media use among children and adolescents. *Health Psychol Behav Med* 2014 Jan 1;2(1):424-439 [[FREE Full text](#)] [doi: [10.1080/21642850.2014.902316](https://doi.org/10.1080/21642850.2014.902316)]
22. Burke TR, Goldstein G. A legal primer for social media. *Mark Health Serv* 2010;30(3):30-31 [[FREE Full text](#)] [Medline: [20804083](#)]
23. Walker M, Thornton L, Choudhury MD, Teevan J, Bulik CM, Levinson CA, et al. Facebook use and disordered eating in college-aged women. *J Adolesc Health* 2015 Aug;57(2):157-163 [[FREE Full text](#)] [doi: [10.1016/j.jadohealth.2015.04.026](https://doi.org/10.1016/j.jadohealth.2015.04.026)] [Medline: [26206436](#)]
24. Harpaz R, Callahan A, Tamang S, Low Y, Odgers D, Finlayson S, et al. Text mining for adverse drug events: the promise, challenges, and state of the art. *Drug Saf* 2014 Oct;37(10):777-790 [[FREE Full text](#)] [doi: [10.1007/s40264-014-0218-z](https://doi.org/10.1007/s40264-014-0218-z)] [Medline: [25151493](#)]
25. Kate K, Negi S, Kalagnanam J. Monitoring food safety violation reports from internet forums. *Stud Health Technol Inform* 2014;205:1090-1094 [[FREE Full text](#)] [Medline: [25160357](#)]
26. Liu M, Hu Y, Tang B. Role of text mining in early identification of potential drug safety issues. *Methods Mol Biol* 2014;1159:227-251 [[FREE Full text](#)] [Medline: [24788270](#)]
27. Kim S, Pinkerton T, Ganesh N. Assessment of H1N1 questions and answers posted on the Web. *Am J Infect Control* 2012 Apr;40(3):211-217 [[FREE Full text](#)] [doi: [10.1016/j.ajic.2011.03.028](https://doi.org/10.1016/j.ajic.2011.03.028)]
28. Lazard AJ, Scheinfeld E, Bernhardt JM, Wilcox GB, Suran M. Detecting themes of public concern: a text mining analysis of the Centers for Disease Control and Prevention's Ebola live Twitter chat. *Am J Infect Control* 2015 Oct 1;43(10):1109-1111 [[FREE Full text](#)] [Medline: [26138998](#)]
29. Odum M, Yoon S. What can we learn about the Ebola outbreak from tweets? *Am J Infect Control* 2015 Jun;43(6):563-571 [[FREE Full text](#)] [Medline: [26042846](#)]
30. Capozza K, Woolsey S, Georgsson M, Black J, Bello N, Lence C, et al. Going mobile with diabetes support: a randomized study of a text message-based personalized behavioral intervention for type 2 diabetes self-care. *Diabetes Spectr* 2015 May;28(2):83-91 [[FREE Full text](#)] [Medline: [25987806](#)]
31. Sawyer A. Let's talk: a narrative of mental illness, recovery, and the psychotherapist's personal treatment. *J Clin Psychol* 2011 Aug;67(8):776-788 [[FREE Full text](#)] [Medline: [21688268](#)]
32. Song MK, Lin FC, Gilet CA, Arnold RM, Bridgman JC, Ward SE. Patient perspectives on informed decision-making surrounding dialysis initiation. *Nephrol Dial Transplant* 2013 Nov;28(11):2815-2823 [[FREE Full text](#)] [Medline: [23901048](#)]
33. Denecke K, Bamidis P, Bond C, Gabarron E, Househ M, Lau AY, et al. Ethical issues of social media usage in healthcare. *Yearb Med Inform* 2015 Aug 13;10(1):137-147 [[FREE Full text](#)] [doi: [10.15265/IY-2015-001](https://doi.org/10.15265/IY-2015-001)] [Medline: [26293861](#)]
34. Bolland JM. Sorting out centrality: an analysis of the performance of four centrality models in real and simulated networks. *Soc Networks* 1988;10(3):233-253 [[FREE Full text](#)] [doi: [10.1016/0378-8733\(88\)90014-7](https://doi.org/10.1016/0378-8733(88)90014-7)]
35. Hjørland B. Towards a theory of aboutness, subject, topicality, theme, domain, field, content...and relevance. *J Am Soc Inf Sci Technol* 2001;52(9):774-778 [[FREE Full text](#)] [doi: [10.1002/asi.1131](https://doi.org/10.1002/asi.1131)]
36. Wilson P. *Two Kinds of Power: An Essay on Bibliographical Control*. Berkeley: University of California Press; 1968.

37. Clauset A, Newman ME, Moore C. Finding community structure in very large networks. *Phys Rev E Stat Nonlin Soft Matter Phys* 2004;70(6):264-277 [FREE Full text] [doi: [10.1103/PhysRevE.70.066111](https://doi.org/10.1103/PhysRevE.70.066111)]
38. de Arruda GF, Costa LF, Rodrigues FA. A complex networks approach for data clustering. *Physica A Stat Mech Appl* 2012 Dec;391(23):6174-6183 [FREE Full text] [doi: [10.1016/j.physa.2012.07.007](https://doi.org/10.1016/j.physa.2012.07.007)]
39. Forum.doctissimo.fr. URL: http://forum.doctissimo.fr/medicaments/antidepresseurs-anxiolytiques/liste_sujet-1.htm [accessed 2017-10-06] [WebCite Cache ID 6u0sj74t9]
40. Young AH, Currie A. Physicians' knowledge of antidepressant withdrawal effects: a survey. *J Clin Psychiatry* 1997;58(Suppl 7):28-30 [FREE Full text] [Medline: [9219491](https://pubmed.ncbi.nlm.nih.gov/9219491/)]
41. Haddad P, Lejoyeux M, Young A. Antidepressant discontinuation reactions. *Br Med J* 1998 May 11;316(7138):1105-1106 [FREE Full text] [doi: [10.1136/bmj.316.7138.1105](https://doi.org/10.1136/bmj.316.7138.1105)]
42. Hansen RA, Gartlehner G, Lohr KN, Gaynes BN, Carey TS. Efficacy and safety of second-generation antidepressants in the treatment of major depressive disorder. *Ann Intern Med* 2005 Sep 20;143(6):415-426 [FREE Full text] [Medline: [16172440](https://pubmed.ncbi.nlm.nih.gov/16172440/)]
43. Frost JH, Massagli MP. Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data. *J Med Internet Res* 2008 May 27;10(3):e15 [FREE Full text] [doi: [10.2196/jmir.1053](https://doi.org/10.2196/jmir.1053)] [Medline: [18504244](https://pubmed.ncbi.nlm.nih.gov/18504244/)]
44. Chen J, Zhu S. Online information searches and help seeking for mental health problems in urban China. *Adm Policy Ment Health* 2016;43(4):535-545 [FREE Full text] [doi: [10.1007/s10488-015-0657-6](https://doi.org/10.1007/s10488-015-0657-6)] [Medline: [25981055](https://pubmed.ncbi.nlm.nih.gov/25981055/)]
45. Frost J, Okun S, Vaughan T, Heywood J, Wicks P. Patient-reported outcomes as a source of evidence in off-label prescribing: analysis of data from PatientsLikeMe. *J Med Internet Res* 2011 Jan 21;13(1):e6 [FREE Full text] [doi: [10.2196/jmir.1643](https://doi.org/10.2196/jmir.1643)] [Medline: [21252034](https://pubmed.ncbi.nlm.nih.gov/21252034/)]
46. Wicks P, Massagli M, Frost J, Brownstein C, Okun S, Vaughan T, et al. Sharing health data for better outcomes on PatientsLikeMe. *J Med Internet Res* 2010 Jun 14;12(2):e19 [FREE Full text] [doi: [10.2196/jmir.1549](https://doi.org/10.2196/jmir.1549)] [Medline: [20542858](https://pubmed.ncbi.nlm.nih.gov/20542858/)]
47. Xiao N, Sharman R, Rao HR, Upadhyaya S. Factors influencing online health information search: an empirical analysis of a national cancer-related survey. *Decis Support Syst* 2014 Jan;57:417-427 [FREE Full text] [doi: [10.1016/j.dss.2012.10.047](https://doi.org/10.1016/j.dss.2012.10.047)]
48. Jin J, Yan X, Li Y, Li Y. How users adopt healthcare information: an empirical study of an online Q&A community. *Int J Med Inform* 2016;86:91-103 [FREE Full text] [doi: [10.1016/j.ijmedinf.2015.11.002](https://doi.org/10.1016/j.ijmedinf.2015.11.002)] [Medline: [26616406](https://pubmed.ncbi.nlm.nih.gov/26616406/)]
49. McKee R. Ethical issues in using social media for health and health care research. *Health Policy* 2013;110(2-3):298-301 [FREE Full text] [doi: [10.1016/j.healthpol.2013.02.006](https://doi.org/10.1016/j.healthpol.2013.02.006)] [Medline: [23477806](https://pubmed.ncbi.nlm.nih.gov/23477806/)]
50. American Psychological Association. APA. Human research protections URL: <http://www.apa.org/research/responsible/human/index.aspx> [accessed 2017-08-28] [WebCite Cache ID 6t3BIXinN]
51. Arseniev-Koehler A, Lee H, McCormick T, Moreno MA. #Proana: pro-eating disorder socialization on Twitter. *J Adolesc Health* 2016;58(6):659-664 [FREE Full text] [doi: [10.1016/j.jadohealth.2016.02.012](https://doi.org/10.1016/j.jadohealth.2016.02.012)] [Medline: [27080731](https://pubmed.ncbi.nlm.nih.gov/27080731/)]
52. Modica RF, Lomax KG, Batzel P, Shapardanis L, Katzer KC, Elder ME. The family journey-to-diagnosis with systemic juvenile idiopathic arthritis: a cross-sectional study of the changing social media presence. *Open Access Rheumatol* 2016;8:61-71 [FREE Full text] [doi: [10.2147/OARRR.S105778](https://doi.org/10.2147/OARRR.S105778)]
53. Ansm.sante.fr. 2014. Analyse des ventes de médicaments en France en 2013 [French] URL: http://ansm.sante.fr/var/ansm_site/storage/original/application/3df7b99f8f4c9ee634a6a9b094624341.pdf [accessed 2017-08-28] [WebCite Cache ID 6t3Bx7OU5]

Abbreviations

API: application program interface
DTM: document-term matrix
HTML: Hyper Text Markup Language
OHCs: online health communities

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Original Paper

The 12-item Self-Report World Health Organization Disability Assessment Schedule (WHODAS) 2.0 Administered Via the Internet to Individuals With Anxiety and Stress Disorders: A Psychometric Investigation Based on Data From Two Clinical Trials

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Abstract

Background: The World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) is a widespread measure of disability and functional impairment, which is bundled with the Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition) for use in psychiatry. Administering psychometric scales via the Internet is an effective way to reach respondents and allow for convenient handling of data.

Objective: The aim was to study the psychometric properties of the 12-item self-report WHODAS 2.0 when administered online to individuals with anxiety and stress disorders. The WHODAS 2.0 was hypothesized to exhibit high internal consistency and be unidimensional. We also expected the WHODAS 2.0 to show high 2-week test-retest reliability, convergent validity (correlations approximately .50 to .90 with other self-report measures of functional impairment), that it would differentiate between patients with and without exhaustion disorder, and that it would respond to change in primary symptom domain.

Methods: We administered the 12-item self-report WHODAS 2.0 online to patients with anxiety and stress disorders (N=160) enrolled in clinical trials of cognitive behavior therapy, and analyzed psychometric properties within a classical test theory framework. Scores were compared with well-established symptom and disability measures, and sensitivity to change was studied from pretreatment to posttreatment assessment.

Results: The 12-item self-report WHODAS 2.0 showed high internal consistency (Cronbach alpha=.83-.92), high 2-week test-retest reliability (intraclass correlation coefficient=.83), adequate construct validity, and was sensitive to change. We found preliminary evidence for a three-factorial structure, but one strong factor accounted for a clear majority of the variance.

Conclusions: We conclude that the 12-item self-report WHODAS 2.0 is a psychometrically sound instrument when administered online to individuals with anxiety and stress disorders, but that it is probably fruitful to also report the three subfactors to facilitate comparisons between studies.

Trial Registration: Clinicaltrials.gov NCT02540317; <https://clinicaltrials.gov/ct2/show/NCT02540317> (Archived by WebCite at <http://www.webcitation.org/6vQEdYAem>); Clinicaltrials.gov NCT02314065; <https://clinicaltrials.gov/ct2/show/NCT02314065> (Archived by WebCite at <http://www.webcitation.org/6vQEjIUU8>)

KEYWORDS

disability; Internet; psychometrics; questionnaire; validity; WHODAS

Introduction

The World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) [1,2] is an assessment tool developed by the World Health Organization (WHO) to measure disability and functional impairment in accordance with the International Classification of Functioning, Disability and Health [3]. The WHODAS 2.0 comes bundled with the *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition; *DSM-5*), and is endorsed as a new and useful measure of functional impairment in psychiatric disorders [4]. The WHODAS 2.0 measures average functioning in everyday situations for the last 30 days, and surveys six domains of functioning: (1) cognition (understanding and communicating), (2) mobility (ability to move and get around), (3) self-care (eg, with regard to hygiene, dressing, and eating) (4) getting along with others, (5) life activities (ability to attend to everyday responsibilities), and (6) participation in society [1]. The most widespread and evaluated form of the WHODAS 2.0 is the 36-item structured interview version, which takes approximately 20 minutes to complete and has excellent psychometric properties [2]. This study, however, concerns the shorter 12-item self-assessment questionnaire version of the WHODAS 2.0. In the WHODAS 2.0 field trials, the reduced 12-item scale, despite only taking approximately 5 minutes to complete, explained 81% of the variance in the 36-item scale [2]. Several large-scale studies have suggested that the 12-item WHODAS 2.0 is a reliable and valid instrument when administered as an interview [5,6] or in a pencil-and-paper format [7,8]. As to dimensionality, both a one-factor structure [6,8] and a second-order model that specifies the six WHODAS 2.0 domains of functioning as subfactors to an overarching disability variable [5,6] have been suggested.

Administering psychometric questionnaires via the Internet is rapidly becoming more common in both research and routine mental care. Compared with conventional pencil-and-paper administration, there are many advantages of this online approach. Respondents can complete the necessary questionnaires wherever an Internet connection is available, and for the clinician or researcher data are quickly and easily stored, scored, analyzed, and interpreted with less risk for human error. Questionnaires are easily integrated with routine care software for evaluation and record keeping, as well as digital monitoring systems and Web-based psychological treatments. Loss of individual item scores may be prevented entirely, time of measurement may be registered and determined by prespecified time schedules, and respondents may be readily contacted via automatic email or text-message reminders. Although it has often been found that well-established scales do well regardless of administration format, online adaptations of validated scales should preferably undergo separate validation [9,10]. There is thus a need for separate validation of the self-rated 12-item WHODAS 2.0 when administered via the Internet and, to the knowledge of the authors, no study has yet

investigated the convergent or discriminant validity, responsiveness, test-retest reliability, or factor structure of the self-rated 12-item WHODAS 2.0 when administered online to individuals with common mental disorders.

Based on data from two clinical trials of cognitive behavior therapy (CBT) for anxiety and stress disorders, we aimed to present estimates of test-retest reliability and thoroughly investigate item score distributions, convergent and discriminant validity, as well as the factor structure of the 12-item online WHODAS 2.0 when administered to individuals with anxiety and stress disorders. We expected the scale to be unidimensional, possibly with the six domains of functioning as subfactors (see previous), and with high internal consistency (Cronbach $\alpha > .80$) as seen in previous studies. We expected strong baseline Pearson correlations (approximately .50 to .90) between the WHODAS 2.0 and other measure of disability or functional impairment, as well as substantial, yet slightly weaker, baseline Pearson correlations (approximately .30 to .70) with the measures of depression and general anxiety. We expected the WHODAS 2.0 to discriminate well between chronic stress patients with and without *International Classification of Diseases, Tenth Revision (ICD-10)* exhaustion disorder, a disorder characterized by burnout-like symptoms including fatigue and cognitive weariness, and typically regarded as highly disabling [11]. We also hypothesized that the WHODAS 2.0 would be sensitive to within-group change in primary psychiatric symptom domain.

Methods

Design

This was a psychometric study of the WHODAS 2.0 administered online to patients with anxiety and stress disorders. Data were collected from clinical trials of CBT for severe health anxiety ($n=60$) and stress disorders ($n=100$) conducted at Karolinska Institutet and Gustavsberg primary care clinic, Stockholm, Sweden. Both trials were approved by the Stockholm regional ethics review board (2015/415-31/5, 2014/1530-31/2), registered at ClinicalTrials.gov (NCT02540317, NCT02314065), and participants provided informed consent. Data used for this study were collected between September 2015 and July 2016.

Recruitment

Both clinical trials employed patient self-referral via the Internet, and advertised in newspapers as well as on online social media networks. Study applicants completed a series of online screening symptom questionnaires before a diagnostic interview with a licensed psychologist. This interview primarily served to survey eligibility criteria and lead up to a decision regarding inclusion or exclusion (ie, this decision was based on the psychiatric interview), but also served to collect important clinical data (eg, comorbid diagnoses). After the pretreatment assessment, which was conducted online, patients underwent

randomization and subsequent treatment. All included patients were at least 18 years of age. The severe health anxiety sample had a principal diagnosis of *DSM-5* somatic symptom disorder or illness anxiety disorder, whereas the stress disorders sample had a principal diagnosis of *DSM-5* adjustment disorder or *ICD-10* exhaustion disorder (for a brief introduction to this disorder, see [11]). We intend to provide an in-depth description of the methods of the clinical trials, including the recruitment process, in the primary publications.

Procedure

All questionnaires were completed through a simple Web-based interface with white background, radio buttons, and checkboxes. All 60 patients in the severe health anxiety sample and 50 patients in the stress disorders trial received CBT (12 weeks, disorder-specific) for their principal disorder. The WHODAS 2.0 was administered before and after CBT. In addition, patients with severe health anxiety completed the WHODAS 2.0 at screening, thus allowing for estimates of test-retest reliability. Other measures used to validate the WHODAS 2.0 were also administered before and after treatment.

Clinical Instruments for Diagnostic Assessment

Both *DSM-5* somatic symptom disorder and illness anxiety disorder were assessed with the Health Preoccupation Diagnostic Interview, which exhibits excellent interrater reliability [12]. Both *ICD-10* exhaustion disorder and *DSM-5* adjustment disorder were assessed with a clinical interview developed specifically for the stress disorders trial that closely followed the diagnostic criteria of *ICD-10* and *DSM-5*. Comorbid psychiatric disorders were surveyed with the Mini-International Neuropsychiatric Interview, which is a reliable and valid instrument for assessing psychiatric disorders [13].

Self-Rated Measures of Functional Impairment

The self-report 12-item WHODAS 2.0 [2] instructs the respondent to determine his or her difficulty in engaging in particular activities (eg, “taking care of [...] household responsibilities” and “maintaining a friendship”), as rated on a scale from “none” (no difficulty) to “extreme or cannot do” and corresponding to six domains of functioning (see Introduction). We employed the WHO simple scoring method [1] that gives a 12-item WHODAS 2.0 score range from 12 to 60, where higher scores indicate higher disability or loss of function. This type of straightforward additive scoring has been shown to correlate strongly ($r > .98$, $p = .999$) with more complex scoring methods incorporating weights based on item response patterns [5,14]. Just like the pencil-and-paper version, the WHODAS 2.0 was presented over two pages with items 1 to 5 on the first page, and items 6 to 12 on the second page.

The Sheehan Disability Scale (SDS) is a well-established three-item measure of psychiatric symptom-related functional impairment with a sum score range from 0 to 30, with a higher score indicating a higher degree of functional impairment [15,16]. The Work Ability Index (WAI) measures work ability with a sum score range from 7 to 49, and higher score indicating higher work ability [17-19]. The SDS and WAI were used as indexes of functional impairment.

Self-Rated Measures of Primary Psychiatric Symptoms

The Health Anxiety Inventory (HAI) is a 64-item questionnaire that measures health anxiety on a scale from 0 to 192, with a higher score indicating more health anxiety [20-22]. The Perceived Stress Scale (PSS) is a 14-item measure of perceived stress with a range from 0 to 56, with a higher score indicating more stress [23]. The HAI and PSS were used to describe the samples in terms of primary symptom domains (ie, health anxiety and stress).

Self-Rated Measures of General Psychiatric Symptoms

The self-reported Montgomery-Åsberg Depression Rating Scale (MADRS-S) is a widely used nine-item questionnaire that measures depressive symptoms on a scale from 0 to 54, with higher scores indicating more symptoms of depression [24-26]. The seven-item Generalized Anxiety Disorder scale (GAD-7) measures general anxiety from 0 to 21, with higher scores indicating more general anxiety [27]. The MADRS-S and GAD-7 were used to assess the common symptom domains of depression and general anxiety and facilitate comparison of the two samples.

Statistical Analysis

Analyses were done in SPSS version 23.0.0.2 (IBM Corp, Armonk, NY, USA) and R 3.3.2 [28] with lavaan 0.5-22 [29]. We pooled the severe health anxiety and stress disorders samples (total $N=160$), dropped three multivariate outliers, and employed structural equation modeling to assess the validity of the simple one-factor model of disability endorsed by the WHO [1], as well as the second-order model fitted in two previous studies [5,6]. The latter had latent variables corresponding both to the six WHODAS 2.0 dimensions of functioning and an overarching latent disability variable. We employed weighted least squares means and variance adjusted estimation, which is adequate for categorical data and nonnormal manifest variables [30]. Based on the recommendations of Byrne [31], we established a priori criteria for acceptable model fit in terms of a comparative fit index (CFI) greater than 0.90, a Tucker-Lewis index (TLI) greater than 0.90, and a root mean square error of approximation (RMSEA) of 0.08 or lower. Post hoc exploratory factor analysis was based on principal axis factoring with promax rotation (ie, factors were assumed to be correlated).

Internal consistency was investigated in terms of Cronbach alpha, complemented by adjusted item-total correlations (ITCs), which are not as strongly affected by the number of scale items. For instruments of typical length, Cronbach alpha $\geq .9$ is usually regarded as excellent, $\geq .8$ as good, and $\geq .7$ as acceptable. Test-retest reliability was estimated based on a two-way mixed-effects model absolute agreement intraclass correlation coefficient (ICC) and data from a subsample ($n=25$) from the severe health anxiety trial that had completed the screening and pretreatment assessments within 14 days (mean 6.8, SD 3.2, range 1-13).

We used an independent samples t test to assess if patients with and without a clinical diagnosis of exhaustion disorder differed with regard to WHODAS 2.0 score, and then performed a receiver operating characteristic analysis to assess the ability (area under the curve [AUC]) of the WHODAS 2.0 to identify

cases of exhaustion disorder. Pearson correlations were used to investigate baseline associations between the WHODAS 2.0 and other self-rated measures.

To evaluate sensitivity to change, we compared pretreatment and posttreatment mean scores using paired samples *t* test and calculated effect sizes as the difference in means at *t*₁ and *t*₂, divided by the *t*₁ standard deviation. Based on the Jacobson and Truax reliable change index [32], we classified patients as either reliably improved (reduction in the HAI>29.9 or reduction in the PSS>7.1) or not reliably improved. As recommended in the assessment of responsiveness, we also further differentiated between reliably improved patients based on whether they improved more than a minimal important difference in their primary symptom domain [33]. In other words, for both samples we estimated change in functional impairment in three strata: (1) patients who did not made a reliable improvement on the HAI or PSS, (2) patients who reliably improved but only to a slight to moderate degree, and (3) patients who reliably improved to a large degree. However, it was necessary to set the threshold for changing more than a minimal important difference relatively high (1.5 SD) due to the precision of the instruments requiring a relatively large score change (1.21 SD in the case of HAI, 1 SD in the case of PSS) for patients to have experienced true change with 95% certainty, as assessed with

the reliable change index [32]. Item-level change was assessed with the Wilcoxon signed-rank test.

The WHODAS 2.0 response rate was 100% for the screening and pretreatment assessments. Because there was a small proportion of missing posttreatment data (for the WHODAS 2.0: 3%, 3/100 in the stress sample; 5%, 3/60 in the severe health anxiety sample), and we did not aim to investigate treatment effects but rather the responsiveness of the scale, data were used on a complete case (not intention-to-treat) basis.

Results

Sample Characteristics

Sample characteristics for the severe health anxiety sample, the stress disorders sample, and the pooled sample are presented in Table 1.

Factor Structure

Neither the one-factor model endorsed by the WHO ($\chi^2_{54}=1699.1$, $P<.001$; CFI=0.29, TLI=0.14, RMSEA=0.44, standardized root mean square residual [SRMR]=0.52) nor the second-order model presented by previous studies achieved acceptable fit ($\chi^2_{48}=132.7$, $P<.001$; CFI=0.96, TLI=0.95, RMSEA=0.11, SRMR=0.09), and we did not see implementing any of the modification indexes as theoretically justifiable.

Table 1. Sample characteristics.

Measure	Severe health anxiety (n=60)	Stress disorders (n=100)	Total (N=160)
Demographics			
Age (years), mean (SD ^a), range	36.4 (11.9), 18-78	46.2 (8.8), 26-65	42.5 (11.1), 18-78
Gender (female), n (%)	40 (67)	85 (85)	125 (78)
Psychiatric symptoms^b			
HAI, mean (SD), range	105.6 (24.7), 51-164	—	—
PSS, mean (SD), range	—	36.8 (7.1), 17-52	—
MADRS-S, mean (SD), range	13.9 (7.4), 1-34	19.7 (7.5), 3-40	17.5 (7.9), 1-40
GAD-7, mean (SD), range	12.0 (5.3), 2-21 ^c	10.8 (4.8), 2-21	11.2 (5.0), 2-21 ^c
MDD, n (%)	11 (18)	13 (13)	24 (15)
≥1 anxiety disorder/OCD ^d , n (%)	34 (57)	19 (19)	53 (33)
Functional impairment^e			
WHODAS 2.0, mean (SD), range	21.1 (6.3), 12-36	24.7 (8.5), 12-51	23.4 (7.9), 12-51
SDS, mean (SD), range	10.4 (6.7), 0-26	—	—
WAI, mean (SD), range	—	33.0 (8.4), 13.0-47.0	—
On sick leave, n (%)	3 (5)	14 (14)	17 (11)

^aSD: standard deviation.

^bHAI: Health Anxiety Inventory; PSS: Perceived Stress Scale; MADRS-S: Montgomery-Åsberg Depression Rating Scale self-report version; GAD-7: Generalized Anxiety Disorder 7-item scale; MDD: major depressive disorder; OCD: obsessive compulsive disorder.

^cGAD-7 data only available from a subsample of the severe health anxiety sample (n=43).

^dAt least one anxiety or obsessive compulsive disorder that is not severe health anxiety.

^eWHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0; SDS: Sheehan Disability Scale; WAI: Work Ability Index.

Table 2. Factor loadings of the WHODAS 2.0^a.

Item	Factor 1: psychosocial ^b	Factor 2: self-care ^b	Factor 3: mobility ^b	A priori dimension ^c
1. Standing long periods	-.008	-.097	.877	Mobility
2. Household responsibilities	.540	-.027	.264	Household
3. Learning new tasks	.740	-.002	.035	Cognitive
4. Joining community activities	.848	-.046	.042	Society
5. Emotionally affected	.652	-.087	.074	Society
6. Concentrating	.683	-.010	-.040	Cognitive
7. Walking long distance	-.003	.329	.597	Mobility
8. Washing whole body	-.068	.893	.132	Self-care
9. Getting dressed	.078	.909	-.126	Self-care
10. Dealing with strangers	.704	.167	-.164	Social
11. Maintaining friendships	.618	.128	-.101	Social
12. Work/school activities	.814	-.059	.037	Household

^aWHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0.

^bFactor loadings (regression coefficients) based on principal axis factoring with promax rotation.

^cCognitive: understanding and communicating; household: life activities; mobility: getting around; social: getting along with others; society: participation in society.

Post hoc exploratory factor analysis (Kaiser-Meyer-Olkin test=0.85, Barlett test<.001) was suggestive of a three-factor solution, with one very strong factor (eigenvalue=5.4, 45.0% of variance explained) and two weak factors (eigenvalues=1.1-1.7, 9.3%-14.2% of variance explained).

After rotation (Table 2) it was clear that one of the two weak factors was primarily associated with items 1 and 7 (“getting around”), and the other weak factor was primarily associated with items 8 and 9 (“self-care”), whereas the strong factor was associated with the remaining items (“understanding and communicating,” “getting along with others,” “life activities,” and “participation in society”). Interfactor correlations were substantial ($r=.40-.46$). Dropping items 1, 7, 8, and 9 had little impact on interindividual sum score variance, and the resulting mean was heavily correlated with the conventional one ($r=.97$). Thus, the factor analysis indicated that a majority of items had high loadings on a general disability factor, but that “mobility” and “self-care” emerged as distinct, but weak, factors.

Item Score Distributions

Parameters related to item score distributions are presented in Table 3. Overall, patients scored low on items that concerned functional impairment in self-care, and higher on items that concerned difficulties participating in society and everyday life activities, as well as items that concerned cognitive impairment. Unlike the summary score, several item distributions were skewed and showed high kurtosis. There was also evidence of a floor effect with regard to several items.

Internal Consistency

Adjusted baseline ITCs are presented in Table 3, where the mean adjusted ITC was 0.60 (SD 0.11). Cronbach alpha values

were good to excellent for both the total sum score and the proposed psychosocial subscale (Table 4).

Test-Retest Reliability

The test-retest reliability of the WHODAS 2.0, based on the severe health anxiety sample data ($n=25$), was estimated at ICC=0.83 (95% CI 0.62-0.92) and the correlation between the measurements was $r=.71$. The test-retest reliability of the proposed psychosocial subscale was similar (ICC=0.85, 95% CI 0.67-0.94; $r=.75$).

Construct Validity: Associations With Other Measures

In the stress disorders sample, patients with a principal diagnosis of exhaustion disorder had a significantly higher WHODAS 2.0 mean score than those who had a principal diagnosis of adjustment disorder (mean difference 8.84, 95% CI 5.96-11.72; $t_{98}=6.10$, $P<.001$), and the WHODAS 2.0 discriminated well between stress patients with and without exhaustion disorder (AUC=0.81, 95% CI 0.73-0.89; $P<.001$). The proposed psychosocial subscale fared about as well (AUC=0.79, 95% CI 0.70-0.87; $P<.001$). Baseline correlations between the WHODAS 2.0 as well as the subscale and other self-assessment questionnaires are shown in Table 5.

Sensitivity to Change

Effect sizes and tests pertaining to responsiveness are presented in Table 6. Wilcoxon signed-rank tests showed that all but one WHODAS 2.0 item (item 9, related to self-care) changed in the severe health anxiety sample, whereas 9 of 12 items changed (but not items 1, 8, or 9—one mobility and both self-care items) in the stress disorders sample.

Table 3. Web-based self-report 12-item WHODAS 2.0 item scores^a.

Item and subscale	Mean (SD) ^b	Median (range)	Floor	Ceiling	Skew	Kurtosis	ITC ^c
Item							
1. Standing long periods	1.54 (0.89)	1 (1-4)	66%	0%	1.58	1.47	0.44
2. Household responsibilities	2.07 (1.02)	2 (1-4)	38%	0%	0.47	-1.00	0.64
3. Learning new tasks	1.87 (1.02)	2 (1-5)	49%	1%	0.85	-0.37	0.70
4. Joining community activities	2.23 (1.19)	2 (1-5)	38%	4%	0.55	-0.77	0.78
5. Emotionally affected	3.21 (1.14)	4 (1-5)	13%	6%	-0.69	-0.60	0.59
6. Concentrating	2.37 (1.05)	2 (1-5)	26%	1%	0.17	-0.90	0.61
7. Walking long distance	1.51 (0.82)	1 (1-5)	66%	1%	1.63	2.29	0.52
8. Washing whole body	1.20 (0.55)	1 (1-4)	86%	0%	3.12	10.22	0.48
9. Getting dressed	1.16 (0.47)	1 (1-4)	88%	0%	3.44	12.87	0.48
10. Dealing with strangers	1.83 (1.01)	2 (1-5)	49%	1%	1.10	0.43	0.66
11. Maintaining friendships	1.85 (1.07)	1 (1-5)	53%	1%	0.97	-0.17	0.59
12. Work/school activities	2.54 (1.20)	3 (1-5)	25%	6%	0.27	-0.88	0.75
Total score	23.37 (7.91)	23 (12-51)	8%	0%	0.68	0.52	—
Subscale							
Psychosocial	12.60 (4.70)	12.76 (5.60-24.84)	8%	0%	0.31	-0.49	—
Self-care	2.12 (0.86)	1.80 (1.80-7.21)	84%	0%	3.20	11.23	—
Mobility	2.25 (1.15)	1.47 (1.47-6.49)	56%	0%	1.56	1.76	—

^aWHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0. Based on baseline data from two clinical trials of severe health anxiety and stress disorders (total N=160, items scored from 1 to 5).

^bSD: standard deviation.

^cITC: adjusted item-total correlation.

Table 4. Web-based self-report 12-item WHODAS 2.0^a internal consistency.

Sample	Screening		Pretreatment		Posttreatment	
	Cronbach alpha	n	Cronbach alpha	n	Cronbach alpha	n
Total score						
Severe health anxiety	.83	60	.86	60	.87	56
Stress disorder	—	—	.90	100	.92	97
Psychosocial subscale^b						
Severe health anxiety	.82	60	.88	60	.87	56
Stress disorder	—	—	.89	100	.91	97

^aWHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0.

^bPsychosocial subscale with regression weights applied.

Table 5. WHODAS 2.0 associations (bivariate Pearson correlations) with other self-rated questionnaires^a.

	WHODAS 2.0 ^b	Psychosocial subscale	MADRS-S ^b	GAD-7 ^b	SDS ^b
WHODAS 2.0	—	.96 ^c	.60 ^c	.58 ^{c,d}	.66 ^c
Psychosocial subscale	.97 ^e	—	.65 ^c	.54 ^{c,d}	.67 ^c
MADRS-S	.65 ^e	.64 ^e	—	.54 ^{c,d}	.59 ^c
GAD-7	.45 ^e	.45 ^e	.71 ^e	—	.40 ^c
WAI	-.71 ^e	-.71 ^e	-.55 ^e	-.28 ^e	—

^aAll bivariate Pearson correlations significant at $\alpha=.05$.

^bWHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0; MADRS-S: Montgomery-Åsberg Depression Rating Scale-self-report version; GAD-7: Generalized Anxiety Disorder 7-item scale; SDS: Sheehan Disability Scale; WAI: Work Ability Index.

^cSevere health anxiety sample (n=60).

^dGAD-7 data only available from a subsample of the severe health anxiety sample (n=43).

^eStress disorder sample (n=100).

Table 6. Responsiveness stratified by change in primary symptom domain^a.

Change in primary symptom domain ^b	n (%)	ES ^c	Mean change (95% CI)	P ^d
Severe health anxiety sample				
HAI reliably improved >1.5 SD^e	32 (5)			
WHODAS 2.0		1.21	7.19 (5.17, 9.22)	<.001
SDS		1.00	7.28 (4.59, 9.98)	<.001
HAI reliably improved ≤1.5 SD	8 (14)			
WHODAS 2.0		0.52	2.75 (-0.85, 6.35)	.11
SDS		0.53	1.88 (-1.07, 4.82)	.18
HAI not reliably improved	18 (31)			
WHODAS 2.0		0.29	2.00 (-0.13, 4.13)	.06
SDS		0.22	1.39 (-0.59, 3.37)	.16
Stress disorder sample				
PSS reliably improved >1.5 SD	33 (34)			
WHODAS 2.0		0.80	6.42 (4.27, 8.58)	<.001
WAI		-0.49	-4.14 (-5.75, -2.52)	<.001
PSS reliably improved ≤1.5 SD	12 (12)			
WHODAS 2.0		0.39	2.83 (0.09, 5.58)	.04
WAI		-0.25	-2.29 (-5.10, 0.51)	.10
PSS not reliably improved	52 (54)			
WHODAS 2.0		0.19	1.75 (-0.10, 3.60)	.06
WAI		-0.13	-0.96 (-2.66, 0.73)	.26

^aAll estimates based on data from patients that completed the posttreatment assessment. Status as improved or not improved based on the Jacobson and Truax reliable change index [32].

^bHAI: Health Anxiety Inventory; WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0; SDS: Sheehan Disability Scale; PSS: Perceived Stress Scale; WAI: Work Ability Index.

^cStandardized effect sizes (ES) are calculated with the stratum-specific pretreatment standard deviation as nominator.

^dP values based on paired samples *t* test.

^eSD: standard deviation.

Discussion

Summary of Principal Results

To our knowledge, this was the first in-depth analysis of the reliability and validity of the self-rated 12-item WHODAS 2.0 when administered online to patients with anxiety and stress disorders. In line with our hypotheses, the WHODAS 2.0 exhibited high internal consistency, acceptable test-retest reliability, and was demonstrated to identify cases of exhaustion disorder. As expected, the WHODAS 2.0 also showed substantial associations with other measures of functioning, as well as slightly weaker but yet substantial associations with primary symptom measures. The instrument was sensitive to change in the primary psychiatric symptom domain, as illustrated by a convincing gradient in change effect size over the nonimproved versus slightly improved versus much improved strata (Table 6). It might be noted that there was no significant change in WHODAS 2.0 for the minimally changed severe health anxiety group, but this is not surprising given the very small size of this subsample ($n=8$). Taken together, our findings suggest that the self-rated 12-item online WHODAS 2.0—when administered to individuals with anxiety and stress disorders—is a valid measure of disability and functional impairment. The results are important because online administration facilitates handling of data in a wide range of research and routine care settings. Key strengths of this study are that two psychiatric samples with different primary conditions could be examined, that other scales could be used to validate the WHODAS 2.0 scores in both samples, and that the ability of the WHODAS 2.0 to identify patients with a clinical diagnosis of exhaustion disorder could be investigated in the stress disorders sample.

Factor Structure

Regarding factor structure, we could neither confirm the expected one-factor WHO solution nor the second-order model put forward by previous investigators [5,6]. A post hoc model derived from exploratory analysis saw most items loading heavily ($>.5$) on one strong factor, and four items (8, 9, 1, and 7) loading heavily on two other factors. The results are somewhat similar to those seen with the WHODAS 2.0 administered to individuals with musculoskeletal pain [34], and suggests that items 8 and 9 (“self-care”), as well as items 1 and 7 (“getting around”), largely tap into sources of variance other than that responsible for most of the sum score (see Table 3). Our subjective impression is that these four items seem more related to physical incapacity than the rest of the scale. Because (1) these items showed apparent evidence of a floor effect (their median sum being zero), (2) the sum score primarily relied on another very strong factor, and (3) the interfactor correlations were moderately strong, the impact of multidimensionality is likely to be very small in the study of change in otherwise healthy samples with anxiety or stress disorders. On the other hand, the interfactorial correlations were small enough to complicate direct comparisons of scores between studies. Especially when anxiety or stress disorder samples differ in terms of somatic comorbidity, it is probably informative to compare the “getting around” and “self-care” subdomains separately. That is, based on the results of this study our tentative

recommendation would be for studies on anxiety and stress disorders to report both the self-rated 12-item WHODAS 2.0 sum score, as well as the three subfactors, here referred to as “psychosocial,” “self-care,” and “getting around” (Table 2). However, we wish to emphasize that this factor solution was solely based on an explorative analysis, that the second-order model with six subfactors [5,6] was not far off the mark, and that additional confirmatory factor analyses based on data from similar samples are warranted to arrive at more firm conclusions.

Score Distribution

On an item level, the most striking aspect of the score distribution was that both items 8 and 9 (ie, the “self-care” items) had a mode score of 1 and appeared to pick up on very little variance in the two samples. This may suggest that individuals with a principal diagnosis of severe health anxiety or a stress disorder are typically not much impaired in terms of ability to carry out everyday self-care tasks such as washing oneself or getting dressed.

Internal Consistency and Test-Retest Reliability

Although the internal consistency and test-retest reliability estimates were in line with our expectations, and also fulfilled commonly accepted quality criteria for health status questionnaires [35], it is conceivable that the estimates of test-retest reliability were deflated because a psychiatric interview and the decision to include patients in a clinical trial took place between the screening and pretreatment measurements. However, the means from these two measurement points were not significantly different ($t_{59}=1.55$, $P=.13$), which for example speaks against patients having altered their responses so as to be included in one of the trials.

Convergent Validity and Sensitivity to Change

In this study, correlations with other measures of psychiatric symptoms and functional impairment corroborate the construct validity of the self-rated 12-item WHODAS 2.0. As this study was based on data from two clinical trials, we do not find it unfit or surprising that the WHODAS 2.0 was highly correlated with measures of anxiety and depression which were likely to be the primary reasons for functional impairment.

Due to the limited sample size and variability in the size of substrata (nonchanged vs minimally changed vs much changed) we wish to emphasize that the significance tests pertaining to change (Table 6) are of limited value, and emphasize that all P values ought to be interpreted alongside their corresponding effect sizes. Over and above the effect size gradient over the nonchanged versus minimally changed versus much changed strata, a general trend was also that the 12-item WHODAS 2.0 changed slightly more from pretreatment to posttreatment than the WAI. This may suggest that the WHODAS 2.0 covers dimensions of functional impairment that, compared to work ability, are more likely to change in a clinical trial of CBT for chronic stress disorders.

Limitations

The primary limitation of this study is that over and above clinical diagnoses we did not have access to “hard” measures of functional impairment, collected by other means than

self-assessment (eg, register data on disability status) that could be used to validate the WHODAS 2.0. One consequence of this is that all indexes of change were to some degree susceptible to social desirability bias or the possibility that patients reported change so as to please their therapist rather than as a consequence of real change in symptoms or disability. However, it has been demonstrated that Web-based survey administration is relatively robust to desirability bias [36], and all scales used to validate the WHODAS 2.0 (ie, the HAI, PSS, MADRS-S, GAD-7, SDS, and WAI) have, at least in conventional form, been shown to be associated with non-self-reported validators such as clinical diagnoses, sick leave, and health care consumption (eg, [16,37-41]).

We also had no control over what equipment the patients used to access the Web-based WHODAS 2.0, meaning we could not determine the significance of filling in the questionnaire via a mobile phone app rather than a conventional browser on a desktop computer, for example. The results showing good psychometric properties of the WHODAS 2.0 also suggest that there was no substantial measurement error related to the type of device used. Another threat to the generalizability of our

findings is that the two samples were relatively homogenous due to the eligibility criteria for the two clinical trials, which were not primarily designed to study the psychometric properties of the WHODAS 2.0. Therefore, it is preferable to validate the findings of this study, particularly with regard to factor structure, in anxiety and stress disorder samples recruited through other means.

Comparison With Prior Work

The item mean score profile seen in this study—with substantial functional impairment in the “understanding and communicating,” “life activities,” and “getting along with others” domains but very low functional impairment in the “self-care” domain—is highly similar to the item mean score profile seen in studies of interview and pencil-and-paper versions of the WHODAS 2.0 administered to individuals with common mental disorders [8,14]. This suggests that the response pattern does not change much due to the online format.

Before this study, the 12-item WHODAS 2.0 had also been administered online to individuals with common anxiety, stress, and mood disorders in several clinical trials (Table 7, see Multimedia Appendices 1 and 2 for details).

Table 7. Previous studies that have administered the 12-item self-report WHODAS 2.0 online to respondents with common mental disorders^a.

Author (year)	N	Diagnosis ^b	Mean			Cronbach alpha	WHODAS 2.0 ^c change over time?
			12-60 scale ^d	0-48 scale ^d	0-100 scale ^d		
Allen et al (2016) [42]	63	PD	26.0	14.0	29.2	.89	Yes
Andrews et al (2011) [43]	37	SAD	26.6	14.6	30.4	—	Yes
Mason & Andrews (2014) [44]	173 ^e	Mixed CMD	25.0	13.0	27.1	—	Yes
Mewton et al (2012) [45]	588	GAD	25.7	13.7	28.5	.90	Yes
Newby et al (2016a) [46]	2109	Mixed CMD	26.3	14.3	29.8	>.88	Yes
Newby et al (2016b) [47]	16	SHA	20.3	8.3	17.3	.83	Yes
Perini et al (2008) [48]	13	MDD	— ^f	— ^f	— ^f	—	Yes
Spence et al (2011) [49]	244	PTSD	32.1	20.1	41.9	.92	—
Titov et al (2008a) [50]	105	SAD	26.3	14.3	29.8	—	Yes
Titov et al (2008b) [51]	88	SAD	25.0	13.0	27.1	—	Yes
Williams et al (2013) [52]	69	MDD	41.2	29.2	60.8	—	Yes
Williams et al (2014) [53]	560	SAD	39.3	27.3	56.9	—	Yes
Williams et al (2015) [54]	75	MDD	44.8	32.8	68.3	.83	Yes
Wootton et al (2011) [55]	118	OCD	30.4	18.4	38.3	.91	—

^aInformation from articles complemented by personal communication via email.

^bPD: panic disorder; SAD: social anxiety disorder; CMD: common mental disorder; GAD: generalized anxiety disorder; SHA: severe health anxiety; MDD: major depressive disorder; PTSD: posttraumatic stress disorder; OCD: obsessive compulsive disorder; . See Multimedia Appendices 1 and 2 for details.

^cWHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0.

^dThe 12-60 scale has items scored 1-5, the 0-48 scale has items scored 0-4, and the 0-100 scale is the 0-48 scale divided by 48 and then multiplied by 100.

^eAnother sample (n=135) in this study completed the WHODAS 2.0 on a computer, but not via the Internet.

^fUnknown; author could not be reached.

Although the primary aim of these trials was not to study the psychometric properties of the WHODAS 2.0, these studies presented estimates of both internal consistency (Cronbach $\alpha \geq .83$) and baseline mean scores that are very much in line with data in this trial, and thus lend further support to the validity and generalizability of our findings.

Conclusions

This is, to date, the most extensive investigation into the psychometric properties of the self-rated 12-item version of the WHODAS 2.0 when administered via the Internet to individuals

with anxiety and stress disorders. When administered online to individuals with anxiety and stress disorders, the WHODAS 2.0 exhibits high internal consistency, high convergent validity, adequate test-retest reliability, and is sensitive to change. We conclude that the psychometric properties of the self-rated 12-item version of the WHODAS 2.0 are acceptable when the instrument is administered via the Internet to individuals with anxiety and stress disorders, but suggest that the three subfactors found in this study be reported alongside the sum score to facilitate comparisons between studies.

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Authors' Contributions

All authors made significant contributions to the planning, recruitment, execution, analysis, and publication of this study.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy and data collection for brief review.

[[PDF File \(Adobe PDF File\), 110KB - mental_v4i4e58_app1.pdf](#)]

Multimedia Appendix 2

Flowchart illustrating study selection process for brief review.

[[PNG File, 43KB - mental_v4i4e58_app2.png](#)]

References

1. Üstün TB, Kostanjsek N, Chatterji S, Rehm J, editors. Measuring Health and Disability: Manual for WHO Disability Assessment Schedule (WHODAS 2.0). Malta: World Health Organization; 2010.
2. Üstün TB, Chatterji S, Kostanjsek N, Rehm J, Kennedy C, Epping-Jordan J, World Health Organization, National Institutes of Health. Developing the World Health Organization Disability Assessment Schedule 2.0. Bull World Health Organ 2010 Nov 1;88(11):815-823 [[FREE Full text](#)] [doi: [10.2471/BLT.09.067231](#)] [Medline: [21076562](#)]
3. World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: World Health Organization; 2001.
4. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. Arlington, VA: American Psychiatric Association; 2013.
5. Andrews G, Kemp A, Sunderland M, Von KM, Ustun TB. Normative data for the 12 item WHO Disability Assessment Schedule 2.0. PLoS One 2009 Dec;4(12):e8343 [[FREE Full text](#)] [doi: [10.1371/journal.pone.0008343](#)] [Medline: [20020047](#)]
6. Weeks M, Garber BG, Zamorski MA. Disability and mental disorders in the Canadian Armed Forces. Can J Psychiatry 2016 Apr;61(1 Suppl):56S-63S [[FREE Full text](#)] [doi: [10.1177/0706743716628853](#)] [Medline: [27270743](#)]
7. McEvoy PM, Mahoney AE. Achieving certainty about the structure of intolerance of uncertainty in a treatment-seeking sample with anxiety and depression. J Anxiety Disord 2011 Jan;25(1):112-122. [doi: [10.1016/j.janxdis.2010.08.010](#)] [Medline: [20828984](#)]
8. Luciano JV, Ayuso-Mateos JL, Fernández A, Serrano-Blanco A, Roca M, Haro JM. Psychometric properties of the twelve item World Health Organization Disability Assessment Schedule II (WHO-DAS II) in Spanish primary care patients with a first major depressive episode. J Affect Disord 2010 Feb;121(1-2):52-58. [doi: [10.1016/j.jad.2009.05.008](#)] [Medline: [19464735](#)]
9. Buchanan T. Internet-based questionnaire assessment: appropriate use in clinical contexts. Cogn Behav Ther 2003;32(3):100-109. [doi: [10.1080/16506070310000957](#)] [Medline: [16291542](#)]

10. Gosling SD, Vazire S, Srivastava S, John OP. Should we trust web-based studies? A comparative analysis of six preconceptions about internet questionnaires. *Am Psychol* 2004 Mar;59(2):93-104. [doi: [10.1037/0003-066X.59.2.93](https://doi.org/10.1037/0003-066X.59.2.93)] [Medline: [14992636](https://pubmed.ncbi.nlm.nih.gov/14992636/)]
11. Grossi G, Perski A, Osika W, Savic I. Stress-related exhaustion disorder - clinical manifestation of burnout? A review of assessment methods, sleep impairments, cognitive disturbances, and neuro-biological and physiological changes in clinical burnout. *Scand J Psychol* 2015 Dec;56(6):626-636. [doi: [10.1111/sjop.12251](https://doi.org/10.1111/sjop.12251)] [Medline: [26496458](https://pubmed.ncbi.nlm.nih.gov/26496458/)]
12. Axelsson E, Andersson E, Ljótsson B, Wallhed Finn D, Hedman E. The health preoccupation diagnostic interview: inter-rater reliability of a structured interview for diagnostic assessment of DSM-5 somatic symptom disorder and illness anxiety disorder. *Cogn Behav Ther* 2016 Jun;45(4):259-269. [doi: [10.1080/16506073.2016.1161663](https://doi.org/10.1080/16506073.2016.1161663)] [Medline: [27096407](https://pubmed.ncbi.nlm.nih.gov/27096407/)]
13. Sheehan DV, Lecrubier Y, Sheehan KH, Amorim P, Janavs J, Weiller E, et al. The Mini-International Neuropsychiatric Interview (M.I.N.I.): the development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. *J Clin Psychiatry* 1998;59 Suppl 20:22-33;quiz 34. [Medline: [9881538](https://pubmed.ncbi.nlm.nih.gov/9881538/)]
14. Sjonnesen K, Bulloch AG, Williams J, Lavorato D. Characterization of disability in Canadians with mental disorders using an abbreviated version of a DSM-5 emerging measure: the 12-Item WHO Disability Assessment Schedule (WHODAS) 2.0. *Can J Psychiatry* 2016 Apr;61(4):227-235 [FREE Full text] [doi: [10.1177/0706743716632514](https://doi.org/10.1177/0706743716632514)] [Medline: [27254415](https://pubmed.ncbi.nlm.nih.gov/27254415/)]
15. Leon AC, Shear MK, Portera L, Klerman GL. Assessing impairment in patients with panic disorder: the Sheehan Disability Scale. *Soc Psychiatry Psychiatr Epidemiol* 1992 Mar;27(2):78-82. [doi: [10.1007/bf00788510](https://doi.org/10.1007/bf00788510)] [Medline: [1594977](https://pubmed.ncbi.nlm.nih.gov/1594977/)]
16. Leon AC, Olsson M, Portera L, Farber L, Sheehan DV. Assessing psychiatric impairment in primary care with the Sheehan Disability Scale. *Int J Psychiatry Med* 1997;27(2):93-105. [doi: [10.2190/t8em-c8yh-373n-luwd](https://doi.org/10.2190/t8em-c8yh-373n-luwd)] [Medline: [9565717](https://pubmed.ncbi.nlm.nih.gov/9565717/)]
17. De Zwart BC, Frings-Dresen MH, van Duivenbooden JC. Test-retest reliability of the Work Ability Index questionnaire. *Occup Med (Lond)* 2002 Jun;52(4):177-181. [doi: [10.1093/occmed/52.4.177](https://doi.org/10.1093/occmed/52.4.177)] [Medline: [12091582](https://pubmed.ncbi.nlm.nih.gov/12091582/)]
18. Radkiewicz P, Widerszal-Bazyl M, NEXT-Study Group. Psychometric properties of Work Ability Index in the light of comparative survey study. : Elsevier; 2005 Presented at: 2nd International Symposium on Work Ability; Oct 18-20, 2004; Verona, Italy.
19. Ilmarinen J. The Work Ability Index (WAI). *Occup Med* 2007 Mar 01;57(2):160. [doi: [10.1093/occmed/kqm008](https://doi.org/10.1093/occmed/kqm008)]
20. Salkovskis PM, Rimes KA, Warwick HMC, Clark DM. The Health Anxiety Inventory: development and validation of scales for the measurement of health anxiety and hypochondriasis. *Psychol Med* 2002 Jul;32(5):843-853. [doi: [10.1017/S0033291702005822](https://doi.org/10.1017/S0033291702005822)] [Medline: [12171378](https://pubmed.ncbi.nlm.nih.gov/12171378/)]
21. Hedman E, Ljótsson B, Andersson E, Andersson G, Lindefors N, Rück C, et al. Psychometric properties of Internet-administered measures of health anxiety: an investigation of the Health Anxiety Inventory, the Illness Attitude Scales, and the Whiteley Index. *J Anxiety Disord* 2015 Apr;31:32-37. [doi: [10.1016/j.janxdis.2015.01.008](https://doi.org/10.1016/j.janxdis.2015.01.008)] [Medline: [25723780](https://pubmed.ncbi.nlm.nih.gov/25723780/)]
22. Hedman E, Lekander M, Ljótsson B, Lindefors N, Rück C, Andersson G, et al. Optimal cut-off points on the health anxiety inventory, illness attitude scales and whiteley index to identify severe health anxiety. *PLoS One* 2015;10(4):e0123412 [FREE Full text] [doi: [10.1371/journal.pone.0123412](https://doi.org/10.1371/journal.pone.0123412)] [Medline: [25849477](https://pubmed.ncbi.nlm.nih.gov/25849477/)]
23. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *J Health Soc Behav* 1983 Dec;24(4):385-396. [doi: [10.2307/2136404](https://doi.org/10.2307/2136404)] [Medline: [6668417](https://pubmed.ncbi.nlm.nih.gov/6668417/)]
24. Svanborg P, Åsberg M. A new self-rating scale for depression and anxiety states based on the Comprehensive Psychopathological Rating Scale. *Acta Psychiatr Scand* 1994 Jan;89(1):21-28. [doi: [10.1111/j.1600-0447.1994.tb01480.x](https://doi.org/10.1111/j.1600-0447.1994.tb01480.x)] [Medline: [8140903](https://pubmed.ncbi.nlm.nih.gov/8140903/)]
25. Svanborg P, Åsberg M. A comparison between the Beck Depression Inventory (BDI) and the self-rating version of the Montgomery Asberg Depression Rating Scale (MADRS). *J Affect Disord* 2001 May;64(2-3):203-216. [doi: [10.1016/s0165-0327\(00\)00242-1](https://doi.org/10.1016/s0165-0327(00)00242-1)] [Medline: [11313087](https://pubmed.ncbi.nlm.nih.gov/11313087/)]
26. Carlbring P, Brunt S, Bohman S, Austin D, Richards J, Öst LG, et al. Internet vs. paper and pencil administration of questionnaires commonly used in panic/agoraphobia research. *Comput Hum Behav* 2007 May;23(3):1421-1434. [doi: [10.1016/j.chb.2005.05.002](https://doi.org/10.1016/j.chb.2005.05.002)]
27. Spitzer RL, Kroenke K, Williams JB, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med* 2006 May 22;166(10):1092-1097. [doi: [10.1001/archinte.166.10.1092](https://doi.org/10.1001/archinte.166.10.1092)] [Medline: [16717171](https://pubmed.ncbi.nlm.nih.gov/16717171/)]
28. R Core Team. R: A Language and Environment for Statistical Computing. Vienna, Austria: R Foundation for Statistical Computing; 2016. URL: <https://www.r-project.org/> [accessed 2017-11-23] [WebCite Cache ID 6vBnUZfhs]
29. Rosseel Y. lavaan: an R package for structural equation modeling. *J Stat Softw* 2012;48(2):1-36. [doi: [10.18637/jss.v048.i02](https://doi.org/10.18637/jss.v048.i02)]
30. Li C. Confirmatory factor analysis with ordinal data: comparing robust maximum likelihood and diagonally weighted least squares. *Behav Res Methods* 2016 Sep;48(3):936-949. [doi: [10.3758/s13428-015-0619-7](https://doi.org/10.3758/s13428-015-0619-7)] [Medline: [26174714](https://pubmed.ncbi.nlm.nih.gov/26174714/)]
31. Byrne BM. Structural Equation Modeling with AMOS: Basic Concepts, Applications and Programming. Mahwah, NJ: Lawrence Erlbaum Associates; 2001.
32. Jacobson NS, Truax P. Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. *J Consult Clin Psychol* 1991 Feb;59(1):12-19. [doi: [10.1037/0022-006x.59.1.12](https://doi.org/10.1037/0022-006x.59.1.12)] [Medline: [2002127](https://pubmed.ncbi.nlm.nih.gov/2002127/)]

33. Revicki D, Hays RD, Cella D, Sloan J. Recommended methods for determining responsiveness and minimally important differences for patient-reported outcomes. *J Clin Epidemiol* 2008 Feb;61(2):102-109. [doi: [10.1016/j.jclinepi.2007.03.012](https://doi.org/10.1016/j.jclinepi.2007.03.012)] [Medline: [18177782](https://pubmed.ncbi.nlm.nih.gov/18177782/)]
34. Saltychev M, Mattie R, McCormick Z, Laimi K. Confirmatory factor analysis of 12-Item World Health Organization Disability Assessment Schedule in patients with musculoskeletal pain conditions. *Clin Rehabil* 2017 May;31(5):702-709. [doi: [10.1177/0269215516652930](https://doi.org/10.1177/0269215516652930)] [Medline: [27260763](https://pubmed.ncbi.nlm.nih.gov/27260763/)]
35. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol* 2007 Jan;60(1):34-42. [doi: [10.1016/j.jclinepi.2006.03.012](https://doi.org/10.1016/j.jclinepi.2006.03.012)] [Medline: [17161752](https://pubmed.ncbi.nlm.nih.gov/17161752/)]
36. Kreuter F, Presser S, Tourangeau R. Social desirability bias in CATI, IVR, and web surveys: the effects of mode and question sensitivity. *Public Opinion Quarterly* 2009 Jan 26;72(5):847-865. [doi: [10.1093/poq/nfn063](https://doi.org/10.1093/poq/nfn063)]
37. Eklund M, Bäckström M, Tuveusson H. Psychometric properties and factor structure of the Swedish version of the Perceived Stress Scale. *Nord J Psychiatry* 2014 Oct;68(7):494-499. [doi: [10.3109/08039488.2013.877072](https://doi.org/10.3109/08039488.2013.877072)] [Medline: [24460116](https://pubmed.ncbi.nlm.nih.gov/24460116/)]
38. Seivewright H, Salkovskis P, Green J, Mullan N, Behr G, Carlin E, et al. Prevalence and service implications of health anxiety in genitourinary medicine clinics. *Int J STD AIDS* 2004 Aug;15(8):519-522. [doi: [10.1258/0956462041558122](https://doi.org/10.1258/0956462041558122)] [Medline: [15307961](https://pubmed.ncbi.nlm.nih.gov/15307961/)]
39. Ericsson M, Poston II WS, Linder J, Taylor JE, Haddock CK, Foreyt JP. Depression predicts disability in long-term chronic pain patients. *Disabil Rehabil* 2002 Apr 15;24(6):334-340. [doi: [10.1080/09638280110096241](https://doi.org/10.1080/09638280110096241)] [Medline: [12017467](https://pubmed.ncbi.nlm.nih.gov/12017467/)]
40. Kroenke K, Spitzer RL, Williams JB, Löwe B. The Patient Health Questionnaire Somatic, Anxiety, and Depressive Symptom Scales: a systematic review. *Gen Hosp Psychiatry* 2010;32(4):345-359. [doi: [10.1016/j.genhosppsych.2010.03.006](https://doi.org/10.1016/j.genhosppsych.2010.03.006)] [Medline: [20633738](https://pubmed.ncbi.nlm.nih.gov/20633738/)]
41. van Den Berg TI, Elders LA, de Zwart BC, Burdorf A. The effects of work-related and individual factors on the Work Ability Index: a systematic review. *Occup Environ Med* 2009 Apr;66(4):211-220. [doi: [10.1136/oem.2008.039883](https://doi.org/10.1136/oem.2008.039883)] [Medline: [19017690](https://pubmed.ncbi.nlm.nih.gov/19017690/)]
42. Allen AR, Newby JM, Mackenzie A, Smith J, Boulton M, Loughnan SA, et al. Internet cognitive-behavioural treatment for panic disorder: randomised controlled trial and evidence of effectiveness in primary care. *BJPsych Open* 2016 Mar;2(2):154-162 [FREE Full text] [doi: [10.1192/bjpo.bp.115.001826](https://doi.org/10.1192/bjpo.bp.115.001826)] [Medline: [27703768](https://pubmed.ncbi.nlm.nih.gov/27703768/)]
43. Andrews G, Davies M, Titov N. Effectiveness randomized controlled trial of face to face versus Internet cognitive behaviour therapy for social phobia. *Aust N Z J Psychiatry* 2011 Apr;45(4):337-340. [doi: [10.3109/00048674.2010.538840](https://doi.org/10.3109/00048674.2010.538840)] [Medline: [21323490](https://pubmed.ncbi.nlm.nih.gov/21323490/)]
44. Mason EC, Andrews G. The use of automated assessments in internet-based CBT: the computer will be with you shortly. *Internet Interv* 2014 Oct;1(4):216-224. [doi: [10.1016/j.invent.2014.10.003](https://doi.org/10.1016/j.invent.2014.10.003)]
45. Mewton L, Wong N, Andrews G. The effectiveness of internet cognitive behavioural therapy for generalized anxiety disorder in clinical practice. *Depress Anxiety* 2012 Oct;29(10):843-849. [doi: [10.1002/da.21995](https://doi.org/10.1002/da.21995)] [Medline: [22949296](https://pubmed.ncbi.nlm.nih.gov/22949296/)]
46. Newby JM, Mewton L, Andrews G. Transdiagnostic versus disorder-specific internet-delivered cognitive behaviour therapy for anxiety and depression in primary care. *J Anxiety Disord* 2017 Mar;46:25-34. [doi: [10.1016/j.janxdis.2016.06.002](https://doi.org/10.1016/j.janxdis.2016.06.002)] [Medline: [27396841](https://pubmed.ncbi.nlm.nih.gov/27396841/)]
47. Newby JM, Mahoney AE, Mason EC, Smith J, Uppal S, Andrews G. Pilot trial of a therapist-supported internet-delivered cognitive behavioural therapy program for health anxiety. *Internet Interv* 2016 Nov;6:71-79. [doi: [10.1016/j.invent.2016.09.007](https://doi.org/10.1016/j.invent.2016.09.007)]
48. Perini S, Titov N, Andrews G. The Climate Sadness program of Internet-based treatment for depression: a pilot study. *EJAP* 2008 Dec 23;4(2):18-24. [doi: [10.7790/ejap.v4i2.135](https://doi.org/10.7790/ejap.v4i2.135)]
49. Spence J, Titov N, Solley K, Dear BF, Johnston L, Wootton B, et al. Characteristics and treatment preferences of people with symptoms of posttraumatic stress disorder: an internet survey. *PLoS One* 2011;6(7):e21864 [FREE Full text] [doi: [10.1371/journal.pone.0021864](https://doi.org/10.1371/journal.pone.0021864)] [Medline: [21818274](https://pubmed.ncbi.nlm.nih.gov/21818274/)]
50. Titov N, Andrews G, Schwencke G, Drobny J, Einstein D. Shyness 1: distance treatment of social phobia over the Internet. *Aust N Z J Psychiatry* 2008 Jul;42(7):585-594. [doi: [10.1080/00048670802119762](https://doi.org/10.1080/00048670802119762)] [Medline: [18612862](https://pubmed.ncbi.nlm.nih.gov/18612862/)]
51. Titov N, Andrews G, Schwencke G. Shyness 2: treating social phobia online: replication and extension. *Aust N Z J Psychiatry* 2008 Jul;42(7):595-605. [doi: [10.1080/00048670802119820](https://doi.org/10.1080/00048670802119820)] [Medline: [18612863](https://pubmed.ncbi.nlm.nih.gov/18612863/)]
52. Williams AD, Blackwell SE, Mackenzie A, Holmes EA, Andrews G. Combining imagination and reason in the treatment of depression: a randomized controlled trial of internet-based cognitive-bias modification and internet-CBT for depression. *J Consult Clin Psychol* 2013 Oct;81(5):793-799 [FREE Full text] [doi: [10.1037/a0033247](https://doi.org/10.1037/a0033247)] [Medline: [23750459](https://pubmed.ncbi.nlm.nih.gov/23750459/)]
53. Williams AD, O'Moore K, Mason E, Andrews G. The effectiveness of internet cognitive behaviour therapy (iCBT) for social anxiety disorder across two routine practice pathways. *Internet Interv* 2014 Oct;1(4):225-229. [doi: [10.1016/j.invent.2014.11.001](https://doi.org/10.1016/j.invent.2014.11.001)]
54. Williams AD, O'Moore K, Blackwell SE, Smith J, Holmes EA, Andrews G. Positive imagery cognitive bias modification (CBM) and internet-based cognitive behavioral therapy (iCBT): a randomized controlled trial. *J Affect Disord* 2015 Jun 01;178:131-141 [FREE Full text] [doi: [10.1016/j.jad.2015.02.026](https://doi.org/10.1016/j.jad.2015.02.026)] [Medline: [25805405](https://pubmed.ncbi.nlm.nih.gov/25805405/)]

55. Wootton BM, Titov N, Dear BF, Spence J, Kemp A. The acceptability of Internet-based treatment and characteristics of an adult sample with obsessive compulsive disorder: an Internet survey. PLoS One 2011;6(6):e20548 [FREE Full text] [doi: [10.1371/journal.pone.0020548](https://doi.org/10.1371/journal.pone.0020548)] [Medline: [21673987](https://pubmed.ncbi.nlm.nih.gov/21673987/)]

Abbreviations

AUC: area under the curve

CBT: cognitive behavior therapy

CFI: comparative fit index

DSM-5: Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition)

GAD-7: Generalized Anxiety Disorder seven-item scale

HAI: Health Anxiety Inventory

ICC: intraclass correlation coefficient

ICD-10: International Classification of Diseases, Tenth Revision

ITC: item-total correlations

MADRS-S: Montgomery-Åsberg Depression Rating Scale-self-report

PSS: Perceived Stress Scale

RMSEA: root mean square error of approximation

SDS: Sheehan Disability Scale

SRMR: standardized root mean square residual

TLI: Tucker-Lewis index

WAI: Work Ability Index

WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0

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Original Paper

Exploring the Therapeutic Affordances of Self-Harm Online Support Communities: An Online Survey of Members

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Abstract

Background: A growing number of online communities have been established to support those who self-harm. However, little is known about the therapeutic affordances arising from engagement with these communities and resulting outcomes.

Objective: The aim of this study was to explore the presence of therapeutic affordances as reported by members of self-harm online support communities.

Methods: In total, 94 respondents (aged 13-63 years, mean=23.5 years; 94% female) completed an online survey exploring their experiences of engaging with a self-harm online support community. Respondents varied in terms of how long they had been accessing an online community, with 22% (21/94) accessing less than 1 year, 39% (37/94) 1 to 2 years, 14% (13/94) 2 to 3 years, and 24.5% (23/94) more than 3 years. Responses were analyzed using deductive thematic analysis.

Results: The results of our analysis describe each of the five therapeutic affordances that were present in the data, namely (1) *connection*, the ability to make contact with others who self-harm for the purposes of mutual support and in so doing reduce feelings of loneliness and isolation; (2) *adaptation*, that is, how use of online support varies in relation to the personal circumstances of the individual user; (3) *exploration*, that is, the ability to learn about self-harm and learn about strategies to reduce or stop self-harming behavior; (4) *narration*, that is, the ability to share experiences, as well as read about the experiences of others; and (5) *self-presentation*, that is, how and what users present about themselves to others in the online community.

Conclusions: Our findings suggest that engagement with self-harm online support communities may confer a range of therapeutic benefits for some users, which may serve to minimize the psychosocial burden of self-harm and promote positive coping strategies. In addition, the online nature of the support available may be helpful to those who are unable to access face-to-face support.

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KEYWORDS

self-harm; social network; social support; qualitative research; online support group

Introduction

Background

Regardless of suicidal intent or other motivations, self-harm is a term used to describe all nonfatal acts of intentional self-injury or self-poisoning [1]. In addition to being a significant risk factor for completed suicide [2], it is also associated with elevated all-cause mortality [3]. Self-harm is also linked to

poorer psychosocial outcomes including depression, anxiety, and substance use [4] and carries with it considerable health services and social costs [5]. Self-harm appears to be more common in females than males, though this gap has narrowed in recent years [6] and appears to further diminish across the lifespan [7]. It tends to be more prevalent in younger age groups [8]. Among females, rates of self-harm appear to be highest in the age group of 15 to 24 years, but for males this tends to be

in their late twenties and early thirties. For older age groups, self-harm appears to be less prevalent but does appear to be related to higher levels of suicidal intent [6].

Internet use has increased globally by 933.8% from June 2000 to March 2017, resulting in approximately 49.6% of the world's population being online [9]. While usage of the Internet continues to increase across all age groups and both genders [10,11], young people aged 16 to 24 years remain the highest users, with 99.2% in the United Kingdom accessing the Internet in the previous 3 months [10] and 96% of young people aged 16 to 29 years having used the Internet in the United States [11]. With the emergence and burgeoning of Internet use, the way in which some individuals communicate their self-harm experiences has changed. Before the Internet, any disclosure around self-harm was restricted to face-to-face networks (eg, friends and family), telephone support lines (eg, Samaritans), or health professionals. Nowadays, it is becoming more common for experiences of self-harm to be shared virtually via photographs, videos, and online discussions [12-16]. Although much of the work exploring Internet use has reported negative effects, including triggering as well as normalizing self-harm [13,14,17], sharing of self-harm methods [18-20], and methods to conceal self-harm from others [13,20], other researchers have demonstrated the positive impact that the Internet can have. For example, Baker and Fortune [21] reported that participants felt that self-harm and suicide sites had contributed to their recovery and facilitated change *better than any therapy*.

As a result of technological advances, there is now a greater opportunity for individuals who self-harm to interact with each other online. In particular, there are a growing number of online support communities (also known as *online support groups*) that have been established to support those who self-harm, and these have typically been developed using asynchronous discussion forum platforms and social networking sites (eg, Facebook). These online support communities offer new opportunities to those who self-harm to obtain information, advice, and support [16]. Furthermore, they enable the connection of otherwise isolated individuals [13,14,22] who can receive support from like-minded individuals, feel less isolated, and find a community that understands their self-harm with whom they can discuss topics of mutual interest [23-25].

Thus, there is a small but growing body of literature that has explored the use of self-harm online support communities, notably discussion forums, and reported both positive and negative consequences [26]. However, the bulk of previous studies that considered self-harm online support communities have been largely descriptive, with no underpinning theory that explores the relationship between users' online behavior and reported outcomes. It is our contention that to advance our knowledge and understanding of the role of online support communities for those who self-harm, there needs to be a greater emphasis placed on understanding the interaction between the individual who uses the online community and the specific functionality afforded by its underpinning platform and how this relates to health outcomes. Therefore, to explore how engagement with self-harm online support communities may

impact on users, our study considered the perceived therapeutic affordances of such interactions.

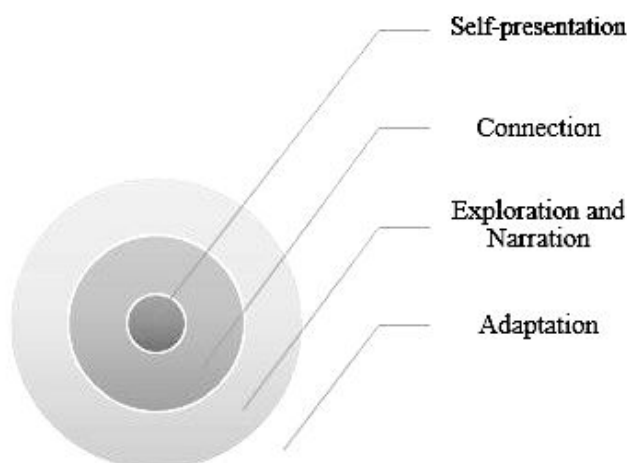
Affordance Theory

The roots of affordance theory can be traced back to perceptual and cognitive psychology and are based on how individuals perceive the objects around them in the environment. That is, what the specific object is and what potential use it affords [27]. The properties of any specific object will therefore contribute to its perceived affordance as will the varying experiences, beliefs, and goals of an individual. What is central to this theory is the interaction between the individual and the object and its subsequent outcomes. Therapeutic affordances have been described as the *actionable possibilities* of the object as determined by the individual [28], and in this instance, the object of our study is an online support community. Therefore, by focusing on the therapeutic affordances conferred by online support communities, we can consider not only their use but also their impact.

The utility of affordance theory can be illustrated by the work of Merolli et al [28]. In a global survey of social media use by patients living with chronic pain, five main therapeutic affordances arising from social media were identified and described: *self-presentation* (ie, the level of information presented to the world via social media), *connection* (ie, the use of social media to reach out to others in similar situations, share or exchange information, and offer support), *exploration* (ie, the use of social media for guidance toward useful information), *narration* (ie, sharing experiences via social media), and *adaptation* (ie, the way social media enabled respondents to adapt their self-management behaviors in relation to their condition status and needs at particular points in time in various ways). These affordances were then used to develop the SCENA model (ie, Self-presentation, Connection, Exploration, Narration, and Adaptation) that is depicted in Figure 1. Merolli et al (2014) propose that at the core of this model are preferences and perceptions relating to one's image or digital identity. *Self-presentation* will then feed into the ability of social media to *connect* individuals. The next layer, they propose is shared by both *exploration* and *narration*, both of which acknowledge varying preferences for self-presentation and how individuals connect. The outer layer in this model depicts *adaptation*, which reflects how social media can be used for self-management behaviors as and when the need arises at different points in time. This, they argue, will influence and be influenced by affordances to varying degrees.

Until now, the potential therapeutic affordances that may be conferred through engagement with self-harm online support communities has not been the focus of investigation. Therefore, the aim of this study was to explore the presence of therapeutic affordances arising from engagement with self-harm online support communities as reported by those individuals who engage with them; specifically, to consider the relationship between any identified therapeutic affordances and subsequent outcomes. To achieve this, our work was guided by Merolli et al (2014) SCENA model and used as a theoretical framework through which to consider and reflect upon the experiences of those who engage with self-harm online communities.

Figure 1. SCENA model (Self-presentation, Connection, Exploration, Narration, and Adaptation) of therapeutic affordance of social media (adapted from Merolli et al, 2014).



Methods

Recruitment and Data Collection

This study involved the recruitment of individuals who access self-harm online support communities. To identify potential communities, a search using Google was undertaken incorporating a range of keywords in various combinations, including “self-harm,” “self-injury,” “online support groups,” “support,” “message boards,” and “forums.” The results of this search yielded nine self-harm online support communities that were deemed eligible to be contacted. Our inclusion criteria included (1) user-led community, (2) active with at least 30+ posts per month, (3) moderators could be identified with contact details available, (4) the terms and conditions of the community did not preclude research-related activity, and (5) English language. Following contact with moderators from each community, positive responses were received from three communities (two asynchronous forums and one Facebook community). The communities that were willing to assist with our study were based in either the United Kingdom (one forum with 1000+ members and the Facebook community with 30,000+ followers) or North America (one forum with 1000+ members). It should be noted that since the time of data

collection, the North American forum has since closed. The remaining communities which were contacted either declined the invitation (N=2; both asynchronous forums) or failed to respond (N=4; three forums and one Facebook group). For the two forums that declined to take part, no explanation was provided.

For those communities granting permission, a recruitment message was posted to their discussion forum outlining the aims of the study and inviting interested members to click on a link to the online survey hosted by Bristol Online Surveys. Upon arrival at the landing page, members were provided with additional information concerning the study and were then asked to complete an online consent form. Following this, members completed some background questions (age, gender, and country of residence) and their self-reported use of self-harm online support communities. Next, they were invited to respond to a set of open-ended questions that explored their motives and experiences of using online support communities, including perceived benefits or problems (see [Textbox 1](#)). The questions used in our survey were based on those very successfully used in previous research, though no direct piloting of these questions with the target group took place. Within the online survey, each question was followed by an expanding text box, which meant participant responses were not limited by space.

Textbox 1. Open-ended questions used in the online survey.

- Why did you decide to become a member of an online support group?
- Has being a member of the group helped you in any way? If so, please give some examples.
- What do you feel are the benefits of taking part in an online support group?
- Have you encountered any problems while being a member of an online support group?
- Has being a member of an online support group had an impact on any of your offline relationships?

Ethical Considerations

Before the commencement of data collection, the research protocol was considered and approved by the institutional ethics review committee of the University of Nottingham. As per

accepted ethical practice [29], our online survey was prefaced with a comprehensive information page that outlined the nature of the study, rights as a research participant, withdrawal procedures, together with contact details of the research team. After considering this information, respondents were then

directed to an online consent page which required them to select “yes” in response to a series of consent statements, all with the option “yes or no.” To ensure that data could be retrieved in the event of a query or a request to withdraw their data, all respondents were asked to create a unique password and quote this password in any correspondence with the research team. Ultimately, no respondent chose to retrospectively withdraw their data.

Participants

In total, 94 online support group members responded to our open-ended questions. Ages ranged from 13 to 63 years, with a mean age of 23.5 years and the majority (88/94, 94%) being female. In terms of country of residence, 51 % (48/94) were from the United Kingdom, 19% (18/94) from North America, and 7% (7/94) from Australia, with remainder from other European countries (6% 6/94), South America (1/94, 1%), and Asia (5/94, 5%), with 10% (9/94) choosing not to report. Respondents varied in terms of how long they had been accessing an online support community, with 22% (21/94) less than 1 year, 39% (37/94) 1 to 2 years, 14% (13/94) 2 to 3 years, and 24.5% (24.5) more than 3 years.

Data Analysis

Responses to the open-ended questions were analyzed by the first author (NC). Initially, all responses were analyzed using a deductive approach (see [Table 1](#) for coding framework), seeking evidence of the presence of the therapeutic affordances outlined by Merolli et al [28] in conjunction with the guidelines set out by Braun and Clarke [30]. In the first instance, each set of survey responses were read and reread several times to become familiar with the data. Next, interesting and salient features and patterns within the data were coded, using the language of the respondents wherever possible. From this, codes were then arranged into meaningful groups to form potential subthemes for each affordance. In cases where codes appeared throughout the data, these were considered as potential themes. All data relevant to each potential theme were gathered together, and then each theme was reviewed, refined, and then allocated a clear definition and label. In addition, reviewing the language typically used in these themes allowed them to be organized into the final set of therapeutic affordances. To check that the themes identified reflected the data, the second and third authors reviewed the survey responses and together with the first author confirmed the final set of themes.

Table 1. Coding framework for deductive thematic analysis with illustrative quotes.

Therapeutic affordance	Definition and illustrative examples
Connection	An ability to connect to others in similar situations; the sharing or exchange of information; offers of support “...people who suffer with similar disorders understand better.”
Exploration	An ability to search for information or advice about self-harm; learning about self-harm, including causes; coping and self-management strategies; sources of support “...reading and learning information about self-harm.”
Narration	An ability to share personal experiences, opinions, and viewpoints; accessing other people’s experiences “...writing my thoughts to a forum where other people can see them, and read other people’s posts has been very helpful.”
Self-presentation	An ability to control or exercise autonomy over information disclosure online; discussion of private versus public nature of online activity “...the anonymity helps when I want to open up without freaking people out.”
Adaptation	An ability to engage with an online support community depending on individual needs, circumstances, priorities, and health status. “I was recovering from years of self harm. Recently, I’ve been feeling urges again.”

Results

Engagement With the Survey

Overall, the number of community members responding to each open-ended question (see [Textbox 1](#)) was as follows: Q1=91/94, Q2=86/94, Q3=84/94, Q4=78/94, and Q5=70/94. In addition, the amount of text written by respondents ranged from 2 to 78 words (mean=16.12) for Q1, 1 to 77 words (mean=20.23) for Q2, 1 to 112 words (mean=17.2) for Q3, 1 to 122 words (mean=10.5) for Q4, and 1 to 54 words (mean=10.01) for Q5.

Findings From the Analysis of Open-Ended Survey Questions

Our deductive thematic analysis described each of the five therapeutic affordances and related outcomes that were present, to varying degrees, in the data (see [Table 2](#)). The most frequently mentioned theme, as determined by the number of individuals commenting, was that of *connection* (83/94, 88%) and *adaptation* (48/94, 51%), followed by *exploration* (44/94, 47%) and *narration* (43/94, 46%), and finally *self-presentation* (37/94, 39%).

Table 2. Therapeutic affordances, processes, and outcomes (+ or –).

Therapeutic affordance	Process	Outcome (positive + or negative –)
Self-presentation	Autonomy	Identity (+ and –)
	Disclosure	
Connection	Interaction	Reduced isolation (+)
	Mutual support	Supportive relationships (+)
		Interpersonal conflict (–)
Exploration	Information-seeking	Knowledge (+)
	Learning	Adaptive coping strategies (+)
Narration	Sharing experiences	Understanding (+)
	Emotional catharsis	
Adaptation	Personal circumstances	Availability (+)

Self-Presentation

At the heart of this affordance was the ability to exercise autonomy over the discussion of self-harm and the disclosure of personal information and experiences, as well as a clear preference for anonymous online interactions to protect their identity and retain privacy.

Several of our respondents commented on the value they placed on being able to reveal aspects of themselves to fellow members of the community. In particular, being able to discuss self-harm with “strangers” rather than to family, friends, and wider face-to-face networks was welcomed:

Sometimes it is easier to open up to a stranger than to a person you know your whole life.

However, the benefits derived from the online communities in terms of self-presentation also included how they revealed aspects of themselves, for example, one respondent stated:

It's sometimes easier to type how you feel than speak it...

Several comments were made describing how they were able to present themselves in a more “honest” or truthful way. What appeared to permeate many of the comments made was the view that traditional face-to-face networks restricted discussion of self-harm, but the online nature of the support communities overcame this and provided new opportunities for their self-harming to be acknowledged and discussed. It was evident in many responses that the discussion of self-harm was for some individuals a new and much needed opportunity, arising directly from their decision to join the online community.

The clear preference for anonymous interactions was evident across many comments made by our respondents. Indeed, the ability to reveal aspects of their identity online appeared to be closely linked to the perceived anonymity that was conferred:

Being anonymous. You can talk about what's going on with you and nobody in your life will find out. It's a beautiful thing

... the anonymity helps when I want to open up without freaking people out.

However, apprehension was evident in some respondents as they expressed concerns around engaging with the Facebook group for fear their self-harming behavior would be revealed to others:

I didn't even like the Facebook page because I was afraid someone might suspect something if they found me liking a self-harm related page.

I didn't like the page, because others can see which pages you like.

Connection

This affordance focused on the ability to connect with others, and respondents used this connection to support each other, to overcome feelings of isolation, and develop supportive relationships. However, at times there appeared to be instances of conflict between members and situations where outsiders would deliberately try to cause harm to community members.

Many of our respondents commented on the fact that through accessing an online support community, they could interact with other people who also self-harmed. On several instances respondents discussed the importance of seeking out and connecting with others because “people who suffer with similar disorders understand better.” Indeed, this notion of understanding resonated across many comments made as respondents described their hopes that by joining an online community they would find others who could “relate,” “listen,” and that were facing “similar struggles.”

A common experience described by respondents was that of feeling “totally alone” with a “lack of support available.” For some, this reflected the fact that their self-harming was done in secret, and this made it difficult to “reach out” and find support from people who would understand:

I self-harmed in secret and felt totally alone. I wanted to stop and needed support to try but no one in real life knew I was even unhappy.

For others, there was nobody in the “real world” who could provide this support, typically because they would “not understand,” and there was a widespread fear that they would be ridiculed:

I'm scared of other people making jokes of me.

A widespread theme within respondents' answers was that of "mutual support" and the potential of the online community to bring people together:

It's great having people to encourage you and understand you. When you have a bad day you can have the support you need, whether that's a pep-talk or sympathy, or just an ear to listen. It's great because everyone knows a bit about what you're going through.

In particular, the ability to connect with others online appeared to provide respondents with a sense of belonging:

It makes you feel like you're part of something greater like people are almost united by their illness.

Indeed, this notion of connection was evident across several respondents' comments particularly as they described the benefits of "having someone to talk to, who knows what you're going through and can relate." A number of comments were made which described how this online support was provided in a way that was nonjudgmental and risk free. As one respondent described:

You get to tell your story and be honest about how you feel knowing that you will not be judged.

Through this connection with similar others, many respondents described how being part of an online support community had reduced their sense of isolation and loneliness and helped them feel less alone:

The greatest benefit is the feeling of not having to feel alone in your issues.

Indeed, the word "alone" was used by several respondents, particularly as they described how it felt to self-harm but to keep it hidden from friends and family. As a result of finding others who are in the same position, several respondents described how they were coming to accept the reality of their position:

It helped me to realize that I'm not strange.

The group has helped me to see that I am not alone, even in the most bizarre behaviours.

It was evident from the responses provided that the connections with others made through the online support communities were meaningful, with some describing the "supportive relationships" that had become established. Respondents discussed their "being part of a community" and the "friendship" that engagement with the online support community brings. One respondent emphasized the role of the online support community in facilitating connections with similar others:

It makes you feel like you are part of something greater like you are almost united by their illness.

Despite this, connecting with others through an online support community was not always a positive experience. For example, respondents described situations in which there existed some conflict, either through a difference of opinion or through deliberate intent to cause trouble:

People passionately disagree at times which can sometimes cause tension

I think there are always going to be the idiots that like to try and start fights.

Exploration

At the heart of the "Exploration" therapeutic affordance was the ability to seek information, learn and acquire knowledge about self-harm, and the impact of this on the development of adaptive coping strategies.

Respondents described how their online support community was helpful in terms of "reading and learning information about self-harm" and a place where they could "ask questions" and get answers. The community was viewed as a valuable repository of information which could be accessed at any point:

There many times I've just needed some info and there's plenty on...[name of community].

For some, the online support community provided a new opportunity to seek information and advice. As one member explained:

I wanted to know more about it, because during endeavours to learn more in years past, information was scarce.

Through the online community, respondents could learn more about the commonly experienced thoughts and "urges." As one member explains, the online community helped them "get answers about why I had certain feelings."

As well as learning more about self-harm generally, respondents described how they obtained practical advice on strategies to cope with and manage their self-harm behavior. As a consequence, several respondents described how they were then able to implement new adaptive coping strategies to combat urges to self-harm:

I've read a lot on this site and have found ways to distract myself when I feel triggered.

Other comments made by fellow respondents also demonstrated how engagement with the online community positively impacted on how they managed their ongoing struggles:

It has enabled me to find other, less damaging coping methods.

...given me ideas about how to manage it.

...also given me practical advice on coping techniques, first aid and other things.

For some, the ability to understand the nature of self-harm and how to manage it had yielded positive outcomes. As one respondent explained:

Yes, it has stopped me from self-harming and the pictures they boost often boost my self-esteem.

Others also confirmed that they now "cut less" or had fewer urges to do so.

Narration

Respondents described how they shared their own experiences of self-harm, as well as hearing about the experiences of others

through the online community. Through this narration, and that of others, respondents described a range of positive benefits, but some problems were also identified (ie, triggering content being posted online).

Through narrating their self-harm experiences online, several respondents noted the positive impact. For example:

...writing my thoughts to a forum where other people can see them, and read other people's posts has been very helpful.

Others noted how writing about their experiences online helped them to organize their thoughts and communicate more effectively:

Writing things out can help to get them out my head and make them clearer.

In contrast, respondents also explained how in some situations reading posts by other community members could be unhelpful. As one respondent explained:

At my lowest I would compare my problems to others and think they were not important.

In other instances, respondents provided examples of why messages posted by others could be distressing:

Sometimes it is hard seeing people who say they want to die.

Some respondents describe altogether more serious problems when the content of messages posted by other community members appeared to “trigger” difficult thoughts, feelings, and behavior:

There have been occasions when members have posted either triggering words or pictures, which have triggered me to feel low or hurt myself.

Adaptation

At the heart of this affordance were the personal circumstances of the individual users and how these were related to engagement with the online community. This affordance reflects both the varying circumstances at the point of deciding to join a self-harm online community, as well as their subsequent and ongoing engagement with each community.

In explaining the decision to join a self-harm online community, many respondents described either the absence of or barriers to accessing face-to-face support for their self-harming behavior:

I needed somewhere to go and talk about my issues that I couldn't talk about with family and friends.

I wasn't receiving any useful help from the NHS [National Health Service] and was on a stupidly long waiting list. I need some support...

In particular, feelings of guilt, shame, or embarrassment were a significant component of their view that face-to-face support was not an option, but online support could be a useful alternative. As one respondent explained:

I am confused and baffled by my behaviour and feel a deep sense of shame and embarrassment and loneliness. I hoped this community might help.

Specifically, notions of privacy and anonymity were salient across many comments, and these were important considerations in their decisions to engage with a self-harm online community.

In other instances, respondents described changes in their self-harm behavior, typically deterioration in their mental health and well-being and/or an escalation of their urges and attempts to self-harm:

Because my self-harm acts were getting out of control.

I was recovering from years of self-harm. Recently, I've been feeling urges again.

Many comments made by the respondents illustrated how they visited and revisited the community for support during critical periods when they were “in crisis” or when they were “falling back into self-injury.” Others considered how their mood was related to their use of the community:

I've managed to stop for a couple of weeks and when I felt low I could talk to people on the ground to distract and advise you.

What was evident across the responses was the fact that engagement with the support community was related to how they were feeling about their self-harm. For some, the challenges were during periods when other sources of support could not be accessed, and so, the 24-hour nature of the community was considered helpful:

It has helped by being 24 hr because I mostly get sad at night so I can't call my consuler [counsellor].

Discussion

Principal Findings

The aim of this study was to explore the therapeutic affordances that may be conferred through engagement with self-harm online support communities, as described by those individuals who use them. We based our deductive thematic analysis on the therapeutic affordances described by Merolli et al (2014), and our findings offer additional support for the validity of these affordances in this group. Our findings describe each of the five therapeutic affordances in the context of engagement with self-harm online support communities.

Connection was the most commonly described therapeutic affordance by our respondents, with emphasis being placed on the benefits of interacting with others who share similar experiences. Previous research within the self-harm literature has pointed to the potential benefits of having support [17,20,31] but has noted that obtaining this support may be difficult, for various reasons including stigma, shame, or embarrassment [32]. This might therefore account for the large number of respondents who noted *connection*, as engaging with an online support community may be one convenient and anonymous way to access support. Furthermore, many respondents described feelings of isolation and loneliness, particularly as they often kept their self-harming behavior hidden from public view. The lack of a supportive face-to-face network may heighten feelings of isolation, and so, connecting with similar others online may provide new opportunities for much needed support.

Although previous work has not always identified the affordance *adaptation* [33], this study did find that several respondents explicitly discussed how their use of an online support community varied depending on how they were feeling and/or current situation with regards self-harm urges or behavior. However, on reading across the responses to our survey questions, it could be argued that use of a self-harm online support community is crucially linked to respondents' needs, current feeling, and general sense of well-being. As a result, many respondents may have used the online community to address a specific need, but this did not necessarily translate into any explicit comment in their responses to our open-ended survey questions.

The affordance of *exploration* was also frequently commented upon by our respondents as they described the ability to find information, ask questions, and gain knowledge about self-harm online. Of importance was the opportunity to find practical advice, which could be used to prevent further self-harm and to help them implement adaptive coping strategies.

In terms of *narration*, the online support community was viewed as a safe place to share stories and experiences, as well as to provide information and advice. The importance of experiential information and advice has been noted elsewhere in the literature [34-37], and the results of our study suggest that the online support community may be a useful venue through which experiences can be shared.

The affordance *self-presentation* was considered valuable to our respondents in relation to the perceived privacy and anonymity, whereas the community conferred. Again, other work in the field of self-harm has confirmed the importance of safe spaces for individuals to freely disclose information and details about their self-harm history and ongoing struggles. Our findings suggest that features of the online community (ie, restricted access and anonymity) may be viewed as particularly helpful in supporting individuals as they open up to others online. Interestingly, some differences were noted between the users of the Facebook group and those using the forums in relation to concerns about privacy.

Despite several positive benefits being discussed, there were some concerns expressed by respondents about their online experiences. By far, the most problematic aspect centered on the content posted by other community members and its potential to trigger self-harm behavior. However, it was noted by several respondents that warnings were helpful, and so, this practice may be encouraged going forward. Other lesser concerns focused on the interactions between members and the fact that sometimes arguments can take place. To limit the impact of these episodes, moderators may usefully step in to restrict content which may cause upset to other members. Finally, some respondents commented upon the existence of people who seemed determined to cause trouble within an online community. Again, the role of the moderator may be crucial in limiting any potential damage to the community dynamics, as well as safeguarding the welfare of individual members.

To date, various theoretical frameworks have been employed to assist in our understanding of how users engage with online support communities and what impact this engagement may

have on their experience of illness and psycho-social well-being. One common example is that of social support, and previous studies adopting this theoretical framework have shed light on the potential health-related benefits of engagement [38]. While there is arguably some conceptual overlap between the various therapeutic affordances and social support, social support has commonly been applied from a health outcome-oriented perspective [39]. It is our belief that as a result of the proliferation in the types of platforms being used for online peer-to-peer support, it is now timely that we adopt a theoretical framework which explicitly acknowledges the interaction between the user, the functionality of the platform, and any resulting outcomes. With this in mind, we considered affordance theory [27] and found this framework to be helpful while interpreting the responses to the open-ended questions posed in our survey. This approach was especially relevant when differences between the affordances across the two platforms represented in the study were recorded (eg, differences in the self-presentation affordance). That said, we believe there are several research avenues to explore going forward, not least the role of individual factors and/or illness-specific factors and how these relate to the engagement with self-harm online support communities and how varying levels of engagement may relate to health outcomes. However, for now, we believe that adoption of this framework to guide our deductive analysis proved beneficial in understanding how people experiencing self-harm may use online support communities.

Limitations of the Study

There are several limitations to this study that should be acknowledged. First, it is not clear how representative the sample is of the self-harm population. Although the mean age of our participants (23.5 years old) is broadly consistent with prevalence studies [6], our sample is heavily skewed toward females. Whereas the bias toward female respondents is both consistent with previous studies of online support group use for conditions that affect both genders [35], it does leave the male *voice* somewhat unheard, and therefore, future work should actively seek to redress this and employ specific strategies to ensure sufficient representation from males. Second, despite receiving positive responses from three online support communities, we were not able to access the other six communities which we approached to take part in the study. Therefore, it remains unclear whether our results may have been different if we were able to access these additional communities. The specific focus and dynamics of these (and other) communities may differ from those included in this study, and therefore, these groups may have offered different opportunities and ultimately different affordances. Finally, we employed an online survey methodology to collect data from members of self-harm online support communities. The decision to use an online survey format was felt to sit comfortably with the fact that the focus of the study is on people's experiences of asynchronous text-based support. In addition, it was evident from the responses provided that the online survey approach conferred a degree of anonymity which was felt important, particularly to those who may not have disclosed their self-harming behavior to their social networks. In addition, we did not observe any responses, which may suggest that our

respondents were answering anything other than honestly. That said, it remains to be seen whether an alternative format may have elicited more detailed, longer, and richer insights into their online experiences. We have reported some basic descriptive analysis of engagement with our survey questions, and although this data is encouraging, it is pertinent to at least acknowledge the potential limitations of this static open-text online survey. In addition, we did not have the opportunity to pilot our survey questions, and future research should ensure that this is undertaken.

Conclusions

Our survey findings suggest that engagement with self-harm online support communities may confer a range of therapeutic benefits for some users, which in turn may serve to minimize the burden of illness. Furthermore, self-harm online support communities may serve as a useful public health intervention through which individuals experiencing a range of negative impacts may engage in anonymous mutual support in ways that foster individual adaptive coping strategies and improve psychosocial well-being.

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Conflicts of Interest

None declared.

References

1. Hawton K, Harriss L, Hall S, Simkin S, Bale E, Bond A. Deliberate self-harm in Oxford, 1990-2000: a time of change in patient characteristics. *Psychol Med* 2003 Aug;33(6):987-995. [Medline: [12946083](#)]
2. Carroll R, Metcalfe C, Gunnell D. Hospital presenting self-harm and risk of fatal and non-fatal repetition: systematic review and meta-analysis. *PLoS One* 2014;9(2):e89944 [FREE Full text] [doi: [10.1371/journal.pone.0089944](#)]
3. Bergen H, Hawton K, Waters K, Ness J, Cooper J, Steeg S, et al. Premature death after self-harm: a multicentre cohort study. *Lancet* 2012 Nov 3;380(9853):1568-1574. [doi: [10.1016/S0140-6736\(12\)61141-6](#)] [Medline: [22995670](#)]
4. Mars B, Heron J, Crane C, Hawton K, Lewis G, Macleod J, et al. Clinical and social outcomes of adolescent self-harm: population based birth cohort study. *Br Med J* 2014;349:g5954 [FREE Full text] [doi: [10.1136/bmj.g5954](#)]
5. Sinclair JM, Gray A, Rivero-Arias O, Saunders KE, Hawton K. Healthcare and social services resource use and costs of self-harm patients. *Soc Psychiatry Psychiatr Epidemiol* 2011 Apr;46(4):263-271 [FREE Full text] [doi: [10.1007/s00127-010-0183-5](#)]
6. Hawton K, Harriss L. The changing gender ratio in occurrence of deliberate self-harm across the lifecycle. *Crisis* 2008;29(1):4-10 [FREE Full text] [doi: [10.1027/0227-5910.29.1.4](#)]
7. Perry IJ, Corcoran P, Fitzgerald AP, Keeley HS, Reulbach U, Arensman E. The incidence and repetition of hospital-treated deliberate self-harm: findings from the world's first national registry. *PLoS One* 2012;7(2):e31663 [FREE Full text] [doi: [10.1371/journal.pone.0031663](#)]
8. Hawton K, Witt KG, Taylor Salisbury TL, Arensman E, Gunnell D, Hazell P, et al. Pharmacological interventions for self-harm in adults. *Cochrane Database Syst Rev* 2015 Jul 6(7):CD011777. [Medline: [26147958](#)]
9. Internetworldstats. World Internet usage and population statistics 2017 URL: <http://www.internetworldstats.com/stats.htm> [WebCite Cache ID 6tWe4bzn]
10. Office for National Statistics. Ons.gov. Internet users in the UK: 2016 URL: <https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016> [WebCite Cache ID 6tXhR30v3]
11. Perrin A, Duggan M. Pewinternet. 2015. Americans' Internet Access: 2000-2015 URL: <http://www.pewinternet.org/2015/06/26/americans-internet-access-2000-2015/> [accessed 2017-09-17] [WebCite Cache ID 6tXhe874m]
12. Duggan JM, Heath NL, Lewis SP, Baxter AL. An examination of the scope and nature of non-suicidal self-injury online activities: implications for school mental health professionals. *School Ment Health* 2012;4(1):56-67 [FREE Full text] [doi: [10.1007/s12310-011-9065-6](#)]
13. Lewis SP, Baker TG. The possible risks of self-injury websites: a content analysis. *Arch Suicide Res* 2011;15(4):390-396. [doi: [10.1080/13811118.2011.616154](#)]
14. Lewis SP, Heath NL, St Denis JM, Noble R. The scope of nonsuicidal self-injury on YouTube. *Pediatrics* 2011 Mar;127(3):e552-e557. [doi: [10.1542/peds.2010-2317](#)] [Medline: [21339269](#)]
15. Rodham K, Gavin J, Lewis S, Bandalli P, St Denis D. The NSSI paradox: discussing and displaying NSSI in an online environment. *Deviant Behav* 2016;37(10):1110-1117. [doi: [10.1080/01639625.2016.1169747](#)]
16. Whitlock J, Lader W, Conterio K. The internet and self-injury: what psychotherapists should know. *J Clin Psychol* 2007 Nov;63(11):1135-1143. [doi: [10.1002/jclp.20420](#)] [Medline: [17932984](#)]
17. Adams J, Rodham K, Gavin J. Investigating the self in deliberate self-harm. *Qual Health Res* 2005 Dec;15(10):1293-1309 [FREE Full text] [doi: [10.1177/1049732305281761](#)]

18. Becker K, Schmidt MH. When kids seek help on-line: Internet chat rooms and suicide. *Reclaiming Children Youth J Strength Based Interv* 2005;13(4):229-230.
19. Fortune SA, Hawton K. Deliberate self-harm in children and adolescents: a research update. *Curr Opin Psychiatry* 2005 Jul;18(4):401-406. [Medline: [16639133](#)]
20. Whitlock JL, Powers JL, Eckenrode J. The virtual cutting edge: the internet and adolescent self-injury. *Dev Psychol* 2006 May;42(3):407-417. [doi: [10.1037/0012-1649.42.3.407](#)] [Medline: [16756433](#)]
21. Baker D, Fortune S. Understanding self-harm and suicide websites: a qualitative interview study of young adult website users. *Crisis* 2008;29(3):118-122. [Medline: [18714907](#)]
22. Gavin J, Rodham K, Poyer H. The presentation of “pro-anorexia” in online group interactions. *Qual Health Res* 2008 Mar;18(3):325-333 [FREE Full text] [Medline: [18235156](#)]
23. Hoffmann WA. Telematic technologies in mental health caring: a web-based psycho educational program for adolescent suicide survivors. *Issues Ment Health Nurs* 2006 Jun;27(5):461-474. [Medline: [16613799](#)]
24. Murray CD, Fox J. Do Internet self-harm discussion groups alleviate or exacerbate self-harming behaviour? *Aust e-J Adv Ment Health* 2006;5(3):225-233. [doi: [10.5172/jamh.5.3.225](#)]
25. Prasad V, Owens D. Using the internet as a source of self-help for people who self-harm. *BJPsych Bull* 2001;25(6):222-225. [doi: [10.1192/pb.25.6.222](#)]
26. Daine K, Hawton K, Singaravelu V, Stewart A, Simkin S, Montgomery P. The power of the web: a systematic review of studies of the influence of the internet on self-harm and suicide in young people. *PLoS One* 2013 Oct 30;8(10):e77555 [FREE Full text] [Medline: [24204868](#)]
27. Gibson J. *The Ecological Approach to Visual Perception*. Hillsdale, NJ: Lawrence Erlbaum Associates; 1986.
28. Merolli M, Gray K, Martin-Sanchez F. Therapeutic affordances of social media: emergent themes from a global online survey of people with chronic pain. *J Med Internet Res* 2014 Dec 22;16(12):e284 [FREE Full text] [doi: [10.2196/jmir.3494](#)] [Medline: [25533453](#)]
29. Bps.org.uk. Leicester: The British Psychological Society; 2017. Ethics guidelines for Internet-mediated research URL: <http://www.bps.org.uk/system/files/Public%20files/Ethics%20Guidelines%20for%20Internet-mediated%20Research%202017%20Revision%20WEB.pdf> [accessed 2017-09-17] [WebCite Cache ID 6tXiHnkfg]
30. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2008;3(2):77-101. [doi: [10.1191/1478088706qp063oa](#)]
31. Lewis SP, Seko Y. A double-edged sword: a review of benefits and risks of online nonsuicidal self-injury activities. *J Clin Psychol* 2016 Mar;72(3):249-262. [doi: [10.1002/jclp.22242](#)] [Medline: [26613372](#)]
32. McAndrew S, Warne T. Hearing the voices of young people who self-harm: implications for service providers. *Int J Ment Health Nurs* 2014 Dec;23(6):570-579 [FREE Full text] [doi: [10.1111/inm.12093](#)] [Medline: [25388869](#)]
33. Shoebotham A, Coulson NS. Therapeutic affordances of online support group use in women with endometriosis. *J Med Internet Res* 2016 May 9;18(5):e109 [FREE Full text] [doi: [10.2196/jmir.5548](#)] [Medline: [27160641](#)]
34. Coulson NS. How do online patient support communities affect the experience of inflammatory bowel disease? An online survey. *JRSM Short Rep* 2013 Jul 1;4(8):2042533313478004 [FREE Full text] [doi: [10.1177/2042533313478004](#)] [Medline: [24040493](#)]
35. Coulson NS, Smedley R, Bostock S, Kyle SD, Gollancz R, Luik AI, et al. The pros and cons of getting engaged in an online social community embedded within digital cognitive behavioral therapy for insomnia: survey among users. *J Med Internet Res* 2016 Apr 25;18(4):e88 [FREE Full text] [doi: [10.2196/jmir.5654](#)] [Medline: [27113540](#)]
36. Holbrey S, Coulson NS. A qualitative investigation of the impact of peer to peer online support for women living with polycystic ovary syndrome. *BMC Womens Health* 2013;13:51 [FREE Full text] [doi: [10.1186/1472-6874-13-51](#)]
37. Rodham K, McCabe C, Blake D. Seeking support: an interpretative phenomenological analysis of an internet message board for people with complex regional pain syndrome. *Psychol Health* 2009 Jul;24(6):619-634. [doi: [10.1080/08870440802563245](#)]
38. Rodgers S, Chen Q. Internet community participation: psychosocial benefits for women with breast cancer. *J Comput Mediat Commun* 2005;10(4):00. [doi: [10.1111/j.1083-6101.2005.tb00268.x](#)]
39. Cobb S. Presidential Address-1976. Social support as a moderator of life stress. *Psychosom Med* 1976;38(5):300-314. [Medline: [981490](#)]

Abbreviations

SCENA: Self-presentation, Connection, Exploration, Narration, and Adaptation

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