JMIR Mental Health

Journal Impact Factor (JIF) (2023): 4.8
Volume 4 (2017), Issue 1 ISSN 2368-7959 Editor in Chief: John Torous, MD, MBI

Contents

Original Papers

Tips and Traps: Lessons From Codesigning a Clinician E-Monitoring Tool for Computerized Cognitive Behavioral Therapy (e3)
Frederick Sundram, Susan Hawken, Karolina Stasiak, Mathijs Lucassen, Theresa Fleming, Matthew Shepherd, Andrea Greenwood, Raechel Osborne, Sally Merry. . . . 2

Use of Online Forums for Perinatal Mental Illness, Stigma, and Disclosure: An Exploratory Model (e6)
Donna Moore, Nicholas Drey, Susan Ayers. . . . 16

Current Views and Perspectives on E-Mental Health: An Exploratory Survey Study for Understanding Public Attitudes Toward Internet-Based Psychotherapy in Germany (e8)
Jennifer Apolinário-Hagen, Viktor Vehreschild, Ramez Alkoudmani. . . . 28

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 (e1)
Murielle Villani, Viviane Kovess-Masfety. . . . 44

A Web-Disseminated Self-Help and Peer Support Program Could Fill Gaps in Mental Health Care: Lessons From a Consumer Survey (e5)
Samantha Bernecker, Kaitlin Banschback, Gennarina Santorelli, Michael Constantino. . . . 56

Social Skills Training for Adolescents With Autism Spectrum Disorder Using Facebook (Project Rex Connect): A Survey Study (e4)
McLeod Gwynette, Danielle Morriss, Nancy Warren, James Truelove, Jennifer Warthen, Charles Ross, George Mood, Charlotte Snook, Jeffrey Borckardt. . . . 73

Using Real-Time Social Media Technologies to Monitor Levels of Perceived Stress and Emotional State in College Students: A Web-Based Questionnaire Study (e2)
Sam Liu, Miaoqi Zhu, Dong Yu, Alexander Rasin, Sean Young. . . . 80

Applying Computerized Adaptive Testing to the Four-Dimensional Symptom Questionnaire (4DSQ): A Simulation Study (e7)
Tessa Magnée, Derek de Beurs, Berend Terluin, Peter Verhaak. . . . 88

Virtual Reality for Management of Pain in Hospitalized Patients: Results of a Controlled Trial (e9)
Vartan Tashjian, Sasan Mosadeghi, Amber Howard, Mayra Lopez, Taylor Dupuy, Mark Reid, Bibiana Martinez, Shahzad Ahmed, Francis Dailey, Karen Robbins, Bradley Rosen, Garth Fuller, Itai Danovitch, Waguih IsHak, Brennan Spiegel. . . . 98

XSL•FO
RenderX

Original Paper

Tips and Traps: Lessons From Codesigning a Clinician E-Monitoring Tool for Computerized Cognitive Behavioral Therapy

Frederick Sundram[1], MB, BCh, BAO, FRCPsych, MA, MSc, PhD; Susan J Hawken[2], MBChB, Dip Obs, FRNZCGP, MHSc (Hons); Karolina Stasiak[1], PhD; Mathijs FG Lucassen[1,3], PhD; Theresa Fleming[1,4], PhD; Matthew Shepherd[5], DClinPsy; Andrea Greenwood[6], BSc (Hons); Raechel Osborne[7], BN, PGDipPHC; Sally N Merry[1], MBChB, FRANZCP, CCAP, MD

[1]Department of Psychological Medicine, Faculty of Medical and Health Sciences, The University of Auckland, Auckland, New Zealand

[2]Department of General Practice and Primary Health Care, The University of Auckland, Auckland, New Zealand

[3]School of Health, Wellbeing and Social Care, The Open University, Milton Keynes, United Kingdom

[4]Department of Paediatrics, Child and Youth Health, The University of Auckland, Auckland, New Zealand

[5]School of Counselling, Human Services and Social Work, The University of Auckland, Auckland, New Zealand

[6]Department of Clinical Psychology, The University of Auckland, Auckland, New Zealand

[7]Kapiti Youth Support, Paraparaumu, New Zealand

Corresponding Author:
Frederick Sundram, MB, BCh, BAO, FRCPsych, MA, MSc, PhD
Department of Psychological Medicine
Faculty of Medical and Health Sciences
The University of Auckland
Private Bag 92019
Auckland Mail Centre
Auckland, 1142
New Zealand
Phone: 64 9 923 7521
Fax: 64 9 373 7013
Email: f.sundram@auckland.ac.nz

Abstract

Background: Computerized cognitive behavioral therapy (cCBT) is an acceptable and promising treatment modality for adolescents with mild-to-moderate depression. Many cCBT programs are standalone packages with no way for clinicians to monitor progress or outcomes. We sought to develop an electronic monitoring (e-monitoring) tool in consultation with clinicians and adolescents to allow clinicians to monitor mood, risk, and treatment adherence of adolescents completing a cCBT program called SPARX (Smart, Positive, Active, Realistic, X-factor thoughts).

Objective: The objectives of our study were as follows: (1) assess clinicians' and adolescents' views on using an e-monitoring tool and to use this information to help shape the development of the tool and (2) assess clinician experiences with a fully developed version of the tool that was implemented in their clinical service.

Methods: A descriptive qualitative study using semistructured focus groups was conducted in New Zealand. In total, 7 focus groups included clinicians (n=50) who worked in primary care, and 3 separate groups included adolescents (n=29). Clinicians were general practitioners (GPs), school guidance counselors, clinical psychologists, youth workers, and nurses. Adolescents were recruited from health services and a high school. Focus groups were run to enable feedback at 3 phases that corresponded to the consultation, development, and postimplementation stages. Thematic analysis was applied to transcribed responses.

Results: Focus groups during the consultation and development phases revealed the need for a simple e-monitoring registration process with guides for end users. Common concerns were raised in relation to clinical burden, monitoring risk (and effects on the therapeutic relationship), alongside confidentiality or privacy and technical considerations. Adolescents did not want to use their social media login credentials for e-monitoring, as they valued their privacy. However, adolescents did want information on seeking help and personalized monitoring and communication arrangements. Postimplementation, clinicians who had used the tool in practice revealed no adverse impact on the therapeutic relationship, and adolescents were not concerned about being e-monitored. Clinicians did need additional time to monitor adolescents, and the e-monitoring tool was used in a different way

XSL•FO
RenderX

than was originally anticipated. Also, it was suggested that the registration process could be further streamlined and integrated with existing clinical data management systems, and the use of clinician alerts could be expanded beyond the scope of simply flagging adolescents of concern.

Conclusions: An e-monitoring tool was developed in consultation with clinicians and adolescents. However, the study revealed the complexity of implementing the tool in clinical practice. Of salience were privacy, parallel monitoring systems, integration with existing electronic medical record systems, customization of the e-monitor, and preagreed monitoring arrangements between clinicians and adolescents.

(JMIR Ment Health 2017;4(1):e3) doi:10.2196/mental.5878

KEYWORDS

e-therapy; psychotherapy; cognitive therapy; depression; psychology, adolescent; primary health care

Introduction

Depression in adolescence is a major cause of disability that is often underreported, unrecognized [1,2], and not addressed by timely and effective treatments [3-5]. Psychological therapies are recommended as a first-line treatment for mild-to-moderate forms of depression [6,7] but are difficult to access. Computer-delivered therapies, especially those based on cognitive behavioral therapy (CBT), have been developed to help address this [8]. Computerized cognitive behavioral therapy (cCBT) can be offered as pure self-help or guided by a clinician [9,10]. The advantages of pure self-help tools include improved cost-effectiveness and nonreliance on clinicians to guide or support adolescents, and ultimately it may be some adolescents' preference to utilize programs independently. However, there is some evidence that clinician-guided interventions or blended therapies (where face-to-face therapy and computerized approaches are used side by side) have better completion rates and are more effective than unsupported self-help therapy [11-15]. An example of a supported program is the virtual MindSpot Clinic in Australia that allows remote screening assessments (phone- or Web-based) and clinician-guided treatment for anxiety and depression [16]. On the contrary, "Beating the Blues" is an unguided Web-based depression treatment program completed by a user at home that enables the prescribing general practitioner (GP) to receive risk alerts and progress updates [17,18].

To date most cCBT programs have been designed for adults, although more recently a number of programs have been created for depressed or anxious children and adolescents. They too range from self-help tools to supported programs. For example, "Think, Feel, Do" [19] relies on a facilitator (who is not required to be a clinician) to be available during the entire delivery of the program to discuss the content covered. BRAVE-ONLINE is a clinician supported anxiety program in which young people receive weekly emails from a clinician designed to give them feedback and encourage their program progression [20]. However, BRAVE-ONLINE does not include the ability to monitor symptoms. SPARX (Smart, Positive, Active, Realistic, X-factor thoughts) is a gamified cCBT program for adolescents, which was shown to be effective in 12- to 19-year-olds presenting to primary care with mild-to-moderate symptoms of depression [21]. SPARX was designed as a pure self-help program in response to young people wanting to maintain privacy and access the program independently. A freely available self-help resource such as SPARX, which is accessible to all young people in New Zealand, can help bring treatment to the estimated three quarters of young people with depression who do not seek help [22]. In the original trial of SPARX, the referring clinicians provided a minimal degree of oversight with only brief contact after a month to ensure adequate progress. Our experience from the trial suggested that while most clinicians endorsed the use of a self-help program, some wanted to have a more formal means of monitoring adolescent users' progress while using SPARX (Merry, personal communication).

Therefore, our study aimed to develop and implement an electronic monitoring (e-monitoring) tool relevant to adolescents with depression who attend youth-oriented primary care settings. The monitoring tool was envisaged to work in settings such as school health and counseling services because this is where many adolescents are likely to seek help [23]. To achieve this, we (1) assessed clinicians' and adolescents' views on using an e-monitoring tool and used this information to help shape development of the tool and (2) assessed clinician experiences with a fully developed version of the tool that was implemented in their clinical service. Of note, the tool was not expected to replace face-to-face contact but rather to offer another means of clinician oversight.

Methods

Study Design and Setting

A qualitative study was undertaken in New Zealand using focus groups with adolescents (aged 12-19 years) who were in contact with mental health services and also clinicians in primary care settings from the services where they worked (Table 1). We approached local secondary schools, a youth health center, and a nongovernmental organization using a snowball approach to recruit English-speaking participants. The clinicians approached were known to the researchers, and had an interest in adolescent health and in using the tool. The clinicians were GPs and allied health staff (school guidance counselors, clinical psychologists, youth workers, and nurses).

We set out to embed within SPARX an e-monitoring tool that would allow a clinician to "prescribe" SPARX and remotely oversee users' progress and mood scores. As a minimum, the tool would have the following features:

1. A registration system for clinicians so that they could use the SPARX e-monitoring tool

XSL•FO
RenderX

2. Electronic linking of SPARX user data to the prescribing clinician

3. A dashboard accessible on the Internet to allow clinicians to track all users they had referred to SPARX

4. An algorithm to automatically generate alerts at specific and concerning levels of depression, or self-harm, and a system to encourage users to access more help

5. A system to deliver alerts or "flags" via email to the clinician

In order to track mood in SPARX, we aimed to use the Patient Health Questionnaire for Adolescents (PHQ-A) [24,25] at 3 time points: module 1 (baseline), module 4 (mid-point), and module 7 (end of intervention). We also consulted a software developer to investigate potential solutions, and schematic blueprints (wireframes) were then developed to visually guide participants through the flow of a given system and illustrate what an e-monitoring system or dashboard might look like. These were then presented at focus groups with the clinicians and adolescents, who provided feedback during the various phases of development of the tool.

Ethics Approval and Consent

Ethics approval was obtained from the Health and Disability Ethics Committee, New Zealand (Reference: 12/CEN/62), and written informed consent was gained from each clinician, adolescent, and parents of any adolescent aged less than 16 years.

Table 1. Details of focus group participants during various phases of the study.

Group	Location	Focus group date	Focus group duration (minutes)	Participants	Phase
Clinician focus groups					
1	Youth health center	December 2012	90	3 General pratitioners (GPs) 4 Allied health staff	Phase 1 Consultation: Gauge needs and wants of clinicians and seek early feedback
2	Youth health center	December 2012	50	5 Allied health staff	
3	Primary care service	March 2013	80	11 GPs	
4	School guidance service	June 2013	60	1 GP 6 Allied health staff 3 Allied health trainees	Phase 2 Development: E-monitoring tool was beta-tested
5	School guidance service	July 2013	70	5 Allied health staff	
6	Youth health center	Dec 2013	60	3 GPs 4 Allied health staff	Phase 3 Postimplementation: Obtain postimplementation clinician feedback
7	Youth health center	Dec 2013	60	5 Allied health staff	
Focus groups with adolescents					
8	Youth health center	Dec 2012	90	14 Adolescents (past service users and youth advisors to the health center)	Phase 1 Consultation: Gauge needs and wants of adolescents and seek early feedback
9	Secondary school	Mar 2013	60	10 Adolescents (students who are nonservice users)	
10	Nongovernmental organization (mental health provider)	Mar 2013	70	5 Adolescents (service users)	

Focus Groups and Data Collection

Focus groups (Table 1) were conducted during 3 phases. Phase 1 was the consultation stage and was carried out prior to the creation of the e-monitor to canvass ideas that would help the design of the e-monitoring system, based on early wireframe designs (December 2012 to March 2013). Phase 2 was the development stage and was conducted after preliminary wireframes had been revised, and it included a broader discussion of how e-monitoring could be used clinically (June to July 2013). Phase 3 was the postimplementation stage and was conducted after clinicians trialed the e-monitoring tool in day-to-day practice (August 2013 to February 2014). A semistructured schedule was used for all the focus groups (Multimedia Appendix 1), and these were digitally recorded and professionally transcribed. Each group was run by 2 of 6 experienced facilitators (FS, KS, ML, TF, MS, and SM) and the duration, while ultimately determined by the participants, was usually 60-90 minutes. FS checked fidelity of the Phases 1 and 2 clinician transcripts, and AG reviewed the transcripts of the adolescent groups and Phase 3 clinician groups.

Data Analysis

A theoretical thematic analysis framework was used for examining the data from focus groups [26]. Transcripts were imported into NVivo before thematic analysis [27], and more specifically, the general inductive approach [28] was used to organize the dataset into multiple coded blocks. A higher level

XSL•FO
RenderX

of data interpretation was then performed, and responses were assessed for what might be implied or inferred. FS checked and coded the transcripts of the Phases 1 and 2 clinician focus groups, and AG similarly reviewed and coded the transcripts of the adolescent focus groups and Phase 3 clinician focus groups. Each dataset was then independently coded (SH, Phases 1 and 2 clinician groups; MS, all adolescent groups; KS, Phase 3 clinician groups). The independent coding by the 2 researchers was then discussed until consensus was reached to determine the final themes. Quotations from focus groups, where relevant, are provided verbatim.

Results

Common themes were identified from both the clinician and adolescent focus groups, as well as from issues reported upon as unique to either group. During Phases 1 and 2, themes were organized into 3 broad categories: clinical progress; confidentiality and privacy; and technical issues. Clinicians who were involved in clinical testing (Phase 3) reflected on some concepts (for instance, the initial themes) and drew on their "hands-on" experiences of using the actual tool postimplementation. Refinements to improve the tool were also suggested (Textboxes 1 and 2).

Development of the E-Monitor (Phases 1 and 2)

Clinical Progress

Engagement, Adherence, and Offering Help

Most participants were positive and supportive of the idea of adding e-monitoring to enhance the effectiveness of cCBT. Some adolescents noted that it might be hard to initiate contact with a clinician if they received a message from SPARX saying "you should seek help," and that the e-monitoring system would help clinicians to make contact with adolescents.

> *I think the monitoring is definitely quite key for like if you're you know making sure you get like consistently doing it and stuff. It could be quite easier if no one was checking up on you and stuff to be like just oh that's enough that kind of thing.* [Adolescent]

Clinical Burden and Effects on Therapeutic Relationship

E-monitoring was seen as a positive step by clinicians and adolescents, but there was also concern that it could potentially contribute to increased clinician burden. Some clinicians felt that the clinician-user therapeutic relationship may be impacted upon by a tool used in place of an ongoing face-to-face relationship, while others were concerned at the possible risk of rapid change in depression severity in adolescents. Similarly, some adolescents were concerned that clinicians might become over-burdened with the monitoring, with potential negative impacts on the clinical relationship and rapport. Clinicians and adolescents suggested the need for a discussion around e-monitoring, so that the adolescent was aware that a clinician had oversight of their progress, and could maintain the therapeutic relationship while simultaneously enhancing the adolescent's autonomy and sense of control.

> *I personally think this is great, so you can give the child a bit more power if you like, to take control of how they think and what they're going to do, because it seems often that it's one of the parents driving what's going to happen next and how quickly they are able to get better.* [Clinician]

Responsibility of Monitoring Risk, Parallel Monitoring, and Backup Systems

Clinicians were concerned about how they could discharge the clinical responsibility of monitoring an adolescent who was using a self-help therapy and might not be seeing the clinician regularly. In particular, there was concern about managing self-harm or suicide if the clinician was unable to monitor progress regularly due to after-hours cover, being part-time, or on annual leave. A potential solution proposed was for other people in the service to check alerts. Having a robust system in place with cross-cover arrangements would allow monitoring to continue in their absence. Similarly, having e-monitoring alerts sent to more than one clinician would allow more staff to better assess and manage risk.

> *I mean if I was working here and I saw it come through and I glance at it out of interest because I'm seeing the patient, I would be very happy and comfortable that the nurses had full ability to follow-up on that and someone else was doing it. It would be great. It would take too much time so that would be good.* [Clinician]

Adolescents realized that mood monitoring was based on honest responses by the user of the program, which may not always happen. They suggested that there should be "check-ins" alongside SPARX to ensure that the adolescent user was truly getting benefits from the treatment.

Confidentiality and Privacy

In keeping with the literature [29], confidentiality was an important consideration for both adolescents and clinicians. There were concerns about privacy, information use, and who had access to the information collected during the process of e-monitoring. Clinicians also had the impression that adolescents would prefer if their parents were not involved and that adolescents preferred to retain anonymity.

There was some discussion about social media, and this was in the context of adolescents possibly using their Facebook login credentials to access the cCBT program, an idea posed as a possible means of reducing registration overheads. Another idea raised was whether mental health programs should have a social media presence, given the potential stigma associated with mental illness. Adolescents were worried that others could see that they had signed up for SPARX through a Facebook announcement, and consequently asked that the option to register using a social media account be removed.

> *It's like when you are depressed or something, you don't like want to tell the whole world about it really.* [Adolescent]

XSL•FO
RenderX

Textbox 1. Key points arising during each phase.

Phases 1 and 2: Clinician and adolescent feedback

Clinicians and adolescents

Monitoring encourages:

- adolescents to continue with therapy
- clinicians to see progress
- clinicians to offer help

Concerns:

- Clinician burden: checking email inboxes regularly for clinician alerts would interfere with clinical time
- Privacy: how information would be used and who would have access to the information
- Linking with social media: others could see whether someone was accessing computerized cognitive behavioral therapy (cCBT)
- Registration process time-consuming
- Adolescents can change their contact numbers frequently; phone/text messaging them can be difficult

Suggestions:

Autonomy in choosing what information to share and how adolescents would be contacted

Clinicians only

Concerns:

- Impaired therapeutic relationship, perceived “brush off”
- Increased clinical responsibility and managing risk
- Depression severity can change quickly and unpredictably
- Clinicians becoming the main contact point during crises
- Receiving notifications when away from work, and need to check alerts several times daily
- Alerts being sent to only one clinician
- Seeking parental involvement for adolescents viewed as an obstacle
- Amount of detail and information recorded (during registration and while completing the program) may be considered intrusive
- Cannot provide e-monitoring to populations in socially disadvantaged areas who frequently do not have reliable Internet access
- Adolescents less likely to use/check email
- Security of email and whether alerts should be sent by email
- Supportive and positive material on cCBT program may result in reduced face-to-face contact
- Not all clinicians are technically minded

Potential benefits:

- Enhance adolescent’s sense of control
- E-monitoring through the use of embedded mood screening instruments would help provide finer detail and pattern of change that is sometimes not possible with face-to-face monitoring

Suggestions:

Care needed with nonclinical staff having access to computerized records, and e-monitoring to be confined to those clinicians seen to have the necessary clinical skills

Adolescents only

Concerns:

- Challenge of initiating first contact with clinician
- Underlying motivation or honesty in answering questions to access help

XSL•FO
RenderX

- The idea of registering via Facebook credentials was rejected (even though it would be quicker or easier) due to privacy concerns

Suggestions:

- Parallel check-ins for adolescents with clinicians when completing cCBT
- Social media sites could act as a platform to improve awareness of cCBT or even normalize its use
- Clinicians could register on their behalf for e-monitoring and send adolescents the registration details
- Need for a sensitive scale to judge severity and determine urgency of help rather than yes or no answers via questionnaires
- Incentives for achieving milestones when using cCBT rather than nagging reminders on the lack of completion
- Choice of communication medium, frequency of alerts, and personalized emails rather than having generic messages
- Details on how to access more help should be provided

Phase 3: Clinicians postimplementation

Benefits:

- Helpful to check whether cCBT completed
- E-monitor provides alternative form of communication

Concerns:

- Increased clinical burden and extra time required to check alerts
- Privacy concerns remained

Suggestions:

- Clarify purpose of e-monitor with adolescents and what information could be accessed via the monitor
- E-monitor and alerts should be integrated with existing electronic data management systems
- Emails to alert clinicians of at-risk adolescents and to remind clinicians to log in to the e-monitoring dashboard
- Emails to provide weekly or regular summaries in terms of adolescents' engagement and progress with SPARX (Smart, Positive, Active, Realistic, X-factor)

Reflections:

- Quality of therapeutic relationship remained good contrary to earlier expectations and, in some cases, was enhanced
- Triage person monitored alerts and then subsequently informed relevant clinicians

XSL•FO
RenderX

Textbox 2. Proposed solutions to issues identified.

Before commencing e-monitoring:

- Provide support and training for clinicians on how to use the computerized cognitive behavioral therapy (cCBT) and e-monitoring systems
- Need for monitoring is dependent on the situation
- Explaining to adolescents when it is helpful to use cCBT or e-monitoring, and how and when help should be accessed
- For those who prefer not to be e-monitored, they should be able to opt out, but the cCBT program should direct adolescents to seek help
- Social media not favored as a way of registering for cCBT or e-monitoring but a way to heighten awareness of cCBT options and availability
- Clinicians who use the e-monitor should be registered with a professional regulatory body
- Only clinical staff involved in care should have access to e-monitoring data

Monitoring arrangements:

Collaboration on the details shared: provide an information sheet to adolescents and parents (if adolescents agree) clarifying monitoring arrangements or level of detail gathered, and adolescents can choose the details that will be shared via e-monitoring

- Pair with a unique clinician registration code(s)
- Registration for both the adolescent and clinician should not be time-consuming or laborious
- Completion of registration for e-monitoring together with their clinician
- Clinicians should schedule periodic face-to-face check-ins alongside cCBT
- A zero-risk approach for clinicians prescribing cCBT and e-monitoring to address concerns of clinical risk and responsibility

Alerts and seeking further help:

- Secure messaging system to alert clinicians and also to prompt adolescents
- Email alerts to clinicians about adolescents' SPARX (Smart, Positive, Active, Realistic, X-factor) progress and weekly summaries rather than only alerts to flag concerns
- Email, phone, or text alerts to be sent to adolescents rather than any one particular medium; this is an opportunity to personalize e-monitoring and with supportive messages at certain milestones
- Clinician receipt of an alert would prompt a face-to-face assessment
- Involvement of more than one clinician in order to support work patterns; checking of alerts and clinical responsibility
- Acutely suicidal adolescents should be prompted to seek help
- Emergency helpline contact numbers that adolescents can access when distressed
- Multiagency support involving primary care, schools, 24-hour helplines, and community mental health services

Some clinicians believed there would be reduced adolescent uptake should their details be identifiable via social media. However, many clinicians did not have privacy concerns especially if details were provided on the e-monitoring arrangements to the adolescent beforehand. Both adolescents and clinicians generally agreed that SPARX users should be given the option of selecting what information they wanted to share and how to be contacted.

Technical Considerations

Both adolescents and clinicians agreed that the registration process for e-monitoring should not be time-consuming. Ideally, clinicians would like to do it with the individual still present in their office, time permitting. Adolescents may change their contact details frequently, and therefore discussing the right communication medium is necessary. Technical aids such as information booklets with pictorial guides could be provided. Some adolescents suggested that the registration process should be "short and sweet" and there should be shortcuts, for example, a "Play Now" button that takes you straight to the program. Others said it would be easier for their clinician to complete the registration on their behalf and then send them the details.

Some clinicians wondered who should have access to the tool and whether it should be restricted to those with appropriate clinical skills and experience. They suggested that before a clinician was given access to e-monitoring (or the ability to "prescribe" SPARX), their credentials should be verified with the relevant regulatory agencies that maintain the professional registration of clinicians. A minority of clinicians thought that the positive and supportive material within the cCBT program may cause some adolescents to avoid being e-monitored. This is because mood may improve while undergoing cCBT, and consequently the adolescent may view engagement with the clinician as unnecessary. Despite concerns about the security of emails and the way alerts would be sent, overall clinicians were supportive of e-monitoring.

Many clinicians also suggested integrating the e-monitor and alerts with existing patient management systems (including electronic mailboxes that receive laboratory results). Clinicians

XSL•FO
RenderX

supported the use of the Web-based tools built into the e-monitoring system for assessing mood, for example, PHQ-A, as these would potentially allow the "teasing out" of mood symptoms in greater detail so that energy, sleep, concentration, and other dimensions could be clarified. When adolescents describe low-mood symptoms, e-monitoring would potentially allow the assessment of the pattern of change over time. Clinicians felt that the acquisition of such finer detail is currently not possible with many face-to-face meetings. However, internet connectivity is key to e-monitoring, and adolescents experiencing sociodemographic deprivation may be particularly disadvantaged in this regard.

Adolescents had a number of suggestions concerning the technical aspects of e-monitoring, but perhaps unsurprisingly, they were different from those expressed by the clinicians. Adolescents wanted to select a communication method (eg, email, texting) and agree this with the clinician. Adolescents were cognizant that the severity of symptoms varies between individuals and wanted alerts to the clinician set at a threshold high enough to warrant attention. Some also wanted to include a function that would allow the users to determine the urgency of the situation. Adolescents suggested that the following information be included when informing potential SPARX users about the ways to get help: "A recommended doctor," "What to do if you're depressed and you got no one," "And if you don't trust anyone to talk to." Information where and how to access help (including after-hours help) should be prominent, clear, and available to all users (including those who may not need it immediately). Adolescents did not wish to receive many "unnecessary" alerts (via email or text). Therefore, the alerts going back to users should be sent at milestones (eg, completion of levels) and should not be sent too frequently. Personalized messages were favored over automated ones as they would "make you want to read it more."

Clinician Feedback on the E-Monitoring Tool Postimplementation (Phase 3)

Following the use of the e-monitor in clinical practice, clinicians provided feedback that was often consistent with their prior responses during the consultation and development phases of the e-monitoring tool.

Clinical Progress, Confidentiality, and Privacy

Clinicians noted that e-monitoring was "another thing to remember," requiring additional work, and following up with adolescents took more time than they allocated. For many, although the e-monitor was available, it was not used. During use of the tool, one primary contact was allocated to receive all the alerts in a clinic and then notify clinicians as appropriate. This process worked well but required dedicated time. The use of e-monitoring in this way was different from how it was originally conceptualized by the clinicians.

Overall, clinicians explained that e-monitoring was helpful in checking whether adolescents had completed SPARX. They also described that e-monitoring provided another form of communication between them and the adolescent. Clinicians who used the tool believed that the quality of their relationship with adolescents was unaffected by the use of e-monitoring. Some clinicians, contrary to their earlier expectations, reported that it strengthened the therapeutic relationship as the adolescent felt more supported. Clinicians reported that e-monitoring was not on adolescents' "radar" when they were doing it. So, it did not impact the therapeutic relationship, and clinicians continued to engage and talk with adolescents as they normally would. Overall, clinicians thought that the process worked well and shared similar views in terms of privacy considerations described earlier. They clarified with adolescents the purpose of e-monitoring and what information they could access from the e-monitor.

Technical Considerations

Despite attempts to keep the registration process simple, the log-on process was a barrier and "could be simpler." Clinicians suggested an e-monitoring icon that could be integrated onto their current desktop to simplify access and serve as a reminder or prompt to check adolescents' progress. Email alerts were widely discussed, and clinicians thought that these could serve a variety of purposes, including alerting of at-risk adolescents, reminding them to log in, and providing regular summaries in terms of adolescents' engagement and progress with SPARX.

Final Version of the E-Monitor

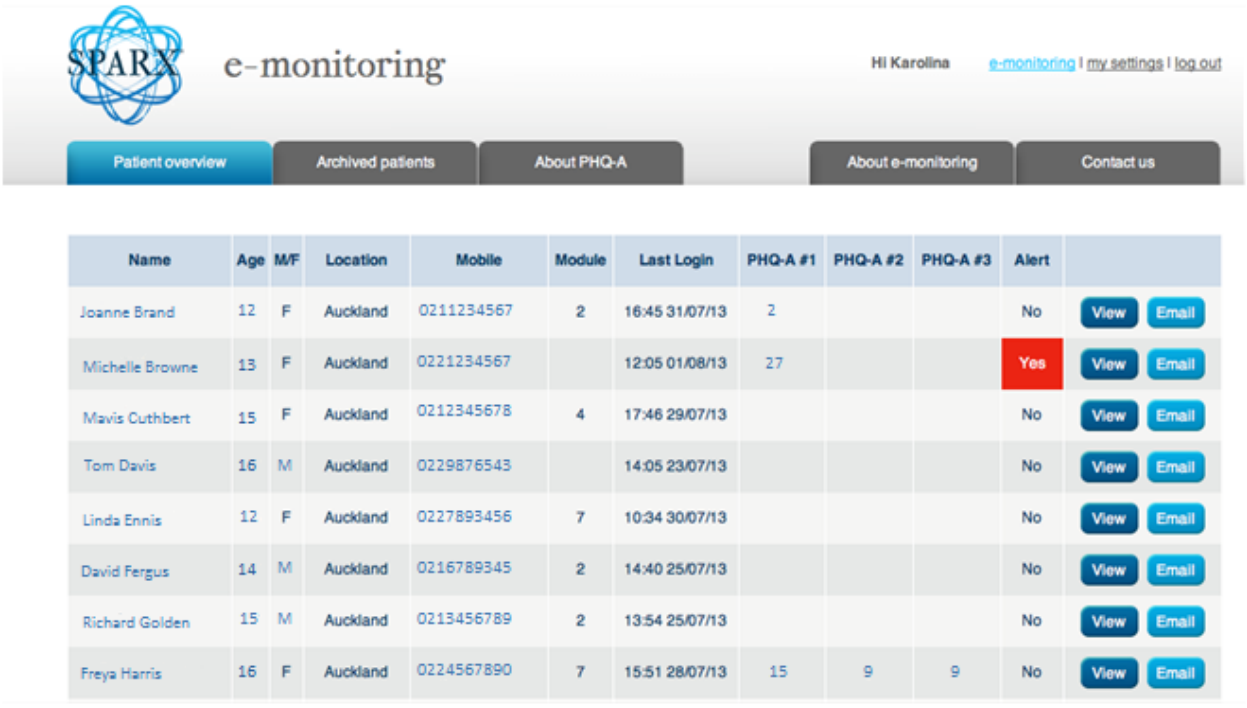
In order to minimize burden on users and increase engagement with the program, mood was tracked in SPARX at the 3 time points originally proposed. Other suggestions from adolescents and clinicians are found in Textboxes 1 and 2, alongside considerations for an e-monitoring system to work effectively. Following the development and postimplementation phases, the e-monitor created (Figures 1 and 2) had the following features in (Textbox 3)

XSL•FO
RenderX

Textbox 3. Key features of the final version of the e-monitor.

- A registration system for clinicians to gain access to the e-monitoring section of SPARX (Smart, Positive, Active, Realistic, X-factor), and a process to ensure that the prescribing clinician is registered with a professional regulatory body
- A unique registration code that is provided to the e-monitored adolescent, which corresponds to their prescribing clinician(s) in the service involved in their care in order to preserve privacy
- Electronic linking of adolescent user data (self-reported mood and rates of completion generated while completing SPARX) to the referring clinician
- Not linking the adolescents' social media account to their computerized cognitive behavioral therapy (cCBT) or e-monitoring log-in
- The ability to personalize the e-monitor by the adolescent customizing the frequency of reminders and preferred communication medium with their clinician
- A Web-based dashboard to allow clinicians to track all the adolescent users (current and historical) who were prescribed SPARX
- An algorithm to automatically generate alerts at specific and concerning levels of depression or self-harm (as evidenced on a self-rated depression rating scale)
- A system to encourage adolescents to access help and contact details for emergency services
- A system of alerts sent directly to the clinician (and also weekly email updates) on the adolescent user being e-monitored

Figure 1. A final version of the e-monitoring dashboard following consultation with clinicians depicting fictional data of adolescents prescribed computerized cognitive behavioral therapy (cCBT) (SPARX [Smart, Positive, Active, Realistic, X-factor]), with an example of an alert. PHQ-A: Patient Health Questionnaire for Adolescents.



Name	Age	M/F	Location	Mobile	Module	Last Login	PHQ-A #1	PHQ-A #2	PHQ-A #3	Alert	
Joanne Brand	12	F	Auckland	0211234567	2	16:45 31/07/13	2			No	View Email
Michelle Browne	13	F	Auckland	0221234567		12:05 01/08/13	27			Yes	View Email
Mavis Cuthbert	15	F	Auckland	0212345678	4	17:46 29/07/13				No	View Email
Tom Davis	16	M	Auckland	0229876543		14:05 23/07/13				No	View Email
Linda Ennis	12	F	Auckland	0227893456	7	10:34 30/07/13				No	View Email
David Fergus	14	M	Auckland	0216789345	2	14:40 25/07/13				No	View Email
Richard Golden	15	M	Auckland	0213456789	2	13:54 25/07/13				No	View Email
Freya Harris	16	F	Auckland	0224567890	7	15:51 28/07/13	15	9	9	No	View Email

XSL•FO
RenderX

Figure 2. Clinician view of progress, mood, and risks for an individual prescribed computerized cognitive behavioral therapy (cCBT) (fictional data). PHQ-A: Patient Health Questionnaire for Adolescents.



Discussion

Principal Findings

Our study focused on the development and use of an e-monitoring tool in clinical practice. It is therefore a timely contribution, as the area of electronically supported psychotherapy is very much in its infancy [30,31]. Using a codesign process, we developed an e-monitoring tool that would enable clinicians to electronically supervise adolescents with depression completing Web-based cCBT. There are various options for providing supported therapy, and the proposed e-monitoring tool for SPARX not only provides a mechanism for clinicians to monitor an adolescent's progress, but also affords them an opportunity to gain regular depression assessment data via the Internet in the absence of face-to-face therapy.

In line with recent treatment preferences, clinicians were in favor of a system of monitoring adolescents with mild-to-moderate depression that embraced technology, various communication modalities, and a clinician-adolescent shared decision-making approach [32,33]. E-monitoring in tandem with face-to-face check-ins could potentially address clinician and adolescent concerns of no one providing oversight of a cCBT program such as SPARX, and this is a solution that has been previously identified in the literature [34]. While computer-based clinician support systems are increasingly gaining traction, it is also important that these do not place additional demands on the clinician's workload [35]. Providing e-monitoring as well as face-to-face supervision may result in duplication of assessments and an increased clinician workload, but the need for such additional face-to-face assessment may reflect the reluctance of clinicians in depending on systems other than their own clinical judgment gathered from direct clinical contact.

Clinicians in our study also recognized the potential difficulties associated with after-hours monitoring and responding to concerns. Therefore, monitoring arrangements should be preagreed with adolescents in relation to checking alerts and also with regard to their preferred communication methods (phone, text alerts, emails). As has been recommended by others, relevant contact numbers can be provided by a GP [36] should a user or client experience a crisis, or these details could be embedded in the cCBT program, or alternatively, integrated between hotlines or emergency services and the cCBT program. Whereas the latter would be a novel and useful contribution (because most programs do not have such integration built-in), there may be additional challenges to implement this, as it involves a wider group of stakeholders. Additionally, clinicians would like e-monitoring integrated with the existing patient data management systems they are familiar with for receiving and monitoring alerts. Logistically this is a challenging prospect, as clinicians in primary care utilize different systems, and there may be little motivation on the part of the developers of patient data management systems to include e-monitors (like the one we have developed) into their systems.

There have been e-monitoring studies on various health conditions such as asthma and human immunodeficiency virus infection focusing on treatment adherence [37,38]. However, there are only a limited number of studies that have directly involved clinicians in a codesign process. For example, a Swiss qualitative study conducted with pharmacists on the implementation of an e-monitoring system for supporting treatment adherence similarly highlighted some of the difficulties we encountered, specifically the challenges of integrating an e-monitor into existing systems, but preexisting

XSL•FO
RenderX

collaboration with physicians on codesigning the system helped [39]. Understandably clinicians would like to use an e-monitoring system that is simple to access, but also ensures privacy and confidentiality. Future developments should strive to fully integrate e-monitoring into existing data management systems, as challenging as this may be, so that e-monitoring is maximally useful to clinicians and acceptable to users [40].

During the development phase of the e-monitor in our study, clinicians noted several concerns. However, when they were followed up after using the tool postimplementation, they found that some of the initially identified concerns did not eventuate. For example, clinicians expected a negative impact on the therapeutic relationship but this did not arise. Also, during the development phase, alerts were envisaged to be sent to clinicians to highlight adolescents who might be critical in terms of mood severity or risks. However, they used the tool somewhat differently from what had been proposed during the postimplementation phase, because clinicians flagged that it required additional time for e-monitoring to occur. So, a dedicated clinician at the primary care service reviewed the dashboard and alerts regularly, and informed the other monitoring clinicians about the progress of their adolescent users. This was not how the e-monitor was originally designed to work, but it demonstrated a practical adaptation at this particular service. As clinicians are also concerned about the practicalities of e-monitoring, when a GP becomes the main crisis-intervention provider, there have been suggestions of a "zero-risk" approach for GPs and sharing of clinical responsibility with crisis teams [36,41].

Adolescents valued their privacy and preferred not to use their social networking login details. They also preferred a quick registration process, but one that either they or clinicians could undertake on their behalf. Moreover, adolescents wanted to discuss and customize e-monitoring arrangements and the timing and frequency of feedback they received via the e-monitor. While adolescents preferred their parents not to be involved in the e-monitoring process, they welcomed parallel monitoring with face-to-face check-ins with their clinician, despite reported difficulties with adolescents seeking help or expressing their concerns directly via face-to-face conversations [42]. Adolescents also wanted information on how to access support, especially after-hours when their clinician might be unavailable. As most adolescents have access to the Internet [43], this makes a Web-based e-monitoring system feasible in practice. With regard to SPARX (with or without e-monitoring), it has the capacity to advise adolescents to seek immediate help if they achieve a high score on mood symptoms or risk, but in practice, it may be difficult for the adolescent to ask for help. Information sheets could be provided prior to e-monitoring or during primary care consults, as depressed adolescents often do not recall details of consultations due to impaired concentration [36].

Limitations

This qualitative study involved adolescents and clinicians in New Zealand who, respectively, had experienced mental health difficulties and those who had managed adolescents with depression in primary care. The main limitation was that we were unable to take our interpretations of the data back to the participants for verification, which limited the study's trustworthiness. Additionally, we were not able to undertake a systematic evaluation of the e-monitoring tool at multiple primary care sites or involve adolescents in the postimplementation phase. This was due to time and resource constraints. However, the multidisciplinary research team consisted of experienced clinicians who were directly involved in adolescent mental health and therefore very familiar with the issues.

Conclusions

Depression often commences during a critical period of early development, so addressing the needs of adolescents yields not only significant improvements in their health care outcomes, but also longer-term benefits over their life span [44,45]. Clinician and adolescent views were acquired on e-monitoring for cCBT, an area with little previous empirical research and even less so in primary care where adolescents are usually seen for depression. Subsequently, an e-monitoring tool was designed in line with clinicians' wishes for oversight of adolescents using SPARX. The e-monitor was also designed with the "needs and wants" of adolescents and included a system that was easy to use with information and alerts. We are currently exploring ways in which the e-monitor for SPARX can be integrated into patient data management systems. Overall, clinical progress, confidentiality or privacy, and technical issues need to be considered alongside discussion between the clinician and the adolescent prior to commencement of e-monitoring arrangements. The findings from this study are potentially applicable beyond the adolescent population and will be of interest to developers of the various cCBT packages who may be considering a monitoring or feedback mechanism.

Acknowledgments

The authors would like to thank the clinicians and adolescents who participated in this study. Additional thanks to the staff and participants from Kapiti Youth Support. The study was funded by the Health Research Council of New Zealand, and the development of SPARX was funded by the New Zealand Ministry of Health. The national distribution of SPARX in New Zealand has been funded by the Prime Minister's Youth Mental Health Project.

Conflicts of Interest

Intellectual property for SPARX is owned by Uniservices Ltd at The University of Auckland. The cocreators of SPARX (SM, KS, TF, MS, and ML) can benefit from its commercialization.

XSL•FO
RenderX

Multimedia Appendix 1

Semi-structured schedule used with focus groups.

[PDF File (Adobe PDF File), 33KB - mental_v4i1e3_app1.pdf]

References

1. Costello EJ, Erkanli A, Angold A. Is there an epidemic of child or adolescent depression? J Child Psychol Psychiatry 2006 Dec;47(12):1263-1271. [doi: 10.1111/j.1469-7610.2006.01682.x] [Medline: 17176381]
2. Lewinsohn PM, Pettit JW, Joiner Jr TE, Seeley JR. The symptomatic expression of major depressive disorder in adolescents and young adults. J Abnorm Psychol 2003 May;112(2):244-252. [Medline: 12784834]
3. Kessler RC, Avenevoli S, Merikangas KR. Mood disorders in children and adolescents: an epidemiologic perspective. Biol Psychiatry 2001 Jun 15;49(12):1002-1014. [Medline: 11430842]
4. Wilkinson P, Dubicka B, Kelvin R, Roberts C, Goodyer I. Treated depression in adolescents: predictors of outcome at 28 weeks. Br J Psychiatry 2009 Apr;194(4):334-341 [FREE Full text] [doi: 10.1192/bjp.bp.108.052381] [Medline: 19336785]
5. Mariu KR, Merry SN, Robinson EM, Watson PD. Seeking professional help for mental health problems, among New Zealand secondary school students. Clin Child Psychol Psychiatry 2012 Apr;17(2):284-297. [doi: 10.1177/1359104511404176] [Medline: 21852315]
6. Computerised Cognitive Behaviour Therapy for the Treatment of Depression and Anxiety. London: National Institute for Health and Clinical Excellence; 2006.
7. Richardson T, Stallard P, Velleman S. Computerised cognitive behavioural therapy for the prevention and treatment of depression and anxiety in children and adolescents: a systematic review. Clin Child Fam Psychol Rev 2010 Sep;13(3):275-290. [doi: 10.1007/s10567-010-0069-9] [Medline: 20532980]
8. Kenardy J, Adams C. Computers in cognitive-behaviour therapy. Aust Psychol 1993;28(3):189-194. [doi: 10.1080/00050069308258900]
9. Naslund JA, Marsch LA, McHugo GJ, Bartels SJ. Emerging mHealth and eHealth interventions for serious mental illness: a review of the literature. J Ment Health 2015;24(5):321-332. [doi: 10.3109/09638237.2015.1019054] [Medline: 26017625]
10. Dowrick C. Computerised self help for depression in primary care. Br Med J 2015;351:h5942. [doi: 10.1136/bmj.h5942] [Medline: 26561033]
11. Perini S, Titov N, Andrews G. Clinician-assisted Internet-based treatment is effective for depression: randomized controlled trial. Aust N Z J Psychiatry 2009 Jun;43(6):571-578. [doi: 10.1080/00048670902873722] [Medline: 19440890]
12. Høifødt RS, Lillevoll KR, Griffiths KM, Wilsgaard T, Eisemann M, Waterloo K, et al. The clinical effectiveness of web-based cognitive behavioral therapy with face-to-face therapist support for depressed primary care patients: randomized controlled trial. J Med Internet Res 2013;15(8):e153 [FREE Full text] [doi: 10.2196/jmir.2714] [Medline: 23916965]
13. van der Vaart R, Witting M, Riper H, Kooistra L, Bohlmeijer ET, van Gemert-Pijnen LJ. Blending online therapy into regular face-to-face therapy for depression: content, ratio and preconditions according to patients and therapists using a Delphi study. BMC Psychiatry 2014;14(1):355 [FREE Full text] [doi: 10.1186/s12888-014-0355-z] [Medline: 25496393]
14. Wentzel J, van der Vaart R, Bohlmeijer ET, van Gemert-Pijnen JE. Mixing online and face-to-face therapy: how to benefit from blended care in mental health care. JMIR Ment Health 2016;3(1):e9 [FREE Full text] [doi: 10.2196/mental.4534] [Medline: 26860537]
15. Kleiboer A, Donker T, Seekles W, van Straten A, Riper H, Cuijpers P. A randomized controlled trial on the role of support in Internet-based problem solving therapy for depression and anxiety. Behav Res Ther 2015 Sep;72:63-71. [doi: 10.1016/j.brat.2015.06.013] [Medline: 26188373]
16. Nielssen O, Dear BF, Staples LG, Dear R, Ryan K, Purtell C, et al. Procedures for risk management and a review of crisis referrals from the MindSpot Clinic, a national service for the remote assessment and treatment of anxiety and depression. BMC Psychiatry 2015;15:304 [FREE Full text] [doi: 10.1186/s12888-015-0676-6] [Medline: 26626712]
17. Hunt S, Howells E, Stapleton B. The addition of a computerised cognitive behavioural therapy program, to a stepped care, primary care mental health service. The Journal of Primary Care Mental Health 2006;9(2):34.
18. Proudfoot J, Goldberg D, Mann A, Everitt B, Marks I, Gray JA. Computerized, interactive, multimedia cognitive-behavioural program for anxiety and depression in general practice. Psychol Med 2003 Feb;33(2):217-227. [Medline: 12622301]
19. Stallard P, Richardson T, Velleman S, Attwood M. Computerized CBT (Think, Feel, Do) for depression and anxiety in children and adolescents: outcomes and feedback from a pilot randomized controlled trial. Behav Cogn Psychother 2011 May;39(3):273-284. [doi: 10.1017/S135246581000086X] [Medline: 21272393]
20. Spence SH, Donovan CL, March S, Gamble A, Anderson R, Prosser S, et al. Online CBT in the treatment of child and adolescent anxiety disorders: issues in the development of BRAVE–ONLINE and Two Case Illustrations. Behav Cogn Psychother 2008;36(4):411-430. [doi: 10.1017/S135246580800444X]
21. Merry SN, Stasiak K, Shepherd M, Frampton C, Fleming T, Lucassen MF. The effectiveness of SPARX, a computerised self help intervention for adolescents seeking help for depression: randomised controlled non-inferiority trial. Br Med J 2012;344:e2598 [FREE Full text] [doi: 10.1136/bmj.e2598] [Medline: 22517917]

XSL•FO
RenderX

22. 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]
23. National Research Council & Institute of Medicine. Preventing mental, emotional, and behavioral disorders among young people: Progress and possibilities. Washington, DC: The National Academies Press; 2009.
24. Johnson JG, Harris ES, Spitzer RL, Williams JB. The patient health questionnaire for adolescents: validation of an instrument for the assessment of mental disorders among adolescent primary care patients. J Adolesc Health 2002 Mar;30(3):196-204. [Medline: 11869927]
25. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. J Am Med Assoc 1999 Nov 10;282(18):1737-1744. [Medline: 10568646]
26. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007 Dec;19(6):349-357 [FREE Full text] [doi: 10.1093/intqhc/mzm042] [Medline: 17872937]
27. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
28. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. Am J Eval 2006 Jun 01;27(2):237-246. [doi: 10.1177/1098214005283748]
29. Ford CA, Millstein SG, Halpern-Felsher BL, Irwin Jr CE. Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future health care. A randomized controlled trial. J Am Med Assoc 1997 Sep 24;278(12):1029-1034. [Medline: 9307357]
30. Wilhelmsen M, Høifødt RS, Kolstrup N, Waterloo K, Eisemann M, Chenhall R, et al. Norwegian general practitioners' perspectives on implementation of a guided web-based cognitive behavioral therapy for depression: a qualitative study. J Med Internet Res 2014;16(9):e208 [FREE Full text] [doi: 10.2196/jmir.3556] [Medline: 25208886]
31. Montero-Marín J, Prado-Abril J, Botella C, Mayoral-Cleries F, Baños R, Herrera-Mercadal P, et al. Expectations among patients and health professionals regarding Web-based interventions for depression in primary care: a qualitative study. J Med Internet Res 2015;17(3):e67 [FREE Full text] [doi: 10.2196/jmir.3985] [Medline: 25757358]
32. Gray JAM. The Resourceful Patient. Oxford: eRosetta Press; 2002.
33. Powell JA, Darvell M, Gray JAM. The doctor, the patient and the world-wide web: how the internet is changing healthcare. J R Soc Med 2003 Feb;96(2):74-76 [FREE Full text] [Medline: 12562977]
34. Rhodes H, Grant S. A review of computerised cognitive behavioural therapy (cCBT) for depression. Cumbria Partnership Journal of Research Practice and Learning 2012;2(1):2-9.
35. Miller P, Phipps M, Chatterjee S, Rajeevan N, Levin F, Frawley S, et al. Exploring a clinically friendly web-based approach to clinical decision support linked to the electronic health record: design philosophy, prototype implementation, and framework for assessment. JMIR Med Inform 2014 Jul;2(2):e20 [FREE Full text] [doi: 10.2196/medinform.3586] [Medline: 25580426]
36. Falconer M, Arroll B. Beating the Blues the online way. New Zealand Doctor. 2012. p. 34-35 URL: http://psychd.co.nz/wp-content/uploads/2012/05/NZD-BtB-article-Mental-Health-18-July-2012.pdf
37. Chan AHY, Reddel HK, Apter A, Eakin M, Riekert K, Foster JM. Adherence monitoring and e-health: how clinicians and researchers can use technology to promote inhaler adherence for asthma. J Allergy Clin Immunol Pract 2013;1(5):446-454. [doi: 10.1016/j.jaip.2013.06.015] [Medline: 24565615]
38. Anderson 3rd WC, Szefler SJ. New and future strategies to improve asthma control in children. J Allergy Clin Immunol 2015 Oct;136(4):848-859. [doi: 10.1016/j.jaci.2015.07.007] [Medline: 26318072]
39. Marquis J, Schneider MP, Spencer B, Bugnon O, Du Pasquier S. Exploring the implementation of a medication adherence programme by community pharmacists: a qualitative study. Int J Clin Pharm 2014 Oct;36(5):1014-1022. [doi: 10.1007/s11096-014-9989-7] [Medline: 25139136]
40. De Bleser L, De Geest S, Vincke B, Ruppar T, Vanhaecke J, Dobbels F. How to test electronic adherence monitoring devices for use in daily life: a conceptual framework. Comput Inform Nurs 2011 Sep;29(9):489-495. [doi: 10.1097/NCN.0b013e31821a1555] [Medline: 21532468]
41. de Montalk J. 'Zero-risk' e-tool beats the blues. New Zealand Doctor 2012:30.
42. Coyle D, McGlade N, Doherty G, O'Reilly G. Exploratory evaluations of a computer game supporting cognitive behavioural therapy for adolescents. 2011 Presented at: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; 2011; Vancouver p. 2937-2946. [doi: 10.1145/1978942.1979378]
43. Madden M, Lenhart A, Duggan M, Cortesi S, Gasser U. Teens and Technology 2013 Pew Research Center. 2013. URL: http://www.pewinternet.org/2013/03/13/teens-and-technology-2013/ [accessed 2016-09-03] [WebCite Cache ID 6kEQO76lI]
44. 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] [Medline: 19699995]
45. Weller EB, Weller RA. Depression in adolescents growing pains or true morbidity? J Affect Disord 2000 Dec;61(Suppl 1):9-13. [Medline: 11155967]

XSL•FO
RenderX

Abbreviations

CBT: cognitive behavioral therapy
cCBT: computerized cognitive behavioral therapy
GP: general practitioner
PHQ-A: Patient Health Questionnaire for Adolescents
SPARX: Smart, Positive, Active, Realistic, X-factor

Edited by G Eysenbach; submitted 16.04.16; peer-reviewed by C Eichenberg, P Yip, R van der Vaart; comments to author 27.07.16; revised version received 05.09.16; accepted 13.12.16; published 11.01.17.

Please cite as:
Sundram F, Hawken SJ, Stasiak K, Lucassen MFG, Fleming T, Shepherd M, Greenwood A, Osborne R, Merry SN
Tips and Traps: Lessons From Codesigning a Clinician E-Monitoring Tool for Computerized Cognitive Behavioral Therapy
JMIR Ment Health 2017;4(1):e3
URL: http://mental.jmir.org/2017/1/e3/
doi:10.2196/mental.5878
PMID:28077345

©Frederick Sundram, Susan J Hawken, Karolina Stasiak, Mathijs FG Lucassen, Theresa Fleming, Matthew Shepherd, Andrea Greenwood, Raechel Osborne, Sally N Merry. Originally published in JMIR Mental Health (http://mental.jmir.org), 11.01.2017. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Mental Health, is properly cited. The complete bibliographic information, a link to the original publication on http://mental.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Use of Online Forums for Perinatal Mental Illness, Stigma, and Disclosure: An Exploratory Model

Donna Moore[1], MSS; Nicholas Drey[2], PhD; Susan Ayers[1], PhD

[1]Centre for Maternal and Child Health, School of Health Sciences, City, University of London, London, United Kingdom

[2]School of Health Sciences, City, University of London, London, United Kingdom

Corresponding Author:
Donna Moore, MSS
Centre for Maternal and Child Health
School of Health Sciences
City, University of London
Northampton Square
London,
United Kingdom
Phone: 44 20 7040 5
Fax: 44 000000000000
Email: Donna.Moore.1@city.ac.uk

Abstract

Background: Perinatal mental illness is a global health concern; however, many women with the illness do not get the treatment they need to recover. Interventions that reduce the stigma around perinatal mental illness have the potential to enable women to disclose their symptoms to health care providers and consequently access treatment. There are many online forums for perinatal mental illness and thousands of women use them. Preliminary research suggests that online forums may promote help-seeking behavior, potentially because they have a role in challenging stigma. This study draws from these findings and theoretical concepts to present a model of forum use, stigma, and disclosure.

Objective: This study tested a model that measured the mediating role of stigma between online forum use and disclosure of affective symptoms to health care providers.

Methods: A Web-based survey of 200 women who were pregnant or had a child younger than 5 years and considered themselves to be experiencing psychological distress was conducted. Women were recruited through social media and questions measured forum usage, perinatal mental illness stigma, disclosure to health care providers, depression and anxiety symptoms, barriers to disclosure, and demographic information.

Results: There was a significant positive indirect effect of length of forum use on disclosure of symptoms through internal stigma, b=0.40, bias-corrected and accelerated (BCa) 95% CI 0.13-0.85. Long-term forum users reported higher levels of internal stigma, and higher internal stigma was associated with disclosure of symptoms to health care providers when controlling for symptoms of depression and anxiety.

Conclusions: Internal stigma mediates the relationship between length of forum use and disclosure to health care providers. Findings suggest that forums have the potential to enable women to recognize and reveal their internal stigma, which may in turn lead to greater disclosure of symptoms to health care providers. Clinicians could refer clients to trustworthy and moderated online forums that facilitate expression of perinatal mental illness stigma and promote disclosure to health care providers.

(JMIR Ment Health 2017;4(1):e6) doi:10.2196/mental.5926

KEYWORDS

Internet; social stigma; depression; postpartum; mood disorder; female

XSL•FO
RenderX

Introduction

Perinatal Mental Illness and Stigma

The term *perinatal mental illnesses* is used throughout this paper to refer to conditions that include depression, anxiety, obsessive compulsive disorder, post-traumatic stress disorder, and puerperal psychosis. Perinatal mental illness is a global health concern [1]. However, prevalence varies depending on a variety of factors such as the instrument used to measure symptoms, developed versus less developed countries, time of evaluation in the gestational or postnatal period, and whether the sample is high risk. Antenatal depression and anxiety occur in approximately 7% to 25% of pregnant women [2-4]. Postnatal depression has a prevalence of 12% to 20% and postnatal anxiety affects 3% to 43% of women [5,6]. Post-traumatic stress disorder occurs in 3.17% of new mothers and can affect up to 15% of women in high-risk groups [7]. Puerperal psychosis occurs in approximately 1-2 per 1000 women [8,9]. Moreover, many women suffer from symptoms associated with mental illness without detection because they do not conform to all the diagnostic criteria [10].

Approximately half the women with perinatal mental illness fail to get professional treatment despite regular contact with health care providers [11]. One reason for this is that the stigma associated with perinatal mental illness can be a barrier to women disclosing and seeking help [12]. External stigma is a negative attitude held by the general public toward an individual or group based on an undesirable quality, for example, mental illness [13]. These negative social stereotypes can lead to labeling the individual as deviant or inferior. Consequently, discriminatory behavior can occur toward the stigmatized group, for example, through social exclusion and marginalization [14]. A UK survey showed that 85% of respondents believed people with mental illness experience stigma and discrimination [15]. There has been noteworthy research and interventions to combat this pervasive social problem; for example, Mind and Rethink Mental Illness developed the “Time to Change” campaign [16].

Internal stigma can occur when stigmatized individuals agree with external stigma and apply it to themselves or they may feel external stigma is unreasonable yet still appraise themselves negatively. There are many detrimental outcomes of internal stigma including lowered self-esteem, lowered life satisfaction, and avoidance of both disclosure and help-seeking behavior [17,18]. High levels of internal stigma have been identified in approximately a third of people with severe mental illnesses [19]. Furthermore, it is important to distinguish between discrimination an individual experiences and external stigma the individual believes others hold without actually experiencing it (known as perceived external stigma). Perceived external stigma correlates with adverse health and mental health outcomes [20,21]. One consequence of perceived external stigma and internal stigma is that they can contribute to stigma associated with disclosure [22]. This paper defines this as “disclosure stigma”: the anticipated negative appraisal and anticipated negative behavior toward the stigmatized individual if he or she chose to disclose to others. This means that stigma could be a key component in an individual’s decision-making process when choosing whether or not to disclose his or her symptoms of mental illness.

Internet Forums for Stigmatized Mental Illnesses

Internet forums are online discussions where users can have conversations with others by posting messages. They have potential to be an acceptable aid to people with stigmatized conditions as they can use them anonymously, thus circumventing possible negative outcomes associated with stigma [23,24]. Anonymity may also assist online disclosure, which may otherwise be difficult offline [25,26]. Forums for mental health have shown potential for helping people manage or recover from a variety of mental illnesses, in particular, depression [27-29]. They provide an opportunity to connect with similar others and share informational and emotional support [30]. Benefits include social support, communicating experiences with others who share their illness, expressing emotions, group identity, and empowerment and can reduce isolation [29,31-35]. There is some evidence from randomized controlled trials that forum use reduces depressive symptoms [36]. These and other benefits have been reported by both active users (visitors who post on forums) and lurkers (visitors who only read forum messages and do not post), although some evidence suggests lurkers benefit less than active users [37,38]. It is estimated that lurkers make up the majority of forum visitors, with reports of between 45% and 90% of users lurking [39,40].

There is some evidence that engagement with online forums has the potential to reduce stigma [41,42]. Online forums may challenge stigma, help cope with stigma, provide useful tools in testing out disclosing of symptoms and conversing about stigma surrounding mental health. Some research suggests that online forums could challenge stigma through empowerment, giving hope of recovery, and increasing knowledge of health care decisions [29]. Theoretically, all these factors could positively influence disclosure to health care providers and subsequently increase treatment uptake and recovery rates. Disclosure may also be encouraged through social support and posts that direct posters to consult health care providers [30]. Nonetheless, it should be noted that recent research highlights concerns regarding forum use and detrimental outcomes such as social avoidance, Internet addiction, and enabling negative behaviors, such as pro-anorexic forums [43-45].

Online Forums for Perinatal Mental Illness and Stigma

It is arguable that stigma associated with perinatal mental illness is distinct from mental illness stigma experienced at other times. There are specific concerns related to maternal identity and mental illness such as worries about social services’ involvement, custodial rights, and being judged by others and judging themselves as a “bad mother” [46]. This is complex as some symptoms are highly stigmatized and propagate guilt, shame, and consequent concealment of their illness, for example, suicidal ideation and thoughts of child abuse. Goffman’s (1963) theory of spoiled identity could be applied to understand how women may experience stigma affecting their maternal identity [13]. Many symptoms of perinatal mental illness are seen as incompatible with being a good mother and can exacerbate women’s illness. For example, a woman with postnatal obsessive

XSL•FO
RenderX

compulsive disorder might have persistent intrusive thoughts about harming her baby even though she does not act on them. This is a symptom of the illness, but it generates substantial distress and can damage her identity as a mother as these thoughts are not what she thinks a good mother should have.

Indeed, perinatal mental illness stigma could be conceptualized as multifaceted: comprising stigma associated with mental illness and stigma associated with being a mother with a mental illness. This stigma could comprise perceived external stigma, internal stigma, and disclosure stigma. All facets of this stigma could contribute to a woman's reluctance to disclose symptoms to health care providers [47,48]. It is vital that research and interventions target perinatal mental illness stigma to enable women to disclose, which is the first step to recovery.

One possible avenue for reducing stigma are online forums for perinatal mental illness. There are thousands of online forums for perinatal mental illness with a large flow of traffic indicating that they are highly used [49]. Some evidence highlights that perinatal mental illness forums might provide women with valuable peer support outside the hours of health care provider appointments [50]. Moreover, some research suggests that these forums provide social support that may challenge stigma. One study found an online forum for postnatal depression to be nonjudgmental and posts encouraged users to disclose and seek professional help [51]. Another study documented how online support forums for lesbians with postnatal depression provided social support and a space to communicate stigma [52]. Many women were reluctant to disclose and seek help because of stigma; they were worried about being seen as an unfit mother and concerned their child would be taken away. The dichotomy of "good mother, bad mother" deterred help-seeking behavior; this may be because it contributed to stigma. However, little is known about the relationships between perinatal mental illness forum use, stigma associated with perinatal mental illness, and help-seeking behavior of forum visitors.

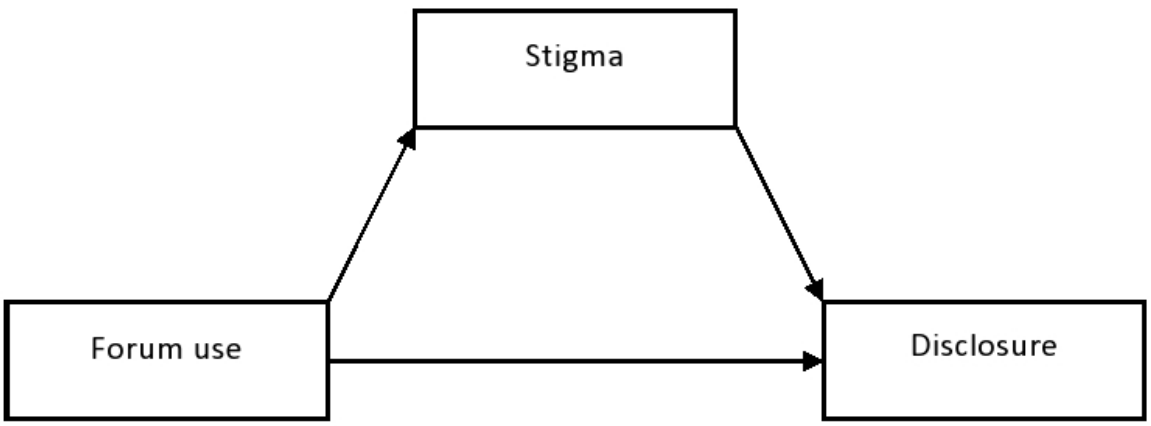
A qualitative interview study (N=15) with women who had used forums to assist their recovery from perinatal mental illness explored how women visited forums to reduce their feelings of inadequacy as a mother and perceived stigma from others [53]. Benefits were reported by both active users and lurkers and women valued the anonymity provided by these forums as they could access social support without fear of judgment. Interestingly, most women suggested that forum culture normalized and validated their stigmatized symptoms and unraveled their identity as a "bad mother" with a mental illness from their identity as a "good mother." Many women felt they were helped by visiting these forums by developing a collective understanding and discourse about their illness. They suggested that this discourse challenged their internal stigma and empowered them to disclose to others offline.

A thematic analysis of posts on an antenatal and postnatal depression forum suggested that use may increase women's disclosure to health care providers, possibly by reducing stigma [22]. Posts provided positive experiences of disclosure to health care providers that challenged women's concerns about external stigma. Discourse addressed internal stigma by promoting that a "good mother" can have perinatal mental illness and if a woman discloses and gets treatment she is a "good mother." Forums for postnatal mental illness may therefore provide a place where women can express internal stigma and concerns about external stigma and disclosure stigma. They offer a unique opportunity to anonymously explore sensitive and highly stigmatized issues around their illness with others who may be experiencing the same problems. Potentially, these types of stigma could be challenged by women sharing positive experiences of disclosure. Forum rhetoric could reconstruct the idea of a good mother as compatible with perinatal mental illness, especially if women seek help. Thus, forum use has the potential to increase women's disclosure to health care providers by influencing stigma.

Aims

This study aimed to test a model that examined the role perinatal mental illness stigma has in mediating between forum use and disclosure to health care providers. It was hypothesized that perinatal mental illness stigma would mediate between online forum usage and disclosure to health care providers (Figure 1).

Figure 1. Hypothesis model.



XSL•FO
RenderX

Methods

Design

A cross-sectional Web-based survey of forum use, stigma, and disclosure in women during pregnancy and up to 5 years after birth who identified themselves as having some level of distress or psychological problems was conducted. Because of the sensitive nature of stigma, the information about the study did not use the term perinatal mental illness as some women might not have wanted to associate with the label; instead, the terms "psychological problems, stress or isolation" were used. Demographic information was collected and symptoms were also measured.

Participants

Respondents were recruited by advertising on perinatal mental illness websites, motherhood-related websites, Facebook groups, and Twitter. A total of 422 women started the questionnaires via a Web-based survey and 200 had complete answers for the measures used in the model [54]. The survey questions can be found in Multimedia Appendix 1. Inclusion criteria stipulated that women were older than 18 years, were pregnant or had a child younger than 5 years, were a UK resident, considered themselves to be experiencing psychological distress, and had used perinatal mental illness forums.

Measures

City Mental Illness Stigma Scale

Stigma was measured using the City Mental Illness Stigma Scale (City MISS), a 15-item scale that measures the unique stigma women with perinatal mental illness experience (see Multimedia Appendix 1). It was developed from a literature review of perinatal mental illness stigma and tested via a Web-based survey with women with perinatal mental illness (n=279). Factor analysis was used to create the final 15-item scale. The scale accounted for 54.0% of the variance in the sample and had good reliability with Cronbach alphas between .81 and .86 for subscales and an overall alpha of .84 for the total scale indicating high reliability. The City MISS was highly correlated with a reliable measure for mental illness stigma (brief version of the Internalized Stigma of Mental Illness; ISMI-10 scale), which suggested good concurrent validity (r_{277}= .56, P<.001).

Respondents were asked to score the extent to which they agreed with a series of statements measured on Likert scales (1-4): "strongly disagree," "disagree," "agree," and "strongly agree," with higher scores signifying greater stigma. The scale has a 3-factor structure: the first concerns perceived external stigma, the second internal stigma, and the third disclosure stigma.

The perceived external stigma subscale comprised 6 statements that measured the respondent's beliefs about what other people think about mothers with psychological problems, for example, "people think mothers with psychological problems will harm themselves." The internal stigma subscale contained 5 questions that extend the concept of a "spoiled identity"; in this case it was specifically related to the respondent's identity as a mother, for example, "I have thoughts about leaving my baby" [13].

The disclosure stigma subscale contained 4 questions that measured respondents' anticipated discrimination if they disclosed their symptoms or diagnosis to health care providers. It contained 2 items that measured how they believed others would perceive them if they disclosed their psychological problems, for example, "I worry that if I told a health care provider about my thoughts they would think I am an abusive mother." It contained 2 items that rated the potential negative consequences of disclosure, for example, "I worry that if I told a health care provider about my psychological problems the social services would get involved."

Hospital Anxiety and Depression Scale

Current affective symptoms were assessed using the Hospital Anxiety and Depression Scale (HADS) [55]. The HADS questionnaire has 14 items, 7 questions to measure depression and 7 questions to measure anxiety; it is widely used to score symptoms for many mental health conditions and is available in many languages [56]. It has good validity and reliability. Many studies from various countries including samples with different health conditions have reported factor analysis results supporting the 2-factor structure: depression and anxiety and significant correlations between the 2 factors [57]. The scale has also shown correlations with other scales that measure depression and anxiety [58].

Assessment of Forum Usage, Disclosure, and Demographic Information

Forum usage was measured with questions specifically developed for the study that measured frequency and duration of forum use, frequency of writing posts, and frequency of reading posts. Participation level was classified in accordance with previous literature that defined active and lurker status [59,60]. Women were categorized as active if they started threads or replied to posts and lurker if they did not contribute to forum conversations. Frequency of forum visits and duration of forum use categories were developed by all authors and subject to data analysis several times using different classifications and cutoffs to see if the results were altered. All authors agreed on the final categories based on face validity and categories with approximately equal numbers. Frequency of forum visits was measured as occasional when women reported visiting 3 times or less a month and frequent when reported as once or more a week. Duration of forum use was measured as long-term for members who had been visiting a year or more and short-term if under a year.

Disclosure was ascertained by participants indicating the people they had disclosed symptoms or diagnosis to, for example, a health visitor, family member, midwife. Results were coded as disclosed to a health care provider or not disclosed to a health care provider.

Demographic information was collected about marital status, ethnicity, occupation, education, number of children, and diagnosis.

Procedure

The survey was pilot-tested with 6 women with children younger than 2 years who had perinatal mental illness; the participants

XSL•FO
RenderX

completed the questionnaire online using a mobile phone and all found it acceptable and easy to understand and answer. Ethical approval was given by City, University of London, United Kingdom. Website and forum administrators were contacted to ask for consent to post information about the study and a hyperlink to the survey. The participant information sheet and the first and last pages of the survey urged women to contact their health care provider should they feel upset and provided details of external organizations that offered support. The first page of the survey was the participant information sheet and participants had to click a box to confirm that they consented to the study before they could progress to the survey.

Data Analysis

Results were included if the respondent had completed all the forum questions and the City MISS questions (n=200). Internet protocol addresses were checked for duplication, but none were identified. The models were analyzed using the statistical software package IBM SPSS 20.0 (IBM Corporation) and the moderation and mediation plug-in PROCESS [61]. Mediation analysis was conducted using the method suggested by Hayes [62]. This method was used because it tests whether there is an indirect effect and has good power because it uses bootstrapping [62,63]. Frequency of forum visits, duration of forum use, and frequency of writing posts were entered as predictor variables. City MISS scores for subscales internal stigma, external stigma, and disclosure stigma were entered as mediators. The outcome variable was disclosure of symptoms to a health care provider. HADS scores were entered as a covariate to account for potential confounding effects on the relationships between variables. The bootstrapping method was used to test the potential mediation effect using 1000 iterations. This method was chosen as it allows for multiple mediators, controls for the effects of covariates, has a higher power than the traditional Sobel test, and reduces the possibility of a type I error. The bootstrapping procedure computes the confidence intervals (CIs) for the indirect path. The null hypothesis is that the indirect path does not significantly differ from zero, so if the CIs do not include zero then the null hypothesis can be rejected and the indirect effect is significant when $P<.05$. Qualitative answers regarding disclosure barriers were transferred to the NVivo 10 (QSR International) software package and coded for external stigma, internal stigma, and disclosure stigma [64].

Results

Sample Characteristics

Participant characteristics are provided in Table 1. Most participants classed themselves as white (n=191) and married or living with a partner (n=133, n=48). More than 60.0% (125/200) were educated to degree level or above and most had 1 child (n=139). The majority of women had a diagnosis of one or more postnatal mental illnesses (142/200, 71.0%), and 23.0% (46/200) of women reported postnatal mental illness but had not sought a professional diagnosis. The remaining women had a diagnosis of antenatal mental illness (3/200, 1.5%) or both antenatal and postnatal mental illness (9/200, 4.5%). On the basis of the HADS measure completed during this study (n=200), 66.5% (133/200) of the women had moderate or severe anxiety and 34.5% (69/200) had moderate or severe depression. Forum use characteristics are presented in Table 2. Women were almost evenly categorized as frequent or occasional users and long-term or short-term users (n=108, n=92). There were nearly 3 times as many active users than lurkers (n=156, n=44).

Correlational Analysis

Relationships between variables are presented in Table 3. The length of forum use was significantly correlated to internal stigma score (subscale of City MISS). Frequency of forum visits was significantly correlated to participation level. Total stigma score was significantly correlated to internal stigma, external stigma, and disclosure stigma (stigma subscales of City MISS). Internal stigma score was significantly correlated to disclosure to a health care provider. Total affective symptoms score was significantly correlated to total stigma score, internal stigma, external stigma, and disclosure stigma. Total affective symptoms score was the only variable that had significant correlations with the model variables, that is, all mediator variables. Therefore, total affective symptoms score was entered as a covariate in the following analyses.

Stigma Mediating the Relationship Between Forum Use and Disclosure

There was a significant indirect effect of length of forum use on disclosure of symptoms to a health care provider through internal stigma, b=0.399, bias-corrected and accelerated (BCa) CI 0.133-0.846. There were no other indirect effects between variables and there was no direct effect between forum variables and disclosure, b=0.133, $P=.79$ (Figure 2).

XSL•FO
RenderX

Table 1. Sample demographic characteristics.

Characteristics	Subcategories	n (%) (N=200[a])
Marital status	Single	12 (6.0)
	Married	133 (66.5)
	Living with partner	48 (24.0)
	Separated	3 (1.5)
	Other	2 (1.0)
Ethnicity	White	191 (95.5)
	Mixed or multiple ethnic groups	5 (2.5)
	Other	2 (1.0)
Occupation	Employed	104 (52.0)
	Self-employed	17 (8.5)
	Out of work	9 (4.5)
	Homemaker	47 (23.5)
	Student	11 (5.5)
	Unable to work	10 (5.0)
Education	GCSE[b]	17 (8.5)
	A Levels	30 (15.0)
	Trade or vocational training	26 (13.0)
	Bachelor's degree	89 (44.5)
	Master's degree	34 (17.0)
	Doctoral degree	1 (0.5)
Number of children	1	139 (69.5)
	2	45 (22.5)
	3	6 (3.0)
Diagnosis	Antenatal depression	2 (1.0)
	Antenatal depression and anxiety	1 (0.5)
	Antenatal depression and postnatal depression	9 (4.5)
	Postnatal depression	53 (26.5)
	Postnatal anxiety	9 (4.5)
	Post-traumatic stress disorder (PTSD)	23 (11.5)
	Postnatal depression and anxiety	23 (11.5)
	Postnatal depression and PTSD	19 (9.5)
	Three or more postnatal mental illnesses	7 (3.5)
	Puerperal psychosis	3 (1.5)
	Other postnatal mental illness	5 (2.5)
	No diagnosis sought	46 (23.0)

[a]The total number of participants in demographic categories does not add up to 200 as not all participants completed the demographic questions.
[b]GCSE: General Certificate of Secondary Education.

XSL•FO
RenderX

Table 2. Sample forum use characteristics.

Variable	Category	n (%) (N=200)
Frequency of visits	Frequent	108 (54.0)
	Occasional	92 (46.0)
Participation level	Active	156 (78.0)
	Lurker	44 (22.0)
Duration of use	Long-term	108 (54.0)
	Short-term	92 (46.0)

Table 3. Bivariate correlations of dependent variables, independent variables, mediators, and control variable.

Variable	1	2	3	4	5	6	7	8	9
1. Disclosure	1	.060	−.004	.045	.138	.230[c]	.074	−.019	.019
2. Length of use		1	−.087	.043	.150[d]	.180[d]	.064	.087	−.020
3. Frequency of visits			1	.285[c]	.088	.065	.031	.111	.066
4. Participation				1	.058	.095	.061	−.041	.032
5. Total City MISS[a]					1	.751[c]	.766[c]	.744[c]	.423[c]
6. Internal stigma						1	.299[c]	.331[c]	.393[c]
7. External stigma							1	.434[c]	.222[c]
8. Disclosure stigma								1	.339[c]
9. HADS[b]									1

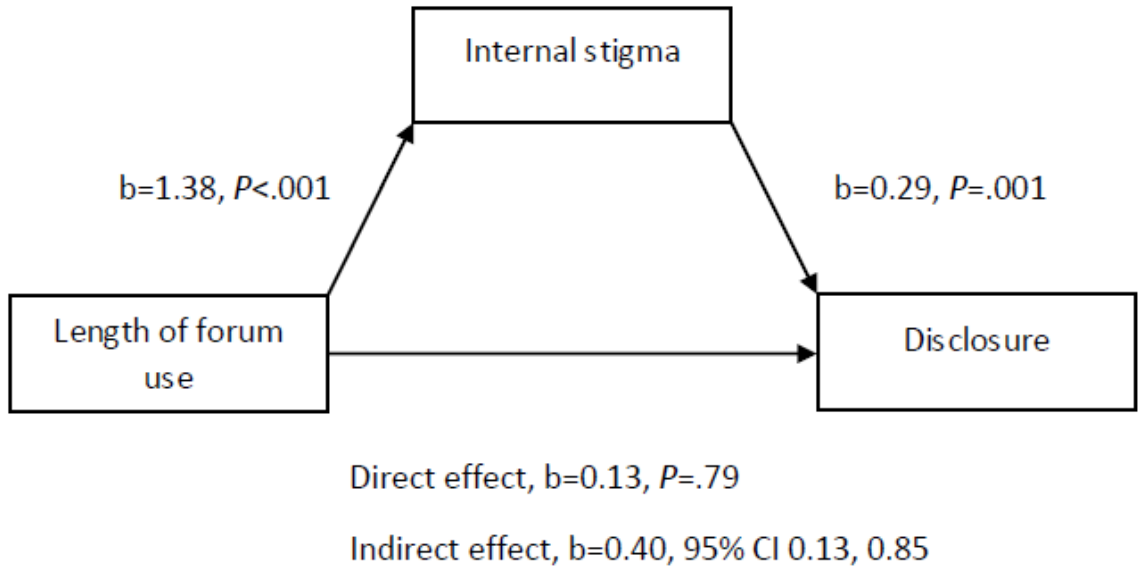
[a]City MISS: Mental Illness Stigma Scale.

[b]HADS: Hospital Anxiety and Depression Scale.

[c]Correlation is significant at the .01 level (two-tailed).

[d]Correlation is significant at the .05 level (two-tailed).

Figure 2. Model with statistics.



XSL•FO
RenderX

Discussion

Principal Findings

This study tested a model based on previous research that proposed perinatal mental illness stigma mediates between forum use and disclosure. There was a significant indirect effect of length of forum use on disclosure of symptoms to health care providers through internal stigma. Long-term forum users reported higher internal stigma scores and higher internal stigma was associated with disclosure to a health care provider. There was no indirect effect of perceived external or disclosure stigma, nor was there a direct effect between length of forum use and disclosure. Qualitative findings support this as many women reported that external stigma, internal stigma, and disclosure stigma specific to perinatal mental illness were barriers to their disclosing to health care providers.

There was theoretical reason to believe that increased forum use would decrease stigma and subsequently increase disclosure to health care providers. Also, social support offered by forum members might be empowering and play a role in disclosure. Results unexpectedly indicated that forum use was associated with increased reported internal stigma. There are a number of possible explanations for this. It is plausible that visiting forums might have adversely affected internal stigma or it may be that women with higher internal stigma use forums for longer. However, this study advocates an alternative explanation of the findings and proposes that forum messages encouraged these women to recognize their feelings of internal stigma, and this increased their self-awareness, enabling them to make a fuller disclosure when completing the stigma questionnaire. Previous research suggests that forums may provide a place where women can explore their feelings, and this may have meant that implicit feelings of internal stigma could have become explicit [22]. Also, women may have overcome barriers to revealing this internal stigma through forum benefits such as social support, identification with the forum group, and an alternative perspective of perinatal mental illness that shifted their "spoiled identity" to an empowered identity as a good mother despite having a mental illness.

Interestingly, there was no direct effect between forum use variables and disclosure. Current research suggests that mediation can occur without results showing a direct effect [65,66]. It is possible that other factors omitted from the analyses may have weakened the direct effect, also known as suppressor variables. Possible suppressor variables are individual differences such as personality traits, experience of discrimination, and social support. Furthermore, there may have been an overrepresentation of a subset of women who do not have a significant relationship between the predictor and outcome variables, and thus a direct effect would have been neutralized. Future research could measure potential suppressor variables to explore this intricate relationship.

Limitations

Caution should be exercised when considering generalization from this sample as there are a number of characteristics that might not be true of the general population of forum users. First, the women were mostly white and educated to A Level or above. There was also an overrepresentation of active users, possibly because active users have a more vested interest in forum research or they have different traits that might make them more likely to post on forums and participate in Web-based surveys [45]. The majority of women had experienced symptoms in the postnatal period, and thus findings might not extend to antenatal populations. The model could benefit from future modifications such as including a measure of whether women had experienced discrimination when disclosing, such as "health professional stigma" [67]. Similarly, there was no measure of other social media use that may affect stigma levels and have further implications for disclosure behavior. The type of forum or combination of forums women used may have had an impact on the results, for example, if the forum was moderated or unmoderated. The study cannot determine the direction of causality because it was cross-sectional. It may therefore be that women who disclosed may be more likely to visit forums rather than forum use in itself increasing disclosure behavior. Future research should use experimental and longitudinal designs to be able to ascertain the direction of this potential effect and include a measure of forum type. Future research could test the theories suggested as part of prevention and intervention studies. It might also be beneficial to include other means of social support into the model.

Comparison With Prior Work

This study supports and extends previous research that suggests forum use may affect internal stigma and in turn lead to disclosure; however, this relationship may be more complex than our initial model proposed [41,42]. Interpretation of the findings suggests that perceived external stigma and disclosure stigma do not mediate between forum use and disclosure. This is surprising because prior studies showed that perinatal mental illness forum messages are pro-disclosure and supply positive experiences with health care providers [22,51,52].

Another consideration is that forums differ in their posts concerning health care providers. Recent research has highlighted that some forums include many negative experiences with illness symptoms and experiences with health care providers [68]. Thus, some forums may contain conversations that reduce disclosure stigma and external stigma, and others, albeit inadvertently, may increase external stigma and disclosure stigma. Women in this sample may have been visiting a mixture of these types of forums and they may have had different effects on perceived external stigma and disclosure stigma. Therefore, future research should not dismiss exploration of external stigma and disclosure stigma in forum use.

Qualitative findings confirm that stigma is a major barrier to disclosure and details the complex relationship between maternal identity and internal stigma, external stigma, and disclosure stigma [22]. Other studies advocated a negative effect on disclosure from an overreliance on forums, but this was not suggested in our findings [44,45]. However, it may be worth investigating whether there are forums that maintain or generate stigma, for example, through providing negative experiences with health care providers, such as a forum for birth trauma.

XSL•FO
RenderX

Conclusions

Findings suggest internal stigma of perinatal mental illness mediates between forum use and disclosure. Using forums may provide valuable social support and improve women's disclosure to health care providers through enabling expression of their internal stigma. Theoretical reasons for this have been discussed; in particular, it is suggested that women can explore their feelings, so they become more aware of their internal stigma and are empowered to express these feelings. Furthermore, women may be enabled to disclose by reconciling the negative impact of internal stigma on their maternal identity by agreeing with forum discourse that promoted the idea that one can be a good mother despite having perinatal mental illness. Future work could test these theories and continue to strengthen knowledge of perinatal mental illness, forum use, stigma, and disclosure behavior. Clinicians could refer clients to trustworthy and moderated online forums that facilitate expression of perinatal mental illness stigma and promote disclosure to health care providers.

Acknowledgments

We would like to thank all the women who took the time to complete the pilot study and the Web-based survey and the websites, forums, and social media groups that promoted the research.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Web-based survey questions.

[PDF File (Adobe PDF File), 47KB - mental_v4i1e6_app1.pdf]

References

1. UNFPA/WHO. WHO. 2007. Maternal mental health and child health and development in resource-constrained settings--Report of a UNFPA/WHO international expert meeting: the interface between reproductive health and mental health URL: http://www.who.int/reproductivehealth/publications/general/rhr_09_24/en [accessed 2016-02-12] [WebCite Cache ID 6gz4mjot9]
2. Biratu A, Haile D. Prevalence of antenatal depression and associated factors among pregnant women in Addis Ababa, Ethiopia: a cross-sectional study. Reprod Health 2015 Oct 30;12:99 [FREE Full text] [doi: 10.1186/s12978-015-0092-x] [Medline: 26514827]
3. Castro E Couto T, Cardoso MN, Brancaglion MY, Faria GC, Garcia FD, Nicolato R, et al. Antenatal depression: prevalence and risk factor patterns across the gestational period. J Affect Disord 2016 Mar 1;192:70-75. [doi: 10.1016/j.jad.2015.12.017] [Medline: 26707350]
4. Waldie KE, Peterson ER, D'Souza S, Underwood L, Pryor JE, Carr PA, et al. Depression symptoms during pregnancy: evidence from growing up in New Zealand. J Affect Disord 2015 Nov 1;186:66-73. [doi: 10.1016/j.jad.2015.06.009] [Medline: 26231443]
5. Leung BMY, Kaplan BJ. Perinatal depression: prevalence, risks, and the nutrition link--a review of the literature. J Am Diet Assoc 2009 Sep;109(9):1566-1575. [doi: 10.1016/j.jada.2009.06.368] [Medline: 19699836]
6. Glasheen C, Richardson GA, Fabio A. A systematic review of the effects of postnatal maternal anxiety on children. Arch Womens Ment Health 2010 Feb;13(1):61-74 [FREE Full text] [doi: 10.1007/s00737-009-0109-y] [Medline: 19789953]
7. Grekin R, O'Hara MW. Prevalence and risk factors of postpartum posttraumatic stress disorder: a meta-analysis. Clin Psychol Rev 2014 Jul;34(5):389-401. [doi: 10.1016/j.cpr.2014.05.003] [Medline: 24952134]
8. Munk-Olsen T, Laursen TM, Pedersen CB, Mors O, Mortensen PB. New parents and mental disorders: a population-based register study. J Am Med Assoc 2006 Dec 6;296(21):2582-2589. [doi: 10.1001/jama.296.21.2582] [Medline: 17148723]
9. Vesga-López O, Blanco C, Keyes K, Olfson M, Grant BF, Hasin DS. Psychiatric disorders in pregnant and postpartum women in the United States. Arch Gen Psychiatry 2008 Jul;65(7):805-815 [FREE Full text] [doi: 10.1001/archpsyc.65.7.805] [Medline: 18606953]
10. McKenzie-McHarg K, Ayers S, Ford E, Horsch A, Jomeen J, Sawyer A, et al. Post-traumatic stress disorder following childbirth: an update of current issues and recommendations for future research. J Reprod Infant Psychol 2015 Apr 28;33(3):219-237. [doi: 10.1080/02646838.2015.1031646]
11. Dennis C, Chung-Lee L. Postpartum depression help-seeking barriers and maternal treatment preferences: a qualitative systematic review. Birth 2006 Dec;33(4):323-331. [doi: 10.1111/j.1523-536X.2006.00130.x] [Medline: 17150072]
12. Bilszta J, Ericksen J, Buist A, Milgrom J. AJAN. Women's experience of postnatal depression -- beliefs and attitudes as barriers to care URL: http://www.ajan.com.au/Vol27/27-3_Bilszta.pdf [accessed 2017-02-03] [WebCite Cache ID 6o08ivQ69]
13. Goffman E. Stigma: notes on the management of spoiled identity. New Jersey: Prentice-Hall; 1963.

XSL•FO
RenderX

14. Corrigan PW, Penn DL. Lessons from social psychology on discrediting psychiatric stigma. Am Psychol 1999 Sep;54(9):765-776. [Medline: 10510666]
15. HSCIC. Health survey for England - 2011, health, social care and lifestyles URL: http://www.hscic.gov.uk/catalogue/PUB09300 [accessed 2016-04-23] [WebCite Cache ID 6gyub1fb3]
16. Time-to-Change. Time to change URL: http://www.time-to-change.org.uk/ [accessed 2016-04-23] [WebCite Cache ID 6gyudqM9M]
17. Corrigan PW, Rafacz J, Rüsch N. Examining a progressive model of self-stigma and its impact on people with serious mental illness. Psychiatry Res 2011 Oct 30;189(3):339-343 [FREE Full text] [doi: 10.1016/j.psychres.2011.05.024] [Medline: 21715017]
18. Rodrigues S, Serper M, Novak S, Corrigan P, Hobart M, Ziedonis M, et al. Self-stigma, self-esteem, and co-occurring disorders. J Dual Diagn 2013 May;9(2):129-133. [doi: 10.1080/15504263.2013.777988]
19. West ML, Yanos PT, Smith SM, Roe D, Lysaker PH. Prevalence of internalized stigma among persons with severe mental illness. Stigma Res Action 2011;1(1):3-10. [doi: 10.5463/sra.v1i1.9]
20. Pascoe EA, Smart RL. Perceived discrimination and health: a meta-analytic review. Psychol Bull 2009 Jul;135(4):531-554 [FREE Full text] [doi: 10.1037/a0016059] [Medline: 19586161]
21. Schmitt MT, Branscombe NR, Postmes T, Garcia A. The consequences of perceived discrimination for psychological well-being: a meta-analytic review. Psychol Bull 2014 Jul;140(4):921-948. [doi: 10.1037/a0035754] [Medline: 24547896]
22. Moore D, Ayers S, Drey N. A thematic analysis of stigma and disclosure for perinatal depression on an online forum. JMIR Mental Health 2016 May 19;3(2):e18. [doi: 10.2196/mental.5611]
23. Kendal S, Kirk S, Elvey R, Catchpole R, Pryjmachuk S. How a moderated online discussion forum facilitates support for young people with eating disorders. Health Expect 2016 Jan 03:n/a-n/a. [doi: 10.1111/hex.12439]
24. Rains SA. The implications of stigma and anonymity for self-disclosure in health blogs. Health Commun 2014 Jan;29(1):23-31. [doi: 10.1080/10410236.2012.714861] [Medline: 23356432]
25. Bauer R, Bauer M, Spiessl H, Kagerbauer T. Cyber-support: an analysis of online self-help forums (online self-help forums in bipolar disorder). Nord J Psychiatry 2012 Jul 23;67(3):185-190. [doi: 10.3109/08039488.2012.700734]
26. Chang HJ. Online supportive interactions: using a network approach to examine communication patterns within a psychosis social support group in Taiwan. J Am Soc Inf Sci 2009 Jul;60(7):1504-1517. [doi: 10.1002/asi.21070]
27. Griffiths KM, Reynolds J, Vassallo S. An online, moderated peer-to-peer support bulletin board for depression: user-perceived advantages and disadvantages. JMIR Ment Health 2015 Apr;2(2):e14 [FREE Full text] [doi: 10.2196/mental.4266] [Medline: 26543919]
28. Highton-Williamson E, Priebe S, Giacco D. Online social networking in people with psychosis: a systematic review. Int J Soc Psychiatry 2015 Feb;61(1):92-101. [doi: 10.1177/0020764014556392] [Medline: 25381145]
29. 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] [Medline: 26744309]
30. Huh J. Clinical questions in online health communities: the case of “See your doctor” threads. Comput Support Coop Work 2015;2015:1488-1499 [FREE Full text] [doi: 10.1145/2675133.2675259] [Medline: 26146665]
31. Bartlett YK, Coulson NS. An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication. Patient Educ Couns 2011 Apr;83(1):113-119. [doi: 10.1016/j.pec.2010.05.029] [Medline: 20599338]
32. Bauer A, Knapp M, Parsonage M. Lifetime costs of perinatal anxiety and depression. J Affect Disord 2016 Mar 1;192:83-90. [doi: 10.1016/j.jad.2015.12.005] [Medline: 26707352]
33. Malik S, Coulson NS. The therapeutic potential of the internet: exploring self-help processes in an internet forum for young people with inflammatory bowel disease. Gastroenterol Nurs 2011;34(6):439-448. [doi: 10.1097/SGA.0b013e318237a9ba] [Medline: 22129797]
34. Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, Hoving C. A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. J Med Internet Res 2013;15(4):e85 [FREE Full text] [doi: 10.2196/jmir.1933] [Medline: 23615206]
35. Pendry LF, Salvatore J. Individual and social benefits of online discussion forums. Comput Human Behav 2015 Sep;50:211-220. [doi: 10.1016/j.chb.2015.03.067]
36. Griffiths KM, Mackinnon AJ, Crisp DA, Christensen H, Bennett K, Farrer L. The effectiveness of an online support group for members of the community with depression: a randomised controlled trial. PLoS One 2012;7(12):e53244 [FREE Full text] [doi: 10.1371/journal.pone.0053244] [Medline: 23285271]
37. Coulson N. Patterns of engagement with inflammatory bowel disease online support groups: comparing posters and lurkers. Gastroenterol Nurs 2015;38(5):348-353. [doi: 10.1097/SGA.0000000000000131] [Medline: 26166421]
38. Setoyama Y, Yamazaki Y, Nakayama K. Comparing support to breast cancer patients from online communities and face-to-face support groups. Patient Educ Couns 2011 Nov;85(2):e95-100. [doi: 10.1016/j.pec.2010.11.008] [Medline: 21159482]

XSL•FO
RenderX

39. Bishop J. Increasing participation in online communities: a framework for human–computer interaction. Comput Human Behav 2007 Jul;23(4):1881-1893. [doi: 10.1016/j.chb.2005.11.004]
40. van Mierlo T. The 1% rule in four digital health social networks: an observational study. J Med Internet Res 2014 Feb 04;16(2):e33 [FREE Full text] [doi: 10.2196/jmir.2966] [Medline: 24496109]
41. Breuer L, Barker C. Online support groups for depression: benefits and barriers. SAGE Open 2015 Apr 08;5(2). [doi: 10.1177/2158244015574936]
42. Parikh SV, Huniewicz P. E-health: an overview of the uses of the Internet, social media, apps, and websites for mood disorders. Curr Opin Psychiatry 2015 Jan;28(1):13-17. [doi: 10.1097/YCO.0000000000000123] [Medline: 25420193]
43. Chang PF, Bazarova NN. Managing stigma: disclosure-response communication patterns in pro-anorexic websites. Health Commun 2016 Aug;31(2):217-229. [doi: 10.1080/10410236.2014.946218] [Medline: 26266693]
44. Chung JE. Social interaction in online support groups: preference for online social interaction over offline social interaction. Comput Human Behav 2013 Jul;29(4):1408-1414. [doi: 10.1080/10810730.2012.757396] [Medline: 23557148]
45. Lawlor A, Kirakowski J. Online support groups for mental health: a space for challenging self-stigma or a means of social avoidance? Comput Human Behav 2014 Mar;32:152-161. [doi: 10.1016/j.chb.2013.11.015]
46. McLoughlin J. Stigma associated with postnatal depression: a literature review. Br J Midwifery 2013;21(11):784-791. [doi: 10.12968/bjom.2013.21.11.784]
47. 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] [Medline: 23969144]
48. 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]
49. Moore D, Ayers S. A review of postnatal mental health websites: help for healthcare professionals and patients. Arch Womens Ment Health 2011 Dec;14(6):443-452. [doi: 10.1007/s00737-011-0245-z] [Medline: 22109827]
50. Baumel A, Schueller SM. Adjusting an available online peer support platform in a program to supplement the treatment of perinatal depression and anxiety. JMIR Mental Health 2016 Mar 21;3(1):e11. [doi: 10.2196/mental.5335]
51. Evans M, Donelle L, Hume-Loveland L. Social support and online postpartum depression discussion groups: a content analysis. Patient Educ Couns 2012 Jun;87(3):405-410. [doi: 10.1016/j.pec.2011.09.011] [Medline: 22019021]
52. Alang SM, Fomotar M. Postpartum depression in an online community of lesbian mothers: implications for clinical practice. J Gay Lesbian Ment Health 2015 Jan 23;19(1):21-39. [doi: 10.1080/19359705.2014.910853]
53. Moore D, Ayers S. Virtual voices: social support and stigma in postnatal mental illness Internet forums. Psychol Health Med 2016 May 24:1-6. [doi: 10.1080/13548506.2016.1189580] [Medline: 27218265]
54. Qualtrics software, LLC. Qualtrics. 2015. June 2015 - September 2015 Version of Qualtrics URL: https://www.qualtrics.com/
55. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983 Jun;67(6):361-370. [Medline: 6880820]
56. Montazeri A, Vahdaninia M, Ebrahimi M, Jarvandi S. The Hospital Anxiety and Depression Scale (HADS): translation and validation study of the Iranian version. Health Qual Life Outcomes 2003;1:14 [FREE Full text] [doi: 10.1186/1477-7525-1-14] [Medline: 12816545]
57. Al Aseri ZA, Suriya MO, Hassan HA, Hasan M, Sheikh SA, Al Tamimi A, et al. Reliability and validity of the Hospital Anxiety and Depression Scale in an emergency department in Saudi Arabia: a cross-sectional observational study. BMC Emerg Med 2015 Oct;15:28 [FREE Full text] [doi: 10.1186/s12873-015-0051-4] [Medline: 26459412]
58. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. an updated literature review. J Psychosom Res 2002 Feb;52(2):69-77. [Medline: 11832252]
59. Amichai-Hamburger Y, Gazit T, Bar-Ilan J, Perez O, Aharony N, Bronstein J, et al. Psychological factors behind the lack of participation in online discussions. Comput Human Behav 2016 Feb;55:268-277. [doi: 10.1016/j.chb.2015.09.009]
60. Sun N, Rau PP, Ma L. Understanding lurkers in online communities: a literature review. Comput Human Behav 2014 Sep;38:110-117. [doi: 10.1016/j.chb.2014.05.022]
61. Process macro. 2016. The PROCESS macro for SPSS and SAS URL: http://processmacro.org/index.html [accessed 2017-02-06] [WebCite Cache ID 6o4h6iShL]
62. Hayes AF. Introduction to mediation, moderation, and conditional process analysis. New York: Guilford Press; 2013.
63. Jose PE. Doing statistical mediation and moderation. New York: Guilford Press; 2013.
64. QSR International. 2012. NVivo qualitative data analysis [software] URL: http://www.qsrinternational.com/nvivo-product [accessed 2017-02-15] [WebCite Cache ID 6oI9WLTDa]
65. Moran TE, Polanin JR, Wenzel A. The postpartum worry scale-revised: an initial validation of a measure of postpartum worry. Arch Womens Ment Health 2014 Feb;17(1):41-48. [doi: 10.1007/s00737-013-0380-9] [Medline: 24026389]
66. Rucker DD, Preacher KJ, Tormala ZL, Petty RE. Mediation analysis in social psychology: current practices and new recommendations. Soc Personal Psychol Compass 2011;5(6):359-371. [doi: 10.1111/j.1751-9004.2011.00355.x]
67. Ahmedani B. Mental health stigma: society, individuals, and the profession. J Soc Work Values Ethics 2011;8(2):1-16. [Medline: 22211117]

XSL•FO
RenderX

68. Faith J, Thorburn S, Sinky TH. Exploring healthcare experiences among online interactive weight loss forum users. Comput Human Behav 2016;57:326-333. [doi: 10.1016/j.chb.2015.12.048]

Abbreviations

BCa: bias-corrected and accelerated
City MISS: City Mental Illness Stigma Scale
HADS: Hospital Anxiety and Depression Scale

Edited by M Larsen; submitted 29.04.16; peer-reviewed by N Coulson, M Evans; comments to author 20.05.16; revised version received 11.07.16; accepted 12.08.16; published 20.02.17.

Please cite as:
Moore D, Drey N, Ayers S
Use of Online Forums for Perinatal Mental Illness, Stigma, and Disclosure: An Exploratory Model
JMIR Ment Health 2017;4(1):e6
URL: http://mental.jmir.org/2017/1/e6/
doi:10.2196/mental.5926
PMID:28219879

©Donna Moore, Nicholas Drey, Susan Ayers. Originally published in JMIR Mental Health (http://mental.jmir.org), 20.02.2017. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Mental Health, is properly cited. The complete bibliographic information, a link to the original publication on http://mental.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Current Views and Perspectives on E-Mental Health: An Exploratory Survey Study for Understanding Public Attitudes Toward Internet-Based Psychotherapy in Germany

Jennifer Apolinário-Hagen[1], Dr. rer. medic., Dipl-Psych; Viktor Vehreschild[1], Dipl-Math, BSc Psych, MSc Psych; Ramez M Alkoudmani[2], BSc (Pharmaceutical Science), MSc (Pharmacy Practice)

[1]Institute for Psychology, Department of Health Psychology, University of Hagen, Faculty of Humanities and Social Sciences, Hagen, Germany
[2]Kulliyyah of Pharmacy, Pharmacy Practice Department, International Islamic University Malaysia, Kuantan, Pahang, Malaysia

Corresponding Author:
Jennifer Apolinário-Hagen, Dr. rer. medic., Dipl-Psych
Institute for Psychology
Department of Health Psychology
University of Hagen, Faculty of Humanities and Social Sciences
Bldg B, 1th Fl
Universitätsstraße 33
Hagen, 58097
Germany
Phone: 49 2331 987 2272
Fax: 49 2331 987 1047
Email: jennifer.apolinario-hagen@fernuni-hagen.de

Abstract

Background: Despite the advanced development of evidence-based psychological treatment services, help-seeking persons with mental health problems often fail to receive appropriate professional help. Internet-delivered psychotherapy has thus been suggested as an efficient strategy to overcome barriers to access mental health care on a large scale. However, previous research indicated poor public acceptability as an issue for the dissemination of Internet-delivered therapies. Currently, little is known about the expectations and attitudes toward Internet-delivered therapies in the general population. This is especially the case for countries such as Germany where electronic mental health (e-mental health) treatment services are planned to be implemented in routine care.

Objective: This pilot study aimed to determine the expectations and attitudes toward Internet-based psychotherapy in the general population in Germany. Furthermore, it aimed to explore the associations between attitudes toward Internet-based therapies and perceived stress.

Methods: To assess public attitudes toward Internet-based psychotherapy, we conducted both Web-based and paper-and-pencil surveys using a self-developed 14-item questionnaire (Cronbach alpha=.89). Psychological distress was measured by employing a visual analogue scale (VAS) and the 20-item German version of the Perceived Stress Questionnaire (PSQ). In addition, we conducted explorative factor analysis (principal axis factor analysis with promax rotation). Spearman's rank correlations were used to determine the associations between attitudes toward Internet-based therapies and perceived stress.

Results: Descriptive analyses revealed that most respondents (N=1558; female: 78.95%, 1230/1558) indicated being not aware of the existence of Internet-delivered therapies (83.46%, 1141/1367). The average age was 32 years (standard deviation, SD 10.9; range 16-76). Through exploratory factor analysis, we identified 3 dimensions of public attitudes toward Internet-based therapies, which we labeled "usefulness or helpfulness," "relative advantage or comparability," and "accessibility or access to health care." Analyses revealed negative views about Internet-based therapies on most domains, such as perceived helpfulness. The study findings further indicated ambivalent attitudes: Although most respondents agreed to statements on expected improvements in health care (eg, expanded access), we observed low intentions to future use of Internet-delivered therapies in case of mental health problems.

Conclusions: This pilot study showed deficient "e-awareness" and rather negative or ambivalent attitudes toward Internet-delivered therapies in the German-speaking general population. However, research targeting determinants of the large-scale adoption of

XSL•FO
RenderX

Internet-based psychotherapy is still in its infancy. Thus, further research is required to explore the "black box" of public attitudes toward Internet-delivered therapies with representative samples, validated measures, and longitudinal survey designs.

(JMIR Ment Health 2017;4(1):e8) doi:10.2196/mental.6375

KEYWORDS

telemedicine; mental health; online self-help; attitude to computers; acceptability of health care; patient acceptance of health care; cognitive therapy; stress, psychological; diffusion of innovation

Introduction

Background

Mental health problems requiring treatment have a high lifetime prevalence of 29.2%, which has increased over the past decades across the world [1]. The incidence of mental health problems across populations and long waiting times for psychotherapy in many regions indicate a demand for innovative effective prevention and treatment strategies in public health. Despite the advanced development of evidence-based treatments for a broad range of mental health problems, still many individuals requiring treatment fail to receive professional help in primary care [2,3]. In addition, stigmatized beliefs about mental illnesses have been identified as global problem for both help-seeking persons as well as for the diffusion of mental health services [4-6]. With respect to limited capacities of health care, the dissemination of Internet-delivered psychological services is suggested as an efficient strategy to improve the access to professional help by overcoming structural or regional barriers [2,3,7,8] and the stigma of seeking help for mental health problems [9,10]. Internet-delivered computerized, electronic mental health (e-mental health) services include the usage of modern digital technologies and new media in, for instance, monitoring, screening, psychoeducation, prevention, health promotion, self-help, counseling, aftercare, and psychotherapy [11]. Concerning treatment delivered through the Internet, controlled trials have confirmed the effectiveness for guided Internet-based cognitive behavior therapy (iCBT) and related approaches for mood and anxiety disorders [12-14], eating disorders [15], coping with chronic somatic conditions [16], and harmful health behavior [17].

However, these promising findings from controlled studies appear to challenge the overall poor uptake of e-mental health services in health care systems worldwide indicating psychological barriers [18-21]. Although clinical studies have identified individual predictors of engagement or disengagement in active treatment conditions [22-25], the evidence base for predictors of help-seeking intentions and using e-mental health treatments in the general population is still scare. An English study by Musiat et al [26] targeting public acceptability of e-mental health treatment services showed that mental health service users endorsed domains such as helpfulness, credibility, convenience of access, personal support, or suitability with preferences and habits as important for decisions to engage with these services [26]. Taken together, most studies targeting the general population in this field directed to low willingness to future use of e-mental health services in case of emotional distress [10,26-29]. Potential reasons for negative expectations and attitudes toward e-mental health include concerns on privacy [28,30,31], communication [9], therapeutic alliance, and unfamiliarity with technology [1]. Facilitators or positive attitudes and perspectives of Internet-based therapies need to be explored.

Attitudes Toward E-Mental Health and Service Users' Acceptance

Ajzen [32] defined attitudes as the sum of affective appraisals either positive or negative to a psychological object on attributive dimensions ranging, for example, from harmful to beneficial or helpful. Attitudes toward using self-help are assumed to be affected by individual experiences with mental disorders, self-help services and seeking help in primary care, as well as with perceived control, helplessness, engagement, and self-stigma [33]. There are indications for multidimensional (ambivalent) attitudes in terms of health behavior [32,34]. This appears important for the measurement of attitudes toward health-related topics because attitudes are typically assumed to be located within a unidimensional continuum, that is, positive or negative attitudes, but not both for the same object [34]. In recent years, attitudes toward e-mental health treatments have been mainly investigated among patients [35-37] and health care professionals [38-40]. For instance, the "Attitudes towards Psychological Online Interventions Questionnaire" (APOI) [36] is a validated measure with depressive patients in a German clinical setting. Yet, validated measures targeting public attitudes toward Internet-based treatments outside the context of clinical studies are rare. In addition, research findings from countries with advanced eHealth infrastructure, such as Australia, United States, or Canada [2], are not directly applicable to the assessment of public attitudes toward Internet-based therapies in countries such as Germany due to different stages of e-health implementation into health care. There is thus a need to identify general determinants of e-mental health adoption in the general population.

As framework, the technology acceptance model [41] and its extension, the unified theory of acceptance and use of technology (UTAUT) [42], can help to identify determinants of behavioral intentions to use information technology (IT). The multidisciplinary UTAUT [43,44] is based on 8 models developed in psychology, sociology, human-computer-interaction, and IT acceptance research, including the innovation diffusion theory [45] and the theory of planned behavior (TPB) [46]. Four determinants of behavioral intentions to use IT and moderators of key relationships (eg, gender, age, experience) have been confirmed [43,44]. Determinants include performance expectancy, effort expectancy, social influence, and facilitating conditions. The determinant with the best predictive value for usage intentions called "performance expectancy" consists of perceived usefulness, relative advantage, extrinsic motivation,

XSL•FO
RenderX

and outcome expectations. Concerning the assessment of IT in treatment research, perceived usefulness or helpfulness appears particularly relevant. Accordingly, surveys employed perceived helpfulness as an indicator for attitudes and acceptability of e-mental health services [10,47-49].

Social Influence, Perceived Stress, and Attitude Toward E-Mental Health Treatments

Overall, it remains largely unclear how affective and cognitive information processing affects the formation of attitudes [32]. Studies have shown mediating effects of perceived stress on (face-to-face) help-seeking intentions [50]. Predictors of help seeking and using (face-to-face) mental health services are assumed to include positive attitudes toward seeking professional help, increased levels of perceived psychological distress, as well as lower social support [51]. However, little is known about the associations between perceived stress, help-seeking intentions, and attitudes toward using modern technologies. In addition, explorative studies outside of clinical settings mostly identified inconsistent or weak associations. For instance, a pilot study [52] showed that perceived stress was negatively associated with attitudes to computers among students. Considering the outlined limited evidence base on the role of distress (as control variable) in attitudes toward e-mental health services and help-seeking intentions, further research is urgently required. Moreover, the measurement of ambivalent attitudes and their impact on health-related behavior needs clarification [32]. This is relevant given the discrepancy between promising findings and low impact of e-mental health in public health.

E-Mental Health in the German Health Care Context

In 2015, 44.5 million persons (63%) of the general German population used the Internet daily, whereas 56.1 million citizens (79.5%) had access to the Internet [53]. The implementation of e-mental health treatments in German public health could help reducing the gap between supply and demand for psychotherapy [3]. Web-based self-help services are accessible for the German public, but professional regulation is a barrier for the dissemination of (therapist-guided) Internet-based therapies. Currently, treatment delivered by health professionals exclusively through the Internet is prohibited in routine care due to the so-called “Fernbehandlungsverbot” in Germany [54]. However, the implementation of Internet-delivered therapies is considered in German public health [3]. Public opinions about e-mental health treatment services have been rarely explored in Germany. A survey with a representative sample of the German general population by Eichenberg et al [55] showed that more than one-third of 2411 respondents indicated using the Internet for mental health advice. Regarding Web-based interventions, the awareness of respondents was very low. This study [55] also demonstrated that most respondents preferred seeking information or help from face-to-face services in case of emotional distress. In line with international research [10,26], specific subpopulations (eg, young adults) indicated being more willing to use e-mental health [55]. However, the study by Eichenberg [55] did not focus on public attitudes toward Internet-based therapies. In addition, data were collected in 2010. Since then, the diffusion of modern technology into everyday life (eg, mobile phone apps) has likely increased the public awareness in Germany. Therefore, it appears reasonable to explore the “status quo” of public attitudes toward e-mental health treatments in Germany again (5 years later).

Objective

Concerning the intended large-scale implementation of e-mental health treatment services into primary care, this pilot study aimed to determine expectations and attitudes toward Internet-based psychotherapy in the German-speaking general population. Another purpose of this survey was to explore the associations between the attitudes toward Internet-delivered therapies and perceived stress as well as individual differences in attitudes in terms of gender, age, “e-awareness,” and experience with psychotherapy.

Methods

Study Design and Setting

A cross-sectional survey using a psychometric observational study design was conducted. This pilot study combined both validated and self-developed self-report measures. All items were provided in German language through both an anonymously conducted Web-based survey and a paper-and-pencil survey. Data from the paper-and-pencil survey were collected between April and August 2015, whereas data from the Web-based survey were collected between June and August 2015 using Google forms. No ethical approval was required. No details about the medical history (eg, diagnosed mental disorders), clinical screenings, or other problematic areas, including identifiable names or region (protection of confidentiality and privacy), were assessed. A convenience sample was obtained using snowballing techniques (nonprobability sampling). Data were based solely on self-reports.

Participants

Participants older than 16 years were recruited from German-speaking general population through social network sites, such as Facebook, professional networks, and undergraduate psychology courses at different universities across North Rhine Westphalia, Germany. Participation was voluntary. Psychology students could receive credits for their participation. No further incentive was offered.

Measures and Procedure

Candidates received brief text-based information about this survey, including its objectives and conditions for participation (informed consent). The survey consisted of 3 parts. The first part included sociodemographic questions, experience with psychotherapy, Internet usage, awareness of Internet-based therapies, and a single item on the current stress level. The second part was a self-developed 14-item questionnaire on attitudes toward Internet-based therapies. Due to the novelty of the study subject, the term Internet-based therapy was explained for laypersons prior to attitude assessment. The instruction included information about evidence base (especially depression and anxiety) and current stage of implementation of Internet-delivered therapies in German health care in comparison

XSL•FO
RenderX

to other countries. The final part of the survey was the assessment of 20 items on stressful events in the last 4 weeks. The average time for completing the survey amounted to 7 minutes.

Sociodemographic Variables, Mental Health Care Experience, and E-Awareness

Sociodemographic questions included gender, age, housing situation (alone vs not alone), the area of residence (rural vs urban), educational level, and employment status. Participants were asked to indicate whether they had experience with face-to-face psychotherapy. The frequency of Internet usage was measured as an indicator for familiarity with new media. Participants were asked to indicate whether they ever had heard or read about Internet-based psychotherapies to assess the percentage of e-mental health awareness ("e-awareness"). "E-awareness" was only measured in the Web-based survey.

Attitudes Toward Internet-Based Psychotherapy

A 14-item self-developed questionnaire was used to explore public attitudes toward Internet-based psychotherapy (Table 2). We developed this brief self-report measure due to the lack of validated instruments on public attitudes or acceptability of e-mental health treatment services. Existing self-report measures were either developed in clinical contexts [36] or not directly applicable to the German public health context [10,26]. Items of the measure were selected based on a literature review that aimed to identify commonly cited statements about relative advantages of e-mental health treatment services for mental health care [2,3,18]. The main findings of this work were published as rapid review [21]. The first set of items was subsequently modified after an expert interview (licensed psychotherapist with a senior level of clinical expertise). The expert interview was used to clarify and discuss the suitability of items. The pilot version of the measure was pretested with 14 persons (both students and laypersons without health care background). Feedback of this pretesting involved clarity of items to improve the face validity of the instrument. The instruction contained a brief description about the delivery mode and most common indications (best evidence base for mild-to-moderate mood and anxiety disorders). It also mentioned that Internet-delivered therapies are available in the Netherlands and that they are also considered for implementation in German primary care.

Participants were asked to indicate their agreement to each of the 14 statements about Internet-delivered psychological treatments on a 5-point rating scale, ranging from 0 ("strongly disagree") to 4 ("strongly agree"). As shown in Table 2, most items of the measure referred to attitudes in terms of subjective appraisals about statements on proposed benefits of Internet-delivered therapies for persons with mental health problems. Other items reflected expectations about the potential positive impact of Internet-delivered therapies for mental health care. Based on theoretical framework [32,34], we defined attitudes toward Internet-based therapies as sum of negative, neutral, or positive assessments about a psychological object, situation, or setting. As heuristic for the classification of attitudes, we defined threshold or cutoff values in terms of mean and median scores: Values smaller than 1.5 were defined as negative, scores between 1.5 and 2.5 as neutral, and scores greater than 2.5 as positive attitudes toward Internet-based therapies. In addition, we assessed ambivalent attitudes indirectly considering the qualitative coherence or match of positive or negative attitude toward Internet-based therapies across extracted factors and items of the self-developed survey. For instance, despite positive views regarding the helpfulness of Internet-delivered therapies, other aspects such as intentions to future use Internet-based therapy could be assessed negatively at the same time (indicating ambivalent attitudes). The labeling and mapping of items to factors derived through explorative factor analyses were intended to be based on the UTAUT framework [42,43]. Cronbach alpha reliability of the 14-item measure amounted to .89 in this survey.

Assessment of Stress Perceptions

Current Stress Level

A single-item rating scale was used to assess the current subjective stress level. Such visual analogue scales (VAS) were widely used to measure subjective feelings in medical conditions [56]. VAS included a continuous line with 2 endpoints containing only the smallest and maximal value for the subjective assessment. Participants were asked to indicate to what extent they felt stressed at the moment on a VAS ranging from 0 ("not at all") to 10 ("maximal").

Perceived Stress Questionnaire

The 20-item short version of the Perceived Stress Questionnaire (PSQ-20) [57] was used to assess stress perceptions during the last 4 weeks. Participants were asked to indicate how often the presented statements applied to themselves on a 4-point Likert scale ranging from 1 "almost never" to 4 "usually." The PSQ-20 consisted of the 4 subscales "worries," "demands," "tension," and "joy" and an overall score. In a German validation study on the PSQ long version, internal consistency was good; Cronbach alpha amounted to .86 for the overall score and ranged between .80 and .85 for the 4 subscales [57].

Statistical Analyses

Data of respondents with completed attitude measure analyses were considered for analyses. Descriptive analyses were applied to summarize scores of self-report measures, including means, median scores, and standard deviations (SDs). For data reduction purposes, we conducted an exploratory factor analysis (EFA) for the attitude measure using principal axis factoring as extraction method and promax with Kaiser normalization as oblique rotation procedure (κ=4). Oblique rotation was chosen due to the assumption that the items were not independent from each other (attitude definition). The number of extracted factors was derived using the Kaiser-Guttman criterion for eigenvalues greater than 1. Factor loadings smaller than .10 were suppressed. Additionally, the scree plot was examined for characteristic changes in slope. Both Bartlett test of sphericity and Kaiser-Meyer-Olkin (KMO) criterion were used to confirm the suitability of data for the EFA. Regression factor scores were derived. Factor labels were based on both structure and pattern matrices. The mapping was grounded on the UTAUT. Associations between attitudes, stress perceptions, and age were calculated. Spearman rank correlation (ρ coefficient) was used

XSL•FO
RenderX

because it was more robust than Pearson correlation coefficient in case of questionable multivariate normal distribution. Additionally, we explored differences in mean (*t* tests) and variance (univariate variance analysis; analysis of variance, ANOVA) to identify differences in e-therapy attitudes based on gender, "e-awareness," and therapy experience. Internal consistency of the e-therapy attitude measure was assessed using Cronbach alpha. Effect sizes of correlational analyses were classified as small, medium, or large with respect to Cohen criteria [58]. All statistical tests for significance (two-tailed hypotheses with alpha=.05) were performed using SPSS, version 23 (IBM Analytics).

Results

Descriptive Analyses

A total of 1559 responses were collected through both a Web-based survey (1456) and a paper-and-pencil survey (103). One respondent indicated being 14 years old and was thus excluded from data analyses. This resulted in a final sample size of 1558 responses. The average age of participants was 32 years (mean 31.6, SD 10.9, median 28 years). Most respondents were females (78.95%, 1230/1558), residing in a German city or urban region (70.86%, 1104/1558), living together with at least one other person or persons in their household (69.51%, 1083/1558), and using the Internet daily (96.92%, 1510/1558). Table 1 shows a summary of sample characteristics differentiated by data collection through Web-based and paper-and-pencil surveys.

XSL•FO
RenderX

Table 1. Sample characteristics (N=1558).

Variable		Web-based (n=1455)	Paper-and-pencil (n=103)
Age	Mean (SD), years	31.48 (10.72)	31.42 (13.45)
	Range (median), years	16-75 (28)	19-76 (25)
Gender	Female, n (%)	1160 79.73)	70 (67.96)
	Male[d], n (%)	295 (20.27)	33 (32.04)
Employment status[e]	Employment, n (%)	697 (47.90)	63 (60.17)
	University student or full-time, n (%)	468 (32.16)	14 (13.59)
	Occupational studies or part-time, n (%)	118 (8.11)	49 (47.57)
	Trainee or pupil (secondary education), n (%)	96 (6.60)	6 (5.83)
	Self-employment, n (%)	93 (6.39)	3 (2.91)
	Unemployment, n (%)	76 (5.22)	2 (1.94)
	Parental leave, n (%)	62 (4.26)	1 (0.97)
	Retirement, n (%)	51 (3.51)	9 (8.74)
	Vocational retaining or rehabilitation, n (%)	39 (2.68)	1 (0.97)
Education	No school certificate, n (%)	12 (0.82)	1 (0.97)
	Basic school qualification[a], n (%)	87 (5.98)	4 (3.88)
	Secondary school ("Mittlere Reife")[b], n (%)	387 (26.60)	11 (10.68)
	(%) German "Abitur" or "Fachabitur"[c], n (%)	613 (42.13)	70 (67.96)
	University degree (Bachelor- or Master level), n (%)	340 (23.37)	16 (15.53)
	Postgraduate or postdoctoral degree, n (%)	16 (1.10)	1 (0.97)
Region of residence	Area in or near a city or urban area, n (%)	1038 (71.34)	66 (64.08)
Housing situation	Living not alone in the household, n (%)	1011 (69.45)	72 (69.90)
Experience with psychotherapy[f]	No, n (%)	547 (37.59)	50 (48.54)
	Yes, as patient	656 (45.09)	39 (37.86)
	Yes, as relative, n (%)	259 (17.80)	14 (13.59)
	Yes, as professional, n (%)	201 (13.81)	5 (4.85)
Internet usage (frequency)	Daily, n (%)	1423 (97.80)	87 (84.47)
	Several times a week, n (%)	32 (2.20)	10 (9.71)
	Several times a month, n (%)	0 (0)	3 (2.91)
	Rarely or occasionally, n (%)	0 (0)	0 (0)
	Very rare or never, n (%)	0 (0)	3 (2.91)
E- Awareness (Internet-delivered therapies)	No (not aware), n (%)	1141 (83.46)	Not investigated in the paper-and-pencil survey
	Yes (aware), n (%)	190 (13.97)	
	Not sure, n (%)	35 (2.56)	
	Missing	88 (6.05)	

[a]Basic school qualification=9 school years.

[b]Secondary school ("Mittlere Reife")=10 years.

[c]German "Abitur" or "Fachabitur"=12-13 years.

XSL•FO
RenderX

[d]One respondent in the Web-based survey reported male as sex, but being "bigender" (commentary section).

[e]Employment status: maximum 2 answers were possible.

[f]Experience with psychotherapy: multiple answers (max. 3 answers for the "yes" option). A total of 26 of 1558 participants reported experience with psychotherapy in 3 roles (as patient, relative, and professional).

The mean score for the 14-item e-therapy attitude measure amounted to mean 1.79 (SD 0.71; n=1553). Both modes of data collection resulted in comparable mean scores, although it was identified as slightly lower in the paper-and-pencil survey sample (n=103). The mean score for e-therapy attitudes was mean 1.52 (SD 0.59, median 1.5; n=100, n=3 missing) in the paper-and-pencil sample and mean 1.81 (SD 0.59, median 1.79; n=1455) in the Web-based sample. Table 2 summarizes the descriptive analyses for items of the e-therapy attitude measure, the VAS on current stress, and the PSQ-20 on stress perceptions in the last 4 weeks.

Table 2. Summary of means, standard deviations, and median for stress and attitude assessments (N=1558).

Variables	Mean (SD)	Median
Stress perceptions		
PSQ-20 overall score (past 4 weeks)	52.97 (6.08)	53.33
PSQ-20 subscale "demands"	54.87 (12.01)	53.33
PSQ-20 subscale "tension"	50.15 (11.91)	46.67
PSQ-20 subscale "worries"	48.39 (16.53)	46.67
PSQ-20 subscale "joy"	57.42 (25.94)	60.00
Current stress level (range: 0 to 10)	5.94 (2.40)	6.5
E-therapy attitudes		
Overall score attitude assessment (mean score)	1.79 (0.71)	1.79
Internet-based therapies are modern and in line with our modern times[a].	.93 (1.02)	1.0
Internet-based therapies will replace conventional face-to-face psychotherapy in the future.	2.39 (1.01)	3.0
Internet-based therapy is better compatible with work and private life than conventional face-to-face therapy.	0.88 (1.12)	.0
It makes no difference to me whether psychotherapy is conducted through the Internet or in a psychotherapy practice in a clinic.	2.56 (1.16)	3.0
Internet-based therapies will reach more individuals with mental health problems.	3.07 (0.97)	3.0
Internet-based therapies can help bridging waiting time for conventional psychotherapy.	3.02 (1.02)	3.0
Health insurance companies should cover the costs for Internet-based therapies.	1.37 (1.05)	1.0
Internet-based therapy programs are as effective as conventional face-to-face psychotherapies.	1.13 (1.13)	1.0
Trust in a therapist can be just as easily built on the Internet as in conventional face-to-face psychotherapy	1.09 (1.06)	1.0
Regarding therapeutic success, it makes no difference whether contacts with a therapist are provided via the Internet or face-to-face in a psychotherapeutic practice.	1.51 (1.10)	2.0
Internet-based therapies are an appropriate alternative to conventional face-to-face psychotherapy.	1.71 (1.33)	2.0
In case of mental health problems, I would attend an Internet-based therapy.	1.04 (1.22)	1.0
I would prefer an Internet-based therapy to a conventional face-to-face psychotherapy.	2.24 (1.14)	2.0
Internet-based therapies will reach more patients and help them.	2.18 (0.92)	2.0

[a]All items were translated from German language. The rating scale of the e-therapy attitude measure ranged from 0 "strongly disagree" to 4 "strongly agree." Item 1 refers to expectations and can be interpreted best in connection to other attitudinal items.

As presented in Table 2, most respondents tended to disagree to most of presented statements on suggested advantages of Internet-delivered therapies (ie, 6 items with mean and median scores ≤1.5). The number of items with positive assessment (score≥2.5) and neutral assessments (score between 1.5 and 2.5) was equally distributed (each with 4 statements meeting the criteria).

Explorative Factor Analysis for the E-Therapy Attitude Measure

The EFA resulted in the extraction of 3 factors, which were labeled as "usefulness or helpfulness" (factor 1, 6 items), "relative advantage or comparability"(factor 2, 5 items), and "e-Accessibility or health care" (factor 3, 3 items).

As shown in Multimedia Appendix 1, we identified significant inter-correlations between the 14 items of the e-attitude measure

XSL•FO
RenderX

ranging up to r_{1558}=.68 (P<.001) for items 8 and 9. In contrast to the other items, item 14 was regularly uncorrelated with other items of the measure. The identified significant inter-correlations between most items supported the decision to conduct EFA with oblique rotation instead of using more common orthogonal rotation (ie, varimax). Suitability of data for conducting the EFA with oblique rotation was confirmed given both the results of the Bartlett sphericity test (χ^2_{91}=10420.515, P<.001) and the KMO index (.918) for sampling adequacy. Table 3 shows the pattern matrix for the 3-factor-solution EFA. The structure matrix (see Multimedia Appendix 2) and the rationale for labeling factors extracted through the EFA (see Multimedia Appendix 3, [42]) have been presented.

The total explained variance amounted to 63.71% (unrotated sum of square factor solutions with respect to the extraction; “factor 1” with 43.36%, “factor 2” with 13.02%, and “factor 3” with 7.33% of explained variance). The rotated sums of square factor solutions amounted to 40.42% for “factor 1,” 9.02% for “factor 2,” and 3.02% of explained variance for “factor 3.” The rotated sums of squared loadings were as follows: 4.78 (factor 1), 4.70 (factor 2), and 1.50 (factor 3).

Cronbach alpha reliabilities for standardized items were very good for the 14-item measure (14 items, alpha=.88; unstandardized items alpha=.89). Both factors “usefulness or helpfulness” (6 items, alpha=.87 for both standardized and unstandardized items) and “relative advantage“(5 items, alpha=.84 for both standardized and unstandardized items) showed good Cronbach alpha reliability scores (internal consistency). However, for the third factor “e-accessibility,” we identified a poor alpha reliability (3 items, alpha=.30 for unstandardized and alpha=.27 for standardized items). This should be considered because it was no actual factor, but a single item.

Because of the outlined issues for “factor 3,” we calculated a second factor analysis with a 2-factor solution. This 2-factor-solution EFA is presented in Multimedia Appendix 4. Due to a loss of explained variance identified for this 2-factor solution, we decided to focus on the findings of the 3-factor solution in this study. Another reason was that this third factor (item 14) was mostly unrelated to other items of the measure. This indicated another, yet uncovered dimension of e-therapy attitudes. For the calculation of correlations, we used the 3-factor solution.

XSL•FO
RenderX

Table 3. Pattern matrix: factor loadings of the exploratory factor analysis (EFA) with promax for the e-therapy attitude measure (Extraction method: principal axis factor analysis; rotation method: promax with Kaiser normalization).

Items of the e-therapy attitude measure	Factors[a]		
	1. Usefulness or helpfulness	2. Relative advantage	3. e-Accessibility health care
7. Health insurance companies should cover the costs for Internet-based therapies.	.882[c]	–.142	.125
1. Internet-based therapies are modern and in line with our modern times.	.833[c]	–.205	+++[b]
3. Internet-based therapy is better compatible with work and private life than conventional face-to-face therapy.	.807[c]	–.181	+++[b]
12. In case of mental health problems, I would attend an Internet-based therapy.	.574[c]	.284	–.121
9. Trust in a therapist can be just as easily built on the Internet as in conventional face-to-face psychotherapy.	.516[c]	.409	–.151
8. Internet-based therapy programs are as effective as conventional face-to-face psychotherapy.	.506[c]	.374	+++[b]
4. It makes no difference to me whether psychotherapy is conducted through the Internet or in a practice in a clinic.	–.303	.855[c]	.109
13. I would prefer an Internet-based therapy to a conventional psychotherapy.	–.113	.854[c]	+++[b]
2. Internet-based therapies will replace conventional face-to-face psychotherapy in the future.	+++[b]	.578[c]	.177
11. Internet-based therapies are an appropriate alternative to conventional face-to-face psychotherapy.	.309	.545[c]	+++[b]
10. Regarding therapeutic success, it is incidental whether contacts with a therapist are provided via the Internet or face-to-face in a practice.	.400	.488[c]	+++[b]
5. Internet-based therapies will reach more people with mental health problems.	+++[b]	.319	.540[c]
6. Internet-based therapies can help bridging waiting time for conventional psychotherapy.	.341	+++[b]	.473[c]
14. Internet-based therapies will reach more patients and help them.	+++[b]	+++[b]	–.111[c]

[a]Factor loadings smaller than .1 were suppressed (+++).

[b]Item rotation converged in 6 iterations.

[c]Mapping of items to factor: bold values indicate that the highest factor loading on a factor.

Associations Between Perceived Stress and E-Therapy Attitudes

As presented in Table 4, the 3 factors extracted through EFA and overall mean score of the e-therapy attitude measure were all significantly positively correlated with the current stress level (VAS) and the PSQ subscale “joy” (with small effect sizes). Respondents rated Internet-based therapies as more positive if they indicated to feel more stressed at the time of study participation. This was viewed in the context of stress as control variable. However, pleasant experiences or “joy” in last 4 weeks were also slightly associated with positive assessments in the e-therapy attitude measure. Moreover, the factors “usefulness or helpfulness,” “e-accessibility,” and the overall mean score of the e-therapy attitude measure were significantly positively associated with the PSQ-20 overall score (all with small effect sizes). In contrast, the PSQ subscale “worries” correlated significantly negatively with both “relative advantage” and “e-accessibility” (with small effect sizes), but not with the overall mean score of the e-therapy attitude measure. In other words, self-rated worries were associated with tendencies to negative views about the accessibility and relative advantages of Internet-delivered therapies. The only significant (negative) correlation with the PSQ subscale “tension” was identified for the factor “e-accessibility” (albeit with small effect size). No significant correlation was found between the PSQ subscale “demands” and the scores of the e-therapy attitude measure (Table 4).

XSL•FO
RenderX

Table 4. Correlation matrix: associations between perceived stress and e-therapy attitudes (N=1558).

Stress variables	e-Therapy attitudes			
	e-Therapy attitudes (mean score)	Usefulness or helpfulness	Relative advantage or comparability	e-Accessibility health care
PSQ overall score	0.055[a]	.053[a]	.046[b]	.060[a]
PSQ demands	–0.019[b]	–.042[b]	–.043[b]	–.035[b]
PSQ worries	–0.023[b]	–.035[b]	–.069[a]	–.115[a]
PSQ tension	–.011[b]	.001[b]	–.047[b]	–.051[a]
PSQ joy	0.079[a]	.078[a]	.135[a]	.168[a]
Current stress (VAS)	0.056[a]	.077[a]	.080[a]	.147[a]

[a]Spearman rank correlation (rho, ρ), significant correlation ($P \leq .05$).

[b]Spearman rank correlation (rho, ρ), not significant correlation ($P > .05$).

Correlations With Age

Significant positive correlations were found between age and the mean score of e-therapy attitudes ($\rho_{1552}=.109$; $P<.001$), for factor 1 "usefulness or helpfulness" ($\rho_{1552}=.108$; $P<.001$) and factor 2 "relative advantage or comparability" ($\rho_{1552}=.097$; $P<.001$), but not for factor 3 "e-Accessibility or health care" ($\rho_{1552}=.006$; $P=.81$ not significant). In addition, negative correlations between age with PSQ overall score ($\rho_{1455}=-.068$; $P=.009$) were identified. In contrast, age was correlated neither with any of the 4 PSQ-20 subscales nor with the VAS score on the current stress level (all not significant).

Gender Differences

The survey consisted of 1226 females (e-therapy attitudes: mean 1.78; SD 0.70) and 332 males (e-therapy attitudes: mean 1.83; SD 0.74). According to the Levene test, error variances between both gender groups were homogenously distributed ($F_{1551}=.808$; $P=.37$, not significant). As the *t* test showed, there were no significant differences in e-therapy attitudes in mean scores between females and males in this survey ($t_{1551}=1.050$; $P=.29$, not significant).

E-Awareness Differences

About three-quarters of respondents (73.3%, 1141/1558) indicated being not aware of the existence of Internet-delivered therapies (e-therapy attitudes: mean 1.80, SD 0.70, n=1141). In total, 190 respondents stated being aware of Internet-based therapies (e-therapy attitudes: mean 1.87, SD 0.80, n=190) and 36 persons reported being not sure whether they ever heard or read about Internet-delivered therapies (e-therapy attitudes: mean 2.23, SD 0.72, n=36). Although the sample sizes were highly unequal, group comparisons were performed for explorative analyses. As the Levene test showed, the error variances for the mean score of e-therapy attitudes were not homogenously distributed across the 3 e-awareness groups ($F_{3,1451}=2.353$; $P=.07$, not significant). The univariate ANOVA revealed no significant between-subjects effect of "e-awareness" on e-therapy attitudes ($F_{1,3}=1.726$; $P=.16$, not significant).

Experience With Psychotherapy Differences

As the Levene test showed, error variances for the mean score of e-therapy attitudes were homogenously distributed across 7 groups ($F_{7,1447}=1.750$; $P=.09$, not significant). Tests of between-subjects effect were undertaken with e-therapy attitudes as dependent variable. Univariate ANOVA revealed no significant effect of previous psychotherapy on e-therapy attitudes ($F_{1,7}=1.421$; $P=.19$, not significant).

Taken together, explorative analyses of associations between stress perceptions and attitudes toward Internet-delivered therapies yielded significant findings, albeit with weak effect sizes. In addition, age was found to be correlated with attitudes. Other individual differences in e-therapy attitudes were not identified.

Discussion

Principal Findings

This pilot study addressed the question of how Internet-delivered therapies are perceived in the German-speaking population. Another objective of this survey was to explore the associations between attitudes toward Internet-based therapies and perceived stress. Overall, this survey showed ambivalent attitudes. The main findings and implications for future research are discussed in the following sections.

Summary of Main Findings

Public Attitudes Toward Internet-Delivered Psychotherapy

In summary, our study findings indicated ambivalent attitudes toward Internet-based psychotherapy in a sample of 1558 persons from the German-speaking general population. Ambivalent attitudes involved the coemergence of contradicting (both negative and positive) appraisals about Internet-delivered therapies. Analyses revealed predominantly negative views about Internet-delivered therapies. Most respondents disagreed with statements on advocated advantages of Internet-based therapies with respect to subjective norm, effectiveness (outcome expectancy), compatibility, therapeutic support (facilitating factors), and the willingness to the future use. This

XSL•FO
RenderX

was in line with previous studies [10,26,59,60] that also identified negative view acceptability and low likelihood of using Internet-based therapies in case of mental health problems. The lowest agreement was found for the statement that Internet-delivered therapies are better compatible with work and life conditions than traditional psychological services. This finding appears surprising because Internet-based therapies are suggested to provide more flexibility in terms of time and location as barriers to access professional help [2,3,18,26].

As noted earlier, the e-therapy attitude measure also identified positive assessments about the proposed advantages of Internet-delivered therapies. Analyses showed positive views about "e-accessibility." Respondents were rather optimistic about the potential of digital therapies in mental health care to reach more patients and help them through treatment delivered via the Internet. The highest agreement of participants was found for the statement about the expanded public access or reach of Internet-based therapies for people with mental health problems. In addition, respondents endorsed Internet-based therapies as a valid strategy to bridge waiting time of conventional therapies. This optimistic assessment was, however, challenged by other findings. Interestingly, we also identified a low agreement regarding the statement that health insurance should cover the costs for Internet-based therapies. This appeared to contradict the identified positive views on the helpfulness of Internet-based therapies. Thus, these incoherent patterns of ratings could be interpreted as indications for ambivalent public attitudes in this surveyed convenient sample of the German-speaking general population.

Another point to consider was that the labeling and mapping of e-therapy attitudes to factors were associated with uncertainties. This was because of the commonalities of the 3 factors of the e-therapy attitude measure. Data analyses suggested that different dimensions for the assessment of Internet-based therapies were interrelated and partly hard to identify as distinct components of attitudes. Although we tried to achieve match with constructs of the UTAUT [42,43], we were aware that our self-developed 14-item questionnaire had only a loose connection to the original framework. For instance, we understood "perceived usefulness" in a broader sense, which included expectations about both the helpfulness of Internet-delivered treatments for individual adopters and advances in health care in general. Specific adaptions of the UTAUT framework to the measurement of public attitudes toward e-mental health treatment services could be thus the next logic step. Furthermore, the conducted EFA resulted in a 3-factor solution for the e-therapy attitude measure, but the 2-factor solution for the e-attitude measure appeared more plausible given that fact that the third factor was represented by only 1 item. Hence, the e-therapy attitude measure should be tested with a representative sample to make definitive conclusions regarding its structure.

Individual Differences in Attitudes Toward Internet-Delivered Psychotherapy

This study showed significant positive associations between perceived stress and e-therapy attitudes. Respondents who reported perceiving more stressful events were also more likely to assess Internet-delivered therapies as beneficial. Several explanations appear plausible for this finding. Perceived stress and the increased need for social support could affect help-seeking intentions; related coping strategies and attitudes toward seeking help were identified in earlier research [33,50]. In addition, the study findings indicated that respondents with higher perceived distress appeared being more open to future use of Internet-delivered treatment services, such as iCBT. A possible reason for this finding is that distressed persons had sought for professional support on the Internet and were thus rather ready to use mental health services in comparison to persons who felt currently less distressed. Another explanation is that perceived stress had not directly affected attitudes, but mediated the relationship between individual motives and intentions to use mental health services, as shown in an earlier study [50]. Given the exploratory nature of this survey and the novelty of the e-therapy attitude measure, we did not conduct mediation analysis. Moreover, it should be also considered that subjective assessments of current stress perceptions could have been biased by affective heuristics and contextual clues [61]. Both the novelty of e-mental health treatment services and the low awareness of Internet-based therapies identified in this convenience sample could have resulted in participants using affective heuristics, biasing their assessments about the usefulness of Internet-delivered therapies toward more neutral or negative views. The issue of low "e-awareness" and rather negative assessments about e-mental health treatment services was also observed in previous researches [26,48]. This assumption was supported by the finding that most respondents of the online sample in this study (83.46%, 1141/1367) reported being definitely not aware of the existence of Internet-delivered therapies prior to their survey participation.

To sum up, the evidence base for public attitudes toward Internet-based therapies is too small to make definite conclusions. Although this survey provided some insights, it had limitations. Hence, further research is needed to determine the role of both perceived stress and "e-awareness" in public attitudes toward seeking help on the Internet in case of mental health problems.

Limitations

This pilot study has several limitations. Consistent with other studies targeting public attitudes toward e-mental health [10,26,48], we used a self-developed survey that was not validated. In addition, convenience sampling in this study could have been affected by selection bias. This is a common issue in e-mental health research [62]. Nonetheless, sample characteristics of this study were in line with the findings showing that females and well-educated younger persons were the main groups seeking health information on the Web [63,64] and engaging with e-mental health interventions [22]. Moreover, we identified a high percentage of unawareness regarding the existence of Internet-based therapies. The single item on "e-awareness" was also a limitation. Future studies should consider operationalizing "e-awareness" using a multi-item measure with precise descriptions of intervention formats. Comparisons made in the items of attitude measure were also a limitation because conventional therapies might be viewed as "benchmark" and thus Internet-based therapies as inferior [26].

XSL•FO
RenderX

In Germany, Internet-delivered treatments are not covered by health insurances. Additionally, psychotherapists face legal barriers to provide Internet-based treatments. This uncertain legal status could also play a role in forming negative attitudes regarding the effectiveness or appropriateness of Internet-delivered psychotherapy. However, this hypothesis needs further investigation. Additionally, it remains unclear on which basis respondents have built their opinions about Internet-delivered therapies. It can be assumed that subjective definitions of the term "Internet-based therapy" varied broadly. It remains unclear to what extent lacking "e-awareness" has affected the willingness to future using Internet-delivered therapies in case of emotional distress. Moreover, identified associations between attitudes and perceived stress were weak. The theoretical grounding of the correlational research question was also not strong. Thus, for further validation purposes, other constructs than those applied (ie, stress) in this study could be a better choice. A final point to consider is the 3-factor structure of the measure identified through EFA and related psychometric issues. This left some questions open. Taken together, the findings presented in this study should be therefore interpreted with caution.

Implications

It can be assumed that the ongoing diffusion of e-mental health services into everyday life will affect attitudes toward using these services over the course of the next years. Exploring public attitudes toward e-mental health treatment services on a regular basis is thus recommended throughout different stages of their implementation into German health care. Experience with these innovations is likely to influence public opinions. For instance, an Australian study [65] demonstrated that both laypersons and health professionals were more likely to endorse e-mental health treatments as helpful when they had used them in the past. Psychoeducational information and e-mental health literacy could also improve the acceptability and attitudes toward Internet-based therapies [48,66]. Nonetheless, it should be noted that the role of "e-awareness" in attitudes toward Internet-delivered therapies is still understudied [26,48]. There are indications that lacking e-awareness is an obstacle for assessments, resulting in more negative views about e-mental health services [26]. However, in this study we used a vague definition of Internet-based therapies that might have resulted in an overweight of negative assessments. Participants in this pilot study were asked to assess their views on Internet-based therapies, regardless of medical indication, intervention type, or delivery mode of Internet-based therapies. It is possible that presenting specific types or provision modes of Internet-delivered therapies in the survey instruction could have resulted in type-specific differences in e-therapy attitudes, as previous research suggested [10,26,48]. Therefore, different aspects of Internet-based therapies should be considered in the measurement of attitudes to provide deeper insights into the "black box" of individual determinants underlying the adoption of e-mental health treatments [67]. For this purpose, the psychometric assessment of e-therapy attitudes could be combined with qualitative methods, such as in-depth interviews [7] or focus group discussions [9]. Because qualitative approaches require substantially more resources as well as efforts in comparison to quantitative surveys, mixed methods could be a viable strategy to improve the operationalization of constructs in surveys targeting e-therapy attitudes in nonclinical populations.

The findings of this study directed to options to improve the psychometric assessments of attitudes toward Internet-based therapies. As modification of the study design, descriptions of specific formats of Internet-delivered therapies to determine type-specific preferences should be included in the instruction of the e-therapy attitude measure. Another modification for the e-therapy attitude measure we considered was the employment of additional items reflecting disadvantages, concerns, and psychological barriers. For instance, barriers to seek help such as the stigma of mental illness could be diminished on the Internet [27] besides misunderstandings and false interpretations [68], impersonal communication [59], or concerns about privacy and data security [10,27,30,55]. We integrated these aspects in a revised version of e-attitude measure [69]. Based on the EFA presented in this study, we excluded 2 items with high loading scores on more than 1 factor (ie, items 6 and 10) and added 5 novel statements reflecting data security concerns, benefits of anonymous access, risk of misunderstanding, and unequal accessibility for underprivileged populations. With this revised 17-item measure, we expect to cover more components of e-therapy attitudes as it appeared to be a multidimensional construct.

Finally, despite our broad recruitment strategy we had a highly selected sample consisting mainly of young adults and females. Although more female than male persons seek help for mental problems and attend psychotherapy [51], future studies should aim to explore attitudes of populations underrepresented in most studies, such as young men [70]. Given that Internet-delivered therapies such as iCBT mostly reach similar populations as traditional face-to-face CBT [21,62], expanding the public access to professional help remains a great challenge. Understanding the views and needs of a broad range of potential adopters in public health could be a crucial next step to reach more or hard-to-reach persons from the general population.

Conclusions

This study revealed mostly negative, ambivalent attitudes toward Internet-delivered therapies with poor "e-awareness" in the German-speaking general population. However, e-mental health research scoping on public attitudes toward e-mental health treatments is still in its infancy. The self-developed measure, marginal e-awareness, and the nonrepresentative sample were limitations of this study. Hence, further research regarding the development and validation of measures is recommended to shed more light into the "black box" of public perceptions of Internet-based therapies. Nonetheless, active participation of both citizens and patients in the development of Internet-based interventions is important, and thus future research should aim to extend options for innovative ways to assess public attitudes toward e-mental health treatment services.

XSL•FO
RenderX

Acknowledgments

We thank Dr Siegfried Tasseit for his support regarding the measurement development and sample recruitment.

Conflicts of Interest

None declared.

Multimedia Appendix 1

[PDF File (Adobe PDF File), 27KB - mental_v4i1e8_app1.pdf]

Multimedia Appendix 2

[PDF File (Adobe PDF File), 23KB - mental_v4i1e8_app2.pdf]

Multimedia Appendix 3

[PDF File (Adobe PDF File), 22KB - mental_v4i1e8_app3.pdf]

Multimedia Appendix 4

[PDF File (Adobe PDF File), 30KB - mental_v4i1e8_app4.pdf]

References

1. Steel Z, Marnane C, Iranpour C, Chey T, Jackson JW, Patel V, et al. The global prevalence of common mental disorders: a systematic review and meta-analysis 1980-2013. Int J Epidemiol 2014 Apr;43(2):476-493 [FREE Full text] [doi: 10.1093/ije/dyu038] [Medline: 24648481]
2. Lal S, Adair CE. E-mental health: a rapid review of the literature. Psychiatr Serv 2014 Jan 1;65(1):24-32. [doi: 10.1176/appi.ps.201300009] [Medline: 24081188]
3. Moock J. Support from the internet for individuals with mental disorders: advantages and disadvantages of e-mental health service delivery. Front Public Health 2014 Jun;2:65 [FREE Full text] [doi: 10.3389/fpubh.2014.00065] [Medline: 24967221]
4. Vogel D, Wade N, Hackler A. Perceived public stigma and the willingness to seek counseling: the mediating roles of self-stigma and attitudes toward counseling. J Couns Psychol 2007;54(1):40-50. [doi: 10.1037/0022-0167.54.1.40]
5. Gureje O. Public mental health: the need for a broader view of the issues. World Psychiatry 2015 Feb;14(1):54-55 [FREE Full text] [doi: 10.1002/wps.20186] [Medline: 25655158]
6. Wahlbeck K. Public mental health: the time is ripe for translation of evidence into practice. World Psychiatry 2015 Feb;14(1):36-42 [FREE Full text] [doi: 10.1002/wps.20178] [Medline: 25655149]
7. 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;15(9):e193 [FREE Full text] [doi: 10.2196/jmir.2772] [Medline: 24007949]
8. Mayo-Wilson E, Montgomery P. Media-delivered cognitive behavioural therapy and behavioural therapy (self-help) for anxiety disorders in adults. Cochrane Database Syst Rev 2013 Sep 09(9):CD005330. [doi: 10.1002/14651858.CD005330.pub4] [Medline: 24018460]
9. Chan JK, Farrer LM, Gulliver A, Bennett K, Griffiths KM. University students? views on the perceived benefits and drawbacks of seeking help for mental health problems on the internet: a qualitative study. JMIR Hum Factors 2016 Jan 19;3(1):e3 [FREE Full text] [doi: 10.2196/humanfactors.4765] [Medline: 27026140]
10. Klein B, Cook S. Preferences for e-mental health services amongst an online Australian sample? Eur J Appl Physiol 2010 May 25;6(1). [doi: 10.7790/ejap.v6i1.184]
11. Riper H, Andersson G, Christensen H, Cuijpers P, Lange A, Eysenbach G. Theme issue on e-mental health: a growing field in internet research. J Med Internet Res 2010 Dec 19;12(5):e74 [FREE Full text] [doi: 10.2196/jmir.1713] [Medline: 21169177]
12. Arnberg FK, Linton SJ, Hultcrantz M, Heintz E, Jonsson U. Internet-delivered psychological treatments for mood and anxiety disorders: a systematic review of their efficacy, safety, and cost-effectiveness. PLoS One 2014;9(5):e98118 [FREE Full text] [doi: 10.1371/journal.pone.0098118] [Medline: 24844847]
13. 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]
14. Olthuis JV, Watt MC, Bailey K, Hayden JA, Stewart SH. Therapist-supported Internet cognitive behavioural therapy for anxiety disorders in adults. Cochrane Database Syst Rev 2016 Mar 12;3:CD011565. [doi: 10.1002/14651858.CD011565.pub2] [Medline: 26968204]

XSL•FO
RenderX

15. Beintner I, Jacobi C, Taylor CB. Effects of an Internet-based prevention programme for eating disorders in the USA and Germany--a meta-analytic review. Eur Eat Disord Rev 2012 Jan;20(1):1-8. [doi: 10.1002/erv.1130] [Medline: 21796737]
16. van Beugen S, Ferwerda M, Hoeve D, Rovers MM, Spillekom-van KS, 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]
17. Sander L, Rausch L, Baumeister H. Effectiveness of Internet-Based interventions for the prevention of mental disorders: a systematic review and meta-analysis. JMIR Ment Health 2016 Aug 17;3(3):e38 [FREE Full text] [doi: 10.2196/mental.6061] [Medline: 27535468]
18. Musiat P, Tarrier N. Collateral outcomes in e-mental health: a systematic review of the evidence for added benefits of computerized cognitive behavior therapy interventions for mental health. Psychol Med 2014 Nov;44(15):3137-3150. [doi: 10.1017/S0033291714000245] [Medline: 25065947]
19. Sawesi S, Rashrash M, Phalakornkule K, Carpenter JS, Jones JF. The impact of information technology on patient engagement and health behavior change: a systematic review of the literature. JMIR Med Inform 2016 Jan 21;4(1):e1 [FREE Full text] [doi: 10.2196/medinform.4514] [Medline: 26795082]
20. Wallin EE, Mattsson S, Olsson EM. The preference for internet-based psychological interventions by individuals without past or current use of mental health treatment delivered online: a survey study with mixed-methods analysis. JMIR Ment Health 2016 Jun 14;3(2):e25 [FREE Full text] [doi: 10.2196/mental.5324] [Medline: 27302200]
21. Apolinário-Hagen JA, Tasseit S. Access to psychotherapy in the era of web 2.0: new media, old inequalities? Int J Health Prof 2015;2(2):119-129 [FREE Full text] [doi: 10.1515/ijhp-2015-0010]
22. Crisp DA, Griffiths KM. Participating in online mental health interventions: who is most likely to sign up and why? Depress Res Treat 2014:790457. [doi: 10.1155/2014/790457]
23. Donker T, Batterham PJ, Warmerdam L, Bennett K, Bennett A, Cuijpers P, et al. Predictors and moderators of response to internet-delivered Interpersonal Psychotherapy and Cognitive Behavior Therapy for depression. J Affect Disord 2013 Oct;151(1):343-351. [doi: 10.1016/j.jad.2013.06.020] [Medline: 23953024]
24. Deen TL, Fortney JC, Schroeder G. Patient acceptance of and initiation and engagement in telepsychotherapy in primary care. Psychiatr Serv 2013 Apr 01;64(4):380-384 [FREE Full text] [doi: 10.1176/appi.ps.201200198] [Medline: 23370530]
25. Alaoui SEL, Hedman E, Ljótsson B, Lindefors N. Long-term effectiveness and outcome predictors of therapist-guided internet-based cognitive–behavioural therapy for social anxiety disorder in routine psychiatric care. BMJ Open 2015;5(6):e007902. [doi: 10.1136/bmjopen-2015-007902]
26. Musiat P, Goldstone P, Tarrier N. Understanding the acceptability of e-mental health--attitudes and expectations towards computerised self-help treatments for mental health problems. BMC Psychiatry 2014;14:109 [FREE Full text] [doi: 10.1186/1471-244X-14-109] [Medline: 24725765]
27. Horgan A, Sweeney J. Young students' use of the Internet for mental health information and support. J Psychiatr Ment Health Nurs 2010 Mar;17(2):117-123. [doi: 10.1111/j.1365-2850.2009.01497.x] [Medline: 20465756]
28. Wetterlin FM, Mar MY, Neilson EK, Werker GR, Krausz M. eMental health experiences and expectations: a survey of youths' Web-based resource preferences in Canada. J Med Internet Res 2014 Dec 17;16(12):e293 [FREE Full text] [doi: 10.2196/jmir.3526] [Medline: 25519847]
29. 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] [Medline: 22001968]
30. Choi I, Sharpe L, Li S, Hunt C. Acceptability of psychological treatment to Chinese- and Caucasian-Australians: Internet treatment reduces barriers but face-to-face care is preferred. Soc Psychiatry Psychiatr Epidemiol 2015 Jan;50(1):77-87. [doi: 10.1007/s00127-014-0921-1] [Medline: 24993290]
31. Gulliver A, Bennett K, Bennett A, Farrer LM, Reynolds J, Griffiths KM. Privacy issues in the development of a virtual mental health clinic for university students: a qualitative study. JMIR Mental Health 2015 Mar 31;2(1):e9. [doi: 10.2196/mental.4294]
32. Ajzen I. Nature and operation of attitudes. Annu Rev Psychol 2001;52:27-58. [doi: 10.1146/annurev.psych.52.1.27] [Medline: 11148298]
33. Khan N, Bower P, Rogers A. Guided self-help in primary care mental health: meta-synthesis of qualitative studies of patient experience. Br J Psychiatry 2007 Sep;191:206-211 [FREE Full text] [doi: 10.1192/bjp.bp.106.032011] [Medline: 17766759]
34. Hohman ZP, Crano WD, Siegel JT, Alvaro EM. Attitude ambivalence, friend norms, and adolescent drug use. Prev Sci 2014 Feb;15(1):65-74 [FREE Full text] [doi: 10.1007/s11121-013-0368-8] [Medline: 23404670]
35. Boettcher J, Renneberg B, Berger T. Patient expectations in internet-based self-help for social anxiety. Cogn Behav Ther 2013;42(3):203-214. [doi: 10.1080/16506073.2012.759615] [Medline: 23697570]
36. 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] [Medline: 26331687]
37. Jenssen BP, Mitra N, Shah A, Wan F, Grande D. Using digital technology to engage and communicate with patients: a survey of patient attitudes. J Gen Intern Med 2016 Jan;31(1):85-92. [doi: 10.1007/s11606-015-3517-x] [Medline: 26385117]

XSL•FO
RenderX

38. Johansson R, Nyblom A, Carlbring P, Cuijpers P, Andersson G. Choosing between Internet-based psychodynamic versus cognitive behavioral therapy for depression: a pilot preference study. BMC Psychiatry 2013 Oct 18;13(1):268 [FREE Full text] [doi: 10.1186/1471-244X-13-268] [Medline: 24139066]
39. Rho MJ, Choi IY, Lee J. Predictive factors of telemedicine service acceptance and behavioral intention of physicians. Int J Med Inform 2014 Aug;83(8):559-571. [doi: 10.1016/j.ijmedinf.2014.05.005] [Medline: 24961820]
40. Li J, Talaei-Khoei A, Seale H, Ray P, Macintyre CR. Health care provider adoption of eHealth: systematic literature review. Interact J Med Res 2013 Apr 16;2(1):e7 [FREE Full text] [doi: 10.2196/ijmr.2468] [Medline: 23608679]
41. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Q 1989 Sep;13(3):319. [doi: 10.2307/249008]
42. Venkatesh V, Morris M, Davis G. User acceptance of information technology: toward a unified view. MIS Q 2003;27(3):425-478. [doi: 10.2307/30036540]
43. Venkatesh V, Thong JYL, Xu X. Consumer acceptance and use of information technology: extending the unified theory of acceptance and use of technology. MIS Q 2012;36(1):157-178.
44. Williams MD, Rana NP, Dwivedi YK. The unified theory of acceptance and use of technology (UTAUT): a literature review. Journal of Enterprise Information Management 2015 Apr 13;28(3):443-488. [doi: 10.1108/JEIM-09-2014-0088]
45. Rogers E. Diffusion of innovations. New York: Free Press; 2003.
46. Ajzen I. The theory of planned behavior. Organ Behav Hum Decis Process 1991 Dec;50(2):179-211. [doi: 10.1016/0749-5978(91)90020-T]
47. Oh E, Jorm A, Wright A. Perceived helpfulness of websites for mental health information: a national survey of young Australians. Soc Psychiatry Psychiatr Epidemiol 2009;44:293-299. [doi: 10.1007/s00127-008-0443]
48. Casey LM, Joy A, Clough BA. The impact of information on attitudes toward e-mental health services. Cyberpsychol Behav Soc Netw 2013 Aug;16(8):593-598. [doi: 10.1089/cyber.2012.0515] [Medline: 23679567]
49. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. Psychol Bull 1985 Sep;98(2):310-357. [Medline: 3901065]
50. Vogel DL, Wei M. Adult attachment and help-seeking intent: the mediating roles of psychological distress and perceived social support. J Couns Psychol 2005;52(3):347-357. [doi: 10.1037/0022-0167.52.3.347]
51. Jackson H, Judd F, Komiti A, Fraser C, Murray G, Robins G, et al. Mental health problems in rural contexts: what are the barriers to seeking help from professional providers? Aust Psychol. Australian Psycholgist 2007;42(2):147-160 [FREE Full text] [doi: 10.1080/00050060701299532]
52. Ozyurek P, Oztasan N, Kilic I. The relationship between perceived stress and computer technology attitude: an application on health sciences students. Acta Inform Med 2015 Feb;23(1):33-38 [FREE Full text] [doi: 10.5455/aim.2015.23.33-38] [Medline: 25870489]
53. Ard-zdf-onlinestudie.de. ARD-ZDF-Onlinestudie 2015: Knapp 80 Prozent der Deutschen sind online ? User nutzen Internet häufiger und vielfältiger URL: http://www.ard-zdf-onlinestudie.de/fileadmin/Onlinestudie_2015/PM_ARD-ZDF-Onlinestudie_2015-10-12.pdf [accessed 2017-01-30] [WebCite Cache ID 6nsrImwDP]
54. Bauer S, Kordy H. In: Bauer S, editor. E-Mental-Health: Neue Medien in der psychosozialen Versorgung [in Germany]. Berlin, Heidelberg: Springer; 2008.
55. Eichenberg C, Wolters C, Brähler E. The internet as a mental health advisor in Germany--results of a national survey. PLoS One 2013;8(11):e79206 [FREE Full text] [doi: 10.1371/journal.pone.0079206] [Medline: 24278121]
56. Lesage FX, Berjot S. Validity of occupational stress assessment using a visual analogue scale. Occup Med (Lond) 2011 Sep;61(6):434-436. [doi: 10.1093/occmed/kqr037] [Medline: 21505089]
57. Fliege H, Rose M, Arck P, Levenstein S, Klapp BF. Validierung des “Perceived Stress Questionnaire” (PSQ) an einer deutschen Stichprobe. Diagnostica 2001 Jul;47(3):142-152. [doi: 10.1026//0012-1924.47.3.142]
58. Cohen J. Statistical power analysis for the behavioral sciences. Hillsdale, NJ: L Erlbaum Associates; 1988.
59. Mitchell N, Gordon PK. Attitudes towards computerized CBT for depression amongst a student population. Behav Cognit Psychother 2007 May 14;35(04):421. [doi: 10.1017/s1352465807003700]
60. Mohr DC, Siddique J, Ho J, Duffecy J, Jin L, Fokuo JK. Interest in behavioral and psychological treatments delivered face-to-face, by telephone, and by internet. Ann Behav Med 2010 Aug;40(1):89-98 [FREE Full text] [doi: 10.1007/s12160-010-9203-7] [Medline: 20652466]
61. Strough J, Karns TE, Schlosnagle L. Decision-making heuristics and biases across the life span. Ann N Y Acad Sci 2011 Oct;1235:57-74 [FREE Full text] [doi: 10.1111/j.1749-6632.2011.06208.x] [Medline: 22023568]
62. 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 02;14(4):e110 [FREE Full text] [doi: 10.2196/jmir.2084] [Medline: 22858538]
63. Santana S, Lausen B, Bujnowska-Fedak M, Chronaki C, Kummervold PE, Rasmussen J, et al. Online communication between doctors and patients in Europe: status and perspectives. J Med Internet Res 2010 Jun 15;12(2):e20 [FREE Full text] [doi: 10.2196/jmir.1281] [Medline: 20551011]

XSL•FO
RenderX

64. Zschorlich B, Gechter D, Janßen IM, Swinehart T, Wiegard B, Koch K. [Health information on the Internet: who is searching for what, when and how?]. Z Evid Fortbild Qual Gesundhwes 2015;109(2):144-152. [doi: 10.1016/j.zefq.2015.03.003] [Medline: 26028452]
65. 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]
66. 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 01;176:9-17. [doi: 10.1016/j.jad.2015.01.056] [Medline: 25682378]
67. Whitton AE, Proudfoot J, Clarke J, Birch M, Parker G, Manicavasagar V, et al. Breaking open the black box: isolating the most potent features of a web and mobile phone-based intervention for depression, anxiety, and stress. JMIR Mental Health 2015 Mar 04;2(1):e3. [doi: 10.2196/mental.3573]
68. Rochlen A, Zack J, Speyer C. Online therapy: review of relevant definitions, debates, and current empirical support. J Clin Psychol 2004;60(3):269-283. [doi: 10.1002/jclp.10263]
69. Apolinário-Hagen J, Vehreschild V. Proceedings of the 3rd IPLeiria's International Health Congress : Leiria, Portugal. 6-7 May 2016. In: BMC Health Serv Res.: BMC; 2016 Jul 06 Presented at: IP Leira International Health Congress; 2016; Portugal p. 200 URL: https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-016-1423-5 [doi: 10.1186/s12913-016-1423-5]
70. Ellis LA, Collin P, Hurley PJ, Davenport TA, Burns JM, Hickie IB. Young men's attitudes and behaviour in relation to mental health and technology: implications for the development of online mental health services. BMC Psychiatry 2013 Apr 20;13:119 [FREE Full text] [doi: 10.1186/1471-244X-13-119] [Medline: 23601273]

Abbreviations

ANOVA: analysis of variance
CBT: cognitive behavior therapy
e-awareness: e-mental health awareness
EFA: exploratory factor analysis
e-mental health: electronic mental health
e-therapy attitudes: electronic or Internet-based therapy attitudes
iCBT: Internet-based cognitive behavior therapy
IT: information technology
KMO: Kaiser-Meyer-Olkin (index)
NS: not significant
PAF: principal axis factor analysis
TAM: technology acceptance model
TPB: theory of planned behavior
UTAUT: unified theory of acceptance and use of technology
VAS: visual analogue scale

Edited by G Eysenbach; submitted 20.07.16; peer-reviewed by B Meyer, L Lavorgna, M Stuckey; comments to author 18.11.16; revised version received 30.12.16; accepted 25.01.17; published 23.02.17.

Please cite as:
Apolinário-Hagen J, Vehreschild V, Alkoudmani RM
Current Views and Perspectives on E-Mental Health: An Exploratory Survey Study for Understanding Public Attitudes Toward Internet-Based Psychotherapy in Germany
JMIR Ment Health 2017;4(1):e8
URL: http://mental.jmir.org/2017/1/e8/
doi:10.2196/mental.6375
PMID:28232298

©Jennifer Apolinário-Hagen, Viktor Vehreschild, Ramez M Alkoudmani. Originally published in JMIR Mental Health (http://mental.jmir.org), 23.02.2017. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Mental Health, is properly cited. The complete bibliographic information, a link to the original publication on http://mental.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

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

Murielle Villani[1,2*], PhD; Viviane Kovess-Masfety[1,2,3*], MD, PhD

[1]Fondation Pierre Deniker, Paris, France

[2]Laboratoire de Psychopathologie et Processus de Santé, Université Paris Descartes, Boulogne-Billancourt, France

[3]École des Hautes Études en Santé Publique, Paris, France

[*]all authors contributed equally

Corresponding Author:
Murielle Villani, PhD
Fondation Pierre Deniker
36 Avenue Raymond Poincaré
Paris,
France
Phone: 33 6 03 69 60 02
Fax: 33 1 76 53 29 62
Email: muriellevillani@gmail.com

Abstract

Background: Studies show that the Internet has become an influential source of information for people experiencing serious psychiatric conditions such as schizophrenia spectrum disorders or other psychotic disorders, among which the rate of Internet users is growing, with rates ranging from 33.3% to 79.5% given the country. Between 20.5% and 56.4% of these Internet users seek mental health information.

Objective: Focusing on this population's Web searches about their mental health, this paper examines what type of content they look for and what could be the benefits and disadvantages of this navigation.

Methods: We conducted a literature review through medical and psychological databases between 2000 and 2015 using the keywords "Internet," "Web," "virtual," "health information," "schizophrenia," "psychosis," "e-mental health," "e-support," and "telepsychiatry."

Results: People experiencing schizophrenia spectrum disorders or other psychotic disorders wish to find on the Internet trustful, nonstigmatizing information about their disease, flexibility, security standards, and positive peer-to-peer exchanges. E-mental health also appears to be desired by a substantial proportion of them. In this field, the current developments towards intervention and early prevention in the areas of depression and bipolar and anxiety disorders become more and more operational for schizophrenia spectrum disorders and other psychotic disorders as well. The many benefits of the Internet as a source of information and support, such as empowerment, enhancement of self-esteem, relief from peer information, better social interactions, and more available care, seem to outbalance the difficulties.

Conclusions: In this paper, after discussing the challenges related to the various aspects of the emergence of the Internet into the life of people experiencing schizophrenia spectrum disorders or other psychotic disorders, we will suggest areas of future research and practical recommendations for this major transition.

(JMIR Ment Health 2017;4(1):e1) doi:10.2196/mental.5946

KEYWORDS

Internet; health information; e-mental health; e-support; schizophrenia spectrum disorders; psychotic disorders

XSL•FO
RenderX

Introduction

Health information–seeking is the most common online activity in today's world [1], and 50 million websites are devoted to health-related information [2]. Internet, social media, and online technologies have become powerful tools in the mental health sector, leading transformations that go from infodemiology and infoveillance—the monitoring of suicidal tendancies [3-6] or medical antidepressants prescription behaviors [7], for example, with a Google Trends-based approach—to crowdsourcing for conducting randomized trials for the purpose of scientific research [8], not to mention the delivery of evidence-based therapies targeting various mental illnesses [9,10]. Some thought papers have studied the evolution of telepsychiatry, also called "e-mental health care," where this expression defines a "practice supported by electronic processes and communication, (including) mental health applications and links on mobile phones" and services of "information (delivering), peer support services, computer- and Internet-based programs, virtual applications, and games, as well as real time interaction with trained clinicians" [11]. Thus, a large variety of interventions are designated alternatively by the terms eHealth and e-support or mHealth and m-support when online technologies are reached via mobile or smartphone. Research has stressed the fact that this emerging kind of support is a cost-effective and ongoing resource that defies geographical, timely, and social barriers (the "mental health gap") [12,13] without replacing the traditional system [14,15]. While there has been an increase in the number of people using the Internet for information and support relating to mental health disorders, available resources—from psychoeducation to self-help therapy, peer-to-peer support forums, and e-counseling—focus mainly on depression, anxiety, and bipolar disorder, with a particular interest in the monitoring of signs and symptoms by smartphone or digital application [10], together with psychoeducational programs [9] and not so much on schizophrenia spectrum disorders or other psychotic disorders.

People facing severe psychiatric conditions have become more and more active in their treatment and care plan, which is partly due to the legal evolutions of the last decades but also an increasing empowerment of people experiencing mental illnesses and their representing associations [16,17]. Getting information on their disease by themselves contributes to this new balance in the relationship with their doctor. Finally, the change of paradigm about schizophrenia spectrum disorders or other psychotic disorders in the scientific community, with the emergence of the possibility of recovery [18], giving hope to people experiencing those mental illnesses, has also encouraged them to actively seek help, support, and reassurance by using different resources. The Internet is one of those resources and offers unprecedented access to information shared by professionals and peers.

People experiencing stigma, who avoid face-to-face contacts as much as possible, are more likely to use the Internet for accessing health information than those with conditions that do not come with negative stereotypes [19]. People with schizophrenia, a disease that is particularly subject to stigma [20-23], should be well represented among Internet users. As a general background, the relatively scarce but quickly growing body of research on the use of the Internet for mental health–related information among people experiencing serious psychiatric conditions shows that in developed countries where there are available studies on this matter, more and more people living with such conditions use the Internet and a relatively substantial proportion does so in order to access mental health information. Indeed, in populations specifically constituted of people experiencing severe psychiatric conditions, the percentage of Internet users ranged from 33.3% in 2009 the United States [24] to 62.6% in 2008 in Switzerland [25] and 79.5% in 2014 in Germany [26], with the highest rates corresponding to the latest studies. The percentage of people with a serious mental illness or psychiatric condition seeking health-related information on the Internet was 42.9% in Switzerland [25], 53% in the United States [24], and 56.36% in Germany [26]. A recent American study about the connectivity of people with schizophrenia investigated the daily use of social media network websites and found that 27% of the participants used these sites everyday [27]. The predictive factors of this usage are various, including young age and higher education [24], knowledge of English, and private Internet access [25]. As one can also access the Internet through smartphones, the prevalence of smartphone usage among people experiencing schizophrenia is also of interest. In this area, studies have found that a large majority of participants had a cell phone, knew how to text, and were able to use cell phones with few problems [27-29]. The link with specific diagnoses and their severity is controversial: while some studies highlight that people experiencing schizophrenia have a lower access to the Internet due to financial problems, an itinerant way of life, or a low education level [1], more recent research studies have found that the actual Internet usage is not different for these persons [26,30].

In this evolving context, it seems important to further explore the use of the Internet among people experiencing schizophrenia or other psychotic disorders in relationship to their mental health. Our specific research questions include the content of the information looked for and retrieved; the benefits in terms of empowerment, stigma resistance, coping, social interactions, management of the care process, and clinical improvement; and the difficulties they might encounter (for example, the potential risk of aggravating symptoms) in comparison with the absence of use of the Internet. We then suggest recommendations about practical evolutions in this promising field.

Methods

The aim of our review is to identify published literature that would help assess the Internet and Internet-based technology use by people experiencing schizophrenia spectrum disorders or other psychotic disorders, in particular regarding information about their health. The scope of our research included people experiencing schizophrenia spectrum disorders as well as other psychotic disorders [31]. However, we have included in our review some studies investigating people experiencing schizophrenia spectrum disorders or other psychotic disorders' Internet use while sometimes using other terminologies, such as "psychosis," "severe or serious mental illness," or "serious

XSL•FO
RenderX

psychiatric conditions or disorders." We focused on definitions of Internet use that did not specifically addressed addiction issues or the use of a virtual environment as a therapy in itself.

The analysis of people experiencing schizophrenia spectrum disorders or other psychotic disorders' Internet use being relatively recent, most of the studies in that field include small populations and heterogeneous methodologies, which presents an increased risk of error in the context of a meta-analysis [21]. Consequently, we have done as much as we could to approximate a systematic review by following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines; indeed, our motivation was not to measure the effectiveness of Internet use for our target population but to discuss specific aspects of the evolution in this matter in both a contextual and a theoretical approach.

Therefore, we conducted a literature review through the medical and psychological databases PsycInfo, PsycArticles, SantéPsy, Cairn, Medline, Wiley Interscience, and PubPsych between 2000 and 2015 (including those complete years) using the keywords "Internet," "Web," "virtual," "health information," "schizophrenia," and "psychosis." Articles were included only if their scope addressed mainly or subsequently a population with schizophrenia spectrum and other psychotic disorders and if their main topic was related to their Internet use or Internet-based technologies use. Pertinent articles retrieved allowed us to broaden our search, for example, by using additional keywords ("eMental health," "eSupport," "telepsychiatry," "mobile," "online"). Subsequently, all additional relevant articles cited in reference lists were added to our sources of information.

Out of 85 papers retrieved, 11 were removed as outside of our scope and 45 articles were identified as pertinent for our research, read in full text, and used for this paper with their main qualitative and quantitative findings recorded. The body of articles analyzed allowed us to identify themes and issues that are described in our results. Each included article was then re-reviewed in the light of the themes that emerged from our first analysis. The remaining 29 more general papers were kept in order to feed the discussion and are quoted in the paper as well.

Results

What Are People Experiencing Schizophrenia Spectrum Disorders or Other Psychotic Disorders Looking for on the Internet?

Type of Information Requested

In most of the cases, people experiencing schizophrenia spectrum disorders or other psychotic disorders who are regular or occasional Internet users seek health-related information [15,25,26]. With an average contact with their doctor lasting about 15 minutes every 6 months, one can understand that people experiencing schizophrenia may be tempted to seek information on their own [2]. Kalckreuth et al [26] have ranked the different kinds of health information for which people experiencing psychiatric conditions look. General information about mental disorders such as explanations about diagnosis, symptoms, and prognosis comes first (32%), followed by general information on medication such as description of secondary effects (25%). Connected people experiencing severe mental illness also look for information about mental health services: where and how to access them, what quality to expect (22%), and platforms of exchange with peers (11%) or professionals (10%) [26].

A qualitative Austrian study investigating the nature and consequences of health-related Internet use among people experiencing schizophrenia spectrum disorders [32] reported that the Internet is an important and influential source of information for them and that their behavior on the Internet is not significantly different from nonaffected people's behavior. Their subjects of interest on the Internet are general information about schizophrenia, treatments and secondary effects (especially about how to avoid them), diagnosis verification, services access and evaluation, risk factors, and causes [32].

Preferences About Internet Site Characteristics

The Austrian study, analyzing 26 individual semistructured interviews, identified precise elements concerning the content and quality that people experiencing schizophrenia spectrum disorders or other psychotic disorders are searching for on the Web while accessing information about their mental health problem. The quality and reliability of Internet information is judged overall satisfactory by them, with a preference for official pages from universities and magazines over private pages or chat rooms. The evaluation by the users is a function of clarity; usefulness; transparency; advice of family, friends, and relatives; and the link with the users' personal experience. It appears that people experiencing schizophrenia spectrum disorders or other psychotic disorders mainly seek clear, objective, scientific, and actively "destigmatizing" information. They value the points of view and positive case stories of people experiencing the same mental illness, further education about drugs, more doctor recommendations of good websites, and more opportunities to discuss with their doctor about what is found on the Internet [32].

Use of Peer-to-Peer Exchanges

Among Internet users experiencing schizophrenia spectrum disorders or other psychotic disorders, those with a higher frequency of access also used it as social media [26] or a possibility of disclosure [15]. Research analyzing 1200 postings of 576 users in 12 international schizophrenia Internet forums [33] established that, within this kind of usage, people experiencing schizophrenia spectrum disorders or other psychotic disorders' goals are to find and exchange information mainly about diagnosis and daily problems, such as medication, with peers. Interestingly, on the relatively small number of existing schizophrenia forums, one can find that affected users have the same behavior as any other user. Their preferred self-help mechanisms are disclosure and providing information, followed by sharing emotions. The main pursued goal is to exchange information. Other valuable characteristics of Internet forums for them are anonymity and a limited level of commitment [33]. As far as peer-to-peer exchanges are concerned, people experiencing schizophrenia spectrum disorders or other psychotic disorders who are already users

XSL•FO
RenderX

have expressed wishes for structured, moderated, and secure support forums [32].

Use of e-Support and m-Support

Taking place in a digital and virtual environment, Internet interventions designed for people experiencing schizophrenia spectrum disorders or other psychotic disorders have no delivery costs and allow dissemination of specialized interventions without geographic barriers. They can reduce perceived stigma by eliminating face-to-face contacts, which can be particularly appreciated in the context of this condition. Last, they can provide ongoing resources that are available at any time of day and night [14,34,35]. The Internet is also well adapted to the challenges of early intervention, as it appears particularly useful for young people. In addition, the disinhibiting effect of online communications and the suppression of face-to-face contact present interesting opportunities for those who are socially impaired [32].

Service users have expressed interest in those digital interventions that complement or supplement real world initiatives. The German study cited earlier established that among Internet users experiencing psychiatric conditions, 27.6% wished to take part in Web-based programs for mental health self-management [26]. Other research studies have shown that a majority of participants expressed an interest in text message medication reminders after hospital discharge [29] and that young people and other tech-friendly people experiencing psychosis generally ask for more connectivity in treatment [36,37].

Consequently, Internet-based interventions for schizophrenia spectrum disorders or other psychotic disorders have been studied as pilot protocols and are becoming more and more operational [14,34,35]:

- Online peer support forums, which have showed robust links with empowerment and recovery, if structured and moderated (otherwise, the level of distress can be raised) [14] or online peer-based support programs [35,38]
- Online patient psychoeducation [39], which is a cost-effective and acceptable method preferred by younger people [36] and those familiar with new technologies
- Web-based cognitive behavioral therapies using interactive exercises and multimedia materials (eg, video, audio) and targeting specific problems such as auditory hallucinations [40], social cognition [41], or depression on mood and positive symptoms [42]
- Virtual reality programs targeting 3 dimensions of social behavior: facial emotion recognition, social anxiety, and conversation time [43]
- Tablet computers using multimedia tools to promote personal recovery [44]
- Mobile-based interventions, which offer, with easy-to-use phones, great promise for transforming treatment delivery in addressing psychosis and the opportunity to deliver evidence-based tailored interventions; enable real-time support; gather ecologically valid information; efficiently control signs of relapse [45]; and improve medication adherence, auditory hallucination prevalence, and social interactions [46]
- Online family interventions, which improve accessibility and knowledge for family
- Early intervention, which can be revolutionized by new technologies with the access to and the engagement with specialized early intervention services offering an extended support and a comprehensive risk management framework [14,37]

Examples of Existing Technologies

Personal Control in Rehabilitation

This is an Internet platform for people experiencing schizophrenia spectrum disorders or other psychotic disorders and their caregivers in the Netherlands that has provided satisfaction to its users and proved to be helpful in reaching more self-management by service users; facilitating communication between them and their caregivers; and matching treatment, support, and relapse prevention [47]. The service users have been able to communicate, make appointments, give feedback, and look for information about the disease and its treatment. The tool has enabled them to gain better accessibility to caregivers, maintain contacts with peers experiencing the same mental illness, and describe experiences. They have felt relief in being able to write down worries and questions. They have expressed the need for more focus on rehabilitation and less on disease and treatment, more attention on improving personal skills, more interactivity, and more possibilities to control who could look into their personal data. The use was not informal; both people experiencing schizophrenia spectrum disorders or other psychotic disorders and caregivers had to be actively involved and alert to new messages and react within a certain time and period agreed upon. For the caregivers, the benefits of the experience have been to be able to identify worse functioning earlier and react more quickly. Contrary to what they feared, both the number of face-to-face contacts and shorter contacts by email or telephone increased. For the mental health organization, improvements have included more efficient communications, saving time, and more knowledge regarding the care process. For the future, the authors suggest that the tool should be integrated into the daily routine of caregivers, synchronized with the electronic patient record and upgraded with new functionalities like screen-to-screen communications, short message service reminders, electronic dictionary of medical concepts, shared-decision making, and self-management modules for people experiencing schizophrenia spectrum disorders or other psychotic disorders [47].

Schizophrenia-Window-of-Hope.Com

This South African Internet resource was dedicated to people experiencing schizophrenia spectrum disorders or other psychotic disorders with the expectation that an Internet resource would be beneficial in terms of psychoeducation and information for people living far away from health centers and for those experiencing stigma. The benefits, analyzed through informal feedback, have been to extend the information and education possibilities beyond the clinical consultation, which has obvious time constraints, and to offer anonymity to users [48].

XSL•FO
RenderX

e-Motional Training

An online program addressing the social cognition of people experiencing schizophrenia spectrum disorders or other psychotic disorders in Spain, this neuropsychological rehabilitation based on short duration exercises, tutorials, and a short animated film was shown to be a viable, easy to understand, and pleasant program with significant results on several social cognition variables [41].

Horyzon

This Australian moderated online social therapy for long-term recovery in first episode psychosis, designed for computer and Internet-enabled mobile devices (smartphones and tablets) and using peer-to-peer social networking, individually tailored interactive psychosocial interventions, and the involvement of expert and peer moderators, showed a high system usage with no incidents and a significant reduction in depressive symptoms [35].

Self-Management and Recovery Technology Therapy

This digital protocol designed to promote recovery in psychosis has been elaborated, following key processes in self-management and recovery as well as symptom monitoring, coping enhancement, and behavior change material, around 7 topics: recovery, managing stress, physical health, "me," empowerment, relationships, and life. The Self-Management and Recovery Technology (SMART) sessions are delivered through a website accessible via tablets with a mental health worker being present and assisting the self-management of the tool. The intervention is currently being evaluated through a randomized controlled trial [44].

Web-Based Informed Consent Process

Even the informed consent process is now tested in Web-based versions as tools for enhancing the informed consent process in schizophrenia research. A Web-based protocol has proved to be not only feasible but more effective than printed consent forms because of greater interactivity and flexibility. The other asset of this kind of process is that it is easily disseminated [49].

Benefits and Challenges of Internet Use for People Experiencing Schizophrenia Spectrum Disorders or Other Psychotic Disorders

Benefits of Internet Use for This Population

Empowerment Through Knowledge and Peer-to-Peer Help

Authors generally converge to say that the use of the Internet empowers people experiencing schizophrenia spectrum disorders or other psychotic disorders by allowing them to better understanding their disease and gaining knowledge [32]. Also, robust associations have been identified between peer support, empowerment, and recovery [17]. Online peer-to-peer forums enhance coping, self-esteem, and reassurance [33] and provide relief from information exchange and support [32]. They are likely to produce positive outcomes, especially when professionally moderated and focused on self-efficacy, problem solving, and social recovery [14].

Challenging Stigma and Self-Stigma

As a population suffering from especially strong stigma [20-23] and self-stigma [21], a way of internalizing negative stereotypes [50-53], people experiencing schizophrenia spectrum disorders or other psychotic disorders may find ways to challenge those adverse stereotypes thanks to Internet use or Internet interventions. Precisely, interacting with peers online can create greater social connectedness and feelings of group belonging that strengthen stigma resistance [54]. The Internet has the capacity to easily offer contacts with peers within one's marginalized group as well as disclosure possibilities, both of those being key dimensions of stigma reduction strategies [55].

Well-Adapted Media

The Internet provides better social interactions [56] because it reduces social anxiety [32]. Social opportunities offered by the Internet to people experiencing schizophrenia spectrum disorders or other psychotic disorders represent an interesting research field, as the Web offers a semiprotected and less stigmatized social environment. Affected users have shown no difference compared with control group when creating virtual, realistic, or emotional relationships via the Internet. Research exploring Web-browsing habits of 143 individuals experiencing schizophrenia spectrum disorders or other psychotic disorders compared to those of individuals with nonpsychotic disorders and healthy volunteers has established that almost 80% of the group with psychoses wished to create social connections on the Internet [56]. Although this was tempered by the severity of illness, people experiencing schizophrenia spectrum disorders or other psychotic disorders managed to establish contacts leading to real-life relationships, both friendly and romantic, just as the control group did. This population even formed more virtual relationships with less access to the Internet and less Web-browsing time, as if they were using the majority of their time to form social connections. The Internet seems useful for them because there is not the same need for preliminary social skills and motivation. The authors concluded that the Internet represents a promising tool for rehabilitating people experiencing schizophrenia spectrum disorders or other psychotic disorders by providing an accessible platform to social interactions [56].

The other characteristics of the Internet that seem beneficial for people experiencing schizophrenia spectrum disorders or other psychotic disorders are the absence of hierarchy and the limited level of commitment [32]. Also, the Web's technical specificities facilitate multimodal expression including sound, image, and text in an idiosyncratic way that allows the expression of emotions about the disease that seems to suit people experiencing schizophrenia spectrum disorders or other psychotic disorders [32].

More Available Care

As we stressed earlier, the Internet, through e-mental health, offers flexibility and connectivity, which means more available care [57]. This is particularly valuable for those who have difficulties accessing health and mental health care either because of a rural environment or because of limitations due to anticipated discrimination and self-stigma that prevent them from going to the doctor [40,58]. This is also important with

XSL•FO
RenderX

regard to specific treatment deliveries, such as cognitive behavior therapy, for which there are a limited number of trained clinicians [40].

Efficacy and Clinical Improvement

In general, recent studies highlight the benefits for people experiencing schizophrenia spectrum disorders or other psychotic disorders of using Web-based support systems, for example, by assessing service users' physical, psychological, and social conditions despite their cognitive problems [59]. Recent experiences show that innovative and flexible interventions that integrate different technologies (eg, mobile phones, chat rooms), evidence-based therapy, and peer and professional support are likely to be the most acceptable and effective for users [14]. Also, the general conclusion of these protocols is that Internet-based support has the potential to foster global recovery in people experiencing schizophrenia spectrum disorders or other psychotic disorders beyond what is possible in traditional interventions without interfering with face-to-face mental health care: it supplements existing services and augments traditional relationships rather than replacing them [14,34,35].

That being said, while acceptability and feasibility of Internet-based interventions designed for people experiencing schizophrenia spectrum disorders or other psychotic disorders have been well established by several recent studies [27,28,34,60-64], reviews in this field of research have concluded that only a few studies have shown clinical efficacy with a robust methodology and on a quantitatively sufficient population [34,39]; also, people included in the studies were generally clinically stable, which could represent a bias in this area. Although very promising in terms of outcomes, Internet-based interventions including online, social media, and mobile technologies demand further investigation through larger controlled studies [34].

Challenges of Internet Use for This Population

The Disease Itself

Specific difficulties that people experiencing schizophrenia spectrum disorders or other psychotic disorders may encounter with the Internet as a source of information are stimulus overflow, incapacity to overcome the abundance of information, lack of concentration, lack of energy, paranoid ideas, reactive symptoms, and the need to distance themselves from illness-related topics in order to enhance recovery [32]. Also, a study conducted in Greece on 30 outpatients experiencing psychosis and a control group of 71 participants from the general population has underlined that the risk of Internet addiction could be higher for those with a psychosis, a low self-esteem, and difficult interpersonal relationships [65].

With a highly probable link to the disease, there are other reasons not to go on the Internet to seek information, such as lack of access, financial problems, difficulties in the use of technology, fear of viruses, fear of addiction, preference of other sources, expectation of low quality, information request already satisfied through another mean, lack of interest, or preference to receive information from the doctor [32].

Perceived Impact on the Relationship With the Doctor

Another difficulty encountered by people experiencing schizophrenia spectrum disorders or other psychotic disorders using the Internet as a source of information is related to their subjective perception that the Internet could modify their attitude toward medication and their relationship to their doctor. Regarding the medication, Internet-retrieved information, especially about side effects, could lead to a more critical attitude toward one's own medication. Therefore, the information found on the Internet should be discussed with the doctor, but it is far from being systematically the case, mainly because the people experiencing schizophrenia fear that doctors could feel criticized and that they will not change their vision. However, the hierarchic relationship is perceived as modified by the use of the Internet as a source of information by the patient. These relationship changes depend on the quality of the former relationship [32].

Flaws in Dedicated Internet Sites

As Schrank and colleagues [32] have stressed, the nature of Internet sites dedicated to schizophrenia and psychoses can be problematic as well. Indeed, difficulties related not to the people experiencing schizophrenia spectrum disorders or other psychotic disorders themselves but to the sites dedicated to schizophrenia are that these are generally difficult to read. Other authors confirm that these sites are especially difficult to read and navigate [66,67]. Also, the available information is often limited. In an investigation of what schizophrenia-related information is available on the Internet, a survey of 21 schizophrenia sites showed that although 67% of them did contain information about related health problems such as weight gain due to medication, in more than a half of these sites, this content was limited to user-generated comments and represented less than one paragraph of information [2].

Also of concern is the relationship between drug company funding of websites and their content; the study by Read [3] highlighted that 58% of schizophrenia websites receive funding from drug companies and that these sites are more likely to espouse biogenetic causes rather than psychosocial ones; emphasize medication rather than psychosocial treatment; portray schizophrenia as a debilitating, devastating, and long-term illness; and link violence to quitting medication. In conclusion, drug company money has an impact on the content of websites in the sense that perspectives and statements expected to increase drug sales are more likely to appear on drug company–funded websites [3].

In general, there is a lack of ethical control, monitoring, and evaluation of mental health websites [68], which makes their use risky for young people experiencing mental illness who are used to navigating online on their own, often for some years [69]. There are not enough security standards [70]; for example, only 50% of Web-based information on the treatment of schizophrenia and attention deficit hyperactivity disorder advises to clarify information with a professional [66]. These risks are important to take into consideration when it comes to vulnerable populations.

Although interactivity is generally sought by people experiencing schizophrenia spectrum disorders or other

XSL•FO
RenderX

psychotic disorders, sites devoted to schizophrenia and psychoses offer limited interactivity when compared to other information sites [71].

Attrition Rate of e-Mental Health Programs

In the field of other mental diseases such as bipolar disorder, an obstacle constituted by the high rate of attrition of the programs has been identified in the process of e-mental health care and delivery. Indeed, in an attempt to explore the phenomenon of participant adherence, an Australian study surveyed 358 people included in an online psychoeducation program for individuals newly diagnosed with bipolar disorder [72]. The results showed that many of the reasons for leaving the program were independent from program factors (for example, acute phases of bipolar disorder or clinical recruitment setting). But some program specificities had an influence on attrition, in particular the information being too general and not personally tailored or supported by an expert patient "informed supporter." The attrition rate (26.5%) was equivalent to the one of the other Internet interventions (31% average) from the systematic review of 19 Internet-based psychological treatment programs, but, surprisingly, lower than the rate found in a meta-analysis of 125 studies about psychotherapy programs delivered face-to-face. While these results demand to be verified on a target population of persons experiencing schizophrenia or other psychotic disorders, they appear in favor of personalized and guided interventions rather than fully automated interventions [72].

Discussion

Summary

Even if the Internet has shown its effectiveness in many areas, the "Internet paradox" is a new paradigm telling us that it could in the long term lead to a decline in general mental well-being, especially through the use of social networks like Facebook or other networks [11,73]. Developing its access and functionalities for people experiencing schizophrenia spectrum disorders or other psychotic disorders might then seem risky or useless.

However, our review of the literature suggests that despite the ethical and security issues raised by some studies [66,68,70], the Internet is likely to offer mental health services that are effective as interventions [14,37,45,48,59] and relapse prevention tools [10,14,45,47] in the field of severe mental disorders such as schizophrenia spectrum disorders or other psychotic disorders. Getting health information on the Internet and being able to manage one's mental disorder with Web-based tools helps people experiencing schizophrenia spectrum disorders or other psychotic disorders to participate to medical decision-making processes, gain empowerment, and balance relationships with doctors [9,32,33]. In addition, the Internet might well propose specific opportunities in terms of social interactions for people experiencing those illnesses, who are often impaired in the social domain [14,56].

Yet, according to our literature review, information about the way people experiencing schizophrenia spectrum disorders or other psychotic disorders use the Internet regarding their health is not available in every country. As we mentioned in our introduction, the proportion of Internet users in this target population is higher in the most recent studies, which seems to reflect the evolution in the general population. The rates given by the available studies as well as rates of mental health information–seeking activities among Internet users experiencing those conditions, when possible, are presented in Table 1.

This should lead us to ask ourselves if similar proportions are to be observed in other countries with similar Internet access possibilities. This area of research requires further development in order to ascertain if, depending on the country they live in, the habits of people experiencing schizophrenia spectrum disorders or other psychotic disorders vary in their use of the Internet, if they are able to find the content that they are looking for, and if the specific developments and tools to be used are plenty or scarce. Of course, the fact that no study has been published on the matter in a given country does not mean that there is no available Internet-based content that persons experiencing schizophrenia spectrum disorders or other psychotic disorders can access regularly to find information about their mental health or even e-mental health support.

Table 1. Internet use of people experiencing schizophrenia spectrum disorders or other psychotic disorders by country of research.

Service users	Switzerland [25] N=319 n (%)	United States [24] N=100 n (%)	United States [27] N=80 n (%)	Australia, New Zealand [1] N=71 n (%)	Germany [26] N=337 n (%)
Percentage using the Web	200 (62.6)	34 (34)	80 (48)	—	268 (79.5)
Percentage seeking health information online	137 (42.9)	19 (53)	—	71 (35.2)	190 (56.4)

However, a country-by-country approach remains limited in its conception, as the Internet is by definition a worldwide platform as long as one has a sufficient knowledge of English. From our sources, papers focusing on ethical and security issues in the use of the Internet by people experiencing psychiatric conditions like schizophrenia spectrum disorders or other psychotic disorders had all adopted a global approach and had found similar challenges in the studied dedicated Internet sites without establishing any specificity according to their geographic origin [68,70,74]. Therefore, the Internet's nature itself could explain that research studies analyzing advantages and challenges for people experiencing schizophrenia spectrum disorders or other psychotic disorders using the Internet about their mental health prefer to address issues globally. Yet, specificities in the access

XSL•FO
RenderX

to the Internet and new technologies linked to the habits and preferences of this target population remains interesting to evaluate with a country-specific approach from a public health perspective.

Future research studies could also usefully aim to confirm if there is a link between diagnosis and use of the Internet. Indeed, this link remains insufficiently explored, namely by a few studies that found contradictory results. For example, an Australian survey conducted in 2011 on 71 people experiencing schizophrenia spectrum disorders or other psychotic disorders recruited from both community and inpatient settings and 238 general practice attendees on their use of different media to obtain information on health matters found that people with psychotic disorders had less access to the Internet due to financial difficulties, a frequently itinerant way of life, and a lower educational level. Only those with higher education placed an important level of trust in the Internet as a health information source [1].

Another study conducted in Germany involving 337 people recruited in a psychiatric facility showed on the contrary that the Internet use of the psychiatric population corresponded to the use of the general population and that there was no significant difference between the included diagnoses, that is to say schizophrenia and affective, neurotic, stress-related, and somatoform disorders [26,30]. The different methodologies and populations used in these research studies do not allow direct comparisons but imply that there is a need to further explore these results.

The limits of our review are related to the diversity of populations used in the articles reviewed, with different types of recruitments (within psychiatric facilities or not) and sometimes multiple terminologies or even diagnosis being considered. Indeed, we have chosen to include pertinent or important studies that sometimes used other terminologies than our defined focus (schizophrenia spectrum disorders or other psychotic disorders), for example, “psychosis,” “severe or serious mental illness,” or “serious psychiatric conditions or disorders.” While such terminologies include schizophrenia spectrum disorders and other psychotic disorders, some of these studies (although rare in our review) focused on broader populations, for example, people experiencing bipolar disorders with psychotic features, which could represent a bias. Another difficulty is the fact that most of the research studies discussed in our review concern small to very small populations. Also, the small number of studies focusing on specific countries and their offerings in this area could not allow us to establish reliable comparisons between them. Furthermore, being a literature review, our study lacks an up-to-date clinical perspective that would aim to investigate some of the research leads identified in this section. Finally, an important limit to our research is that in the field of new technologies things evolve quickly and have to be constantly reevaluated.

Conclusion and Recommendations

Many issues are raised concerning the access to the Internet by people experiencing schizophrenia spectrum disorders or other psychotic disorders, as well as the impact of the Internet as a source of mental health information; the compliance and relationship with doctors; and the readability, quality, and security of specialized websites and interventions. However, the benefits seem to outbalance the disadvantages as far as users’ wishes and needs are addressed. In any case, the available literature has established that the Internet is already an important and influential source of information and support for people experiencing schizophrenia spectrum disorders or other psychotic disorders and that a significant proportion of users have shown an interest for Internet interventions in the context of their treatment. Most of the existing interventions have shown good feasibility and acceptability. The remaining challenge is to strengthen and generalize the evaluation regarding clinical efficacy. Taking that evolution into account, we have outlined in this paper some recommendations that seem key to us to continue the move toward e-mental health, which alongside with the traditional system will shape the future of care for persons experiencing schizophrenia spectrum disorders or other psychotic disorders:

- Generalize structured and moderated access to the Internet for people experiencing schizophrenia spectrum disorders or other psychotic disorders.
- Inform doctors about alternative sources of information to suggest (or not) to people experiencing schizophrenia spectrum disorders or other psychotic disorders. Some authors suggest that doctors should be knowledgeable not only about medication and secondary effects but also about alternative sources of information available for people experiencing schizophrenia spectrum disorders or other psychotic disorders on this matter, and they should in particular be able to advise service users about what is or is not available on the Internet and to advise the creators of schizophrenia websites about what kind of information is needed.
- Involve doctors and integrate the insights from people experiencing schizophrenia spectrum disorders or other psychotic disorders in the creation of specialized websites and in the development of mobile and Web-based applications [39,64].
- Generalize and extend Web-based interventions integrating different technologies (eg, smartphones, chat rooms with professionals) and evidence-based therapy for a new generation of people experiencing schizophrenia spectrum disorders or other psychotic disorders seeking flexibility and connectivity.
- Implement a regular structured evaluation of websites and Internet interventions within the scope of national health care authorities in order to ensure quality and prevent harm for people experiencing schizophrenia spectrum disorders or other psychotic disorders by, among other things, extending the use of emergency guidelines and contact information.
- Tailor and guide Internet-based and all e-mental health interventions to reduce attrition.
- Invent new types of interventions rather than use online technologies as alternative means to deliver traditional interventions [15].

XSL•FO
RenderX

Conflicts of Interest

None declared.

References

1. Maguire PA, Reay RE, Looi JCL, Cubis J, Byrne GJ, Raphael B. Neither the internist nor the Internet: use of and trust in health information sources by people with schizophrenia. Aust N Z J Psychiatry 2011 Jun;45(6):489-497. [doi: 10.3109/00048674.2011.570308] [Medline: 21563868]
2. Litschge C, Greeno C, Anderson C, Newhill C. Weight gain information on the Internet for people who have schizophrenia. Psychiatr Rehabil J 2005;28(4):387-390. [Medline: 112092415]
3. Bragazzi NL. A Google Trends-based approach for monitoring NSSI. Psychol Res Behav Manag 2013;7:1-8 [FREE Full text] [doi: 10.2147/PRBM.S44084] [Medline: 24376364]
4. Fond G, Gaman A, Brunel L, Haffen E, Llorca P. Google Trends: Ready for real-time suicide prevention or just a Zeta-Jones effect? An exploratory study. Psychiatry Res 2015 Aug 30;228(3):913-917. [doi: 10.1016/j.psychres.2015.04.022] [Medline: 26003510]
5. Gunn JF, Lester D. Using Google searches on the internet to monitor suicidal behavior. J Affect Disord 2013 Jun;148(2-3):411-412. [doi: 10.1016/j.jad.2012.11.004] [Medline: 23182592]
6. Koburger N, Mergl R, Rummel-Kluge C, Ibelshäuser A, Meise U, Postuvan V, et al. Celebrity suicide on the railway network: Can one case trigger international effects? J Affect Disord 2015 Oct 1;185:38-46. [doi: 10.1016/j.jad.2015.06.037] [Medline: 26143403]
7. Gahr M, Uzelac Z, Zeiss R, Connemann BJ, Lang D, Schönfeldt-Lecuona C. Linking annual prescription volume of antidepressants to corresponding Web search query data: a possible proxy for medical prescription behavior? J Clin Psychopharmacol 2015 Dec;35(6):681-685. [doi: 10.1097/JCP.0000000000000397] [Medline: 26355849]
8. Naslund JA, Aschbrenner KA, Marsch LA, McHugo GJ, Bartels SJ. Crowdsourcing for conducting randomized trials of Internet-delivered interventions in people with serious mental illness: A systematic review. Contemp Clin Trials 2015 Jul 16;44:77-88. [doi: 10.1016/j.cct.2015.07.012] [Medline: 26188164]
9. Hidalgo-Mazzei D, Mateu A, Reinares M, Undurraga J, Bonnin CM, Sanchez-Moreno J. Self-monitoring and psychoeducation in bipolar patients with a smart-phone application (SIMPLe) project: design, development and studies protocols. BMC Psychiatry 2015;15. [Medline: 5812249063]
10. Schärer LO, Krienke UJ, Graf S, Meltzer K, Langosch JM. Validation of life-charts documented with the personal life-chart app—a self-monitoring tool for bipolar disorder. BMC Psychiatry 2015 Mar 14;15:49 [FREE Full text] [doi: 10.1186/s12888-015-0414-0] [Medline: 25885225]
11. Moock J. Support from the Internet for individuals with mental disorders: advantages and disadvantages of e-mental health service delivery. Front Public Health 2014:2. [Medline: 5596641522]
12. Deslich S, Stec B, Tomblin S, Coustasse A. Telepsychiatry in the 21st century: transforming healthcare with technology. Perspect Health Inf Manag 2013;10:1f [FREE Full text] [Medline: 23861676]
13. Malhotra S, Chakrabarti S, Shah R. Telepsychiatry: Promise, potential, and challenges. Indian J Psychiatry 2013;55(1):3-11. [Medline: 828635956]
14. Alvarez-Jimenez M, Gleeson J, Bendall S, Lederman R, Wadley G, Killackey E. Internet-based interventions for psychosis: a sneak-peek into the future. PSC Psychiatr Clin N Am 2012;35(3):235-247. [Medline: 4930087548]
15. Daker-White G, Rogers A. What is the potential for social networks and support to enhance future telehealth interventions for people with a diagnosis of schizophrenia: a critical interpretive synthesis. BMC Psychiatry 2013;13:611-633 [FREE Full text] [doi: 10.1186/1471-244X-13-279] [Medline: 24180273]
16. Davidson L, Bellamy C, Guy K, Miller R. Peer support among persons with severe mental illnesses: a review of evidence and experience. World Psychiatry 2012 Jun;11(2):123-128 [FREE Full text] [Medline: 22654945]
17. Corrigan PW. Impact of consumer-operated services on empowerment and recovery of people with psychiatric disabilities. Psychiatr Serv 2006 Oct;57(10):1493-1496. [doi: 10.1176/ps.2006.57.10.1493] [Medline: 17035571]
18. Frese FJ, Knight EL, Saks E. Recovery from schizophrenia: with views of psychiatrists, psychologists, and others diagnosed with this disorder. Schizophr Bull 2009 Mar;35(2):370-380 [FREE Full text] [doi: 10.1093/schbul/sbn175] [Medline: 19304812]
19. Berger M, Wagner T, Baker L. Internet use and stigmatized illness. Soc Sci Med 2005;61(8):1821-1827. [Medline: 110978147]
20. Mestdagh A, Hansen B. Stigma in patients with schizophrenia receiving community mental health care: a review of qualitative studies. Soc Psychiatry Psychiatr Epidemiol 2014 Jan;49(1):79-87. [doi: 10.1007/s00127-013-0729-4] [Medline: 23835576]
21. Wood L, Byrne R, Varese F, Morrison AP. Psychosocial interventions for internalised stigma in people with a schizophrenia-spectrum diagnosis: A systematic narrative synthesis and meta-analysis. Schizophr Res 2016 Oct;176(2-3):291-303. [doi: 10.1016/j.schres.2016.05.001] [Medline: 27256518]

XSL•FO
RenderX

22. Vass V, Morrison AP, Law H, Dudley J, Taylor P, Bennett KM, et al. How stigma impacts on people with psychosis: The mediating effect of self-esteem and hopelessness on subjective recovery and psychotic experiences. Psychiatry Res 2015 Dec 15;230(2):487-495. [doi: 10.1016/j.psychres.2015.09.042] [Medline: 26454406]
23. Thornicroft G, Mehta N, Clement S, Evans-Lacko S, Doherty M, Rose D, et al. Evidence for effective interventions to reduce mental-health-related stigma and discrimination. Lancet 2016 Mar 12;387(10023):1123-1132. [doi: 10.1016/S0140-6736(15)00298-6] [Medline: 26410341]
24. Borzekowski D, Leith J, Medoff D, Potts W, Dixon L, Balis T. Use of the internet and other media for health information among clinic outpatients with serious mental illness. Psychiatr Serv 2009;60(9):1265-1268. [Medline: 435693423]
25. Khazaal Y, Chatton A, Cochand S, Hoch A, Khankarli M, Khan R. Internet Use by Patients with Psychiatric Disorders in Search for General and Medical Informations. Psychiatr Q 2008;79(4):301-309. [Medline: 438697449]
26. Kalckreuth S, Trefflich F, Rummel-Kluge C. Mental health related Internet use among psychiatric patients: a cross-sectional analysis. BMC Psychiatry 2014;14(1):1-25. [Medline: 5726725613]
27. Miller BJ, Stewart A, Schrimsher J, Peeples D, Buckley PF. How connected are people with schizophrenia? Cell phone, computer, email, and social media use. Psychiatry Res 2015 Feb 28;225(3):458-463. [doi: 10.1016/j.psychres.2014.11.067] [Medline: 25563669]
28. Beebe L, Smith KD, Phillips C. A comparison of telephone and texting interventions for persons with schizophrenia spectrum disorders. Issues Ment Health Nurs 2014 May;35(5):323-329. [doi: 10.3109/01612840.2013.863412] [Medline: 24766166]
29. Bogart K, Wong SK, Lewis C, Akenzua A, Hayes D, Prountzos A, et al. Mobile phone text message reminders of antipsychotic medication: is it time and who should receive them? A cross-sectional trust-wide survey of psychiatric inpatients. BMC Psychiatry 2014 Jan 22;14:1-17 [FREE Full text] [doi: 10.1186/1471-244X-14-15] [Medline: 24447428]
30. Trefflich F, Kalckreuth S, Mergl R, Rummel-Kluge C. Psychiatric patients' internet use corresponds to the internet use of the general public. Psychiatry Res 2015 Mar 30;226(1):136-141. [doi: 10.1016/j.psychres.2014.12.037] [Medline: 25623020]
31. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. Washington, DC: American Psychiatric Association Publishing; 2013.
32. Schrank B, Sibitz I, Unger A, Amering M. How patients with schizophrenia use the internet: qualitative study. J Med Internet Res 2010;12(5):e70 [FREE Full text] [doi: 10.2196/jmir.1550] [Medline: 21169176]
33. Haker H, Lauber C, Rössler W. Brief communication: Internet forums: a self-help approach for individuals with schizophrenia? Acta Psychiatr Scand 2005;112(6):474-477. [Medline: 439771985]
34. 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. [doi: 10.1016/j.schres.2014.03.021] [Medline: 24746468]
35. Alvarez-Jimenez M, Bendall S, Lederman R, Wadley G, Chinnery G, Vargas S, et al. On the HORYZON: moderated online social therapy for long-term recovery in first episode psychosis. Schizophr Res 2013 Jan;143(1):143-149. [doi: 10.1016/j.schres.2012.10.009] [Medline: 23146146]
36. Leach L, Christensen H, Griffiths K, Jorm A, Mackinnon A. Websites as a mode of delivering mental health information: perceptions from the Australian public. Soc Psychiatry Psychiatr Epidemiol 2007;42(2):167-172. [Medline: 440384505]
37. Gleeson J, Lederman R, Wadley G, Bendall S, McGorry P, Alvarez-Jimenez M. Safety and privacy outcomes from a moderated online social therapy for young people with first-episode psychosis. Psychiatr Serv ? 2014;65(4):546-550. [Medline: 5564769579]
38. Baumel A, Correll C, Birnbaum M. Adaptation of a peer based online emotional support program as an adjunct to treatment for people with schizophrenia-spectrum disorders. Internet Interv 2016:35-42.
39. Valimaki M, Anttila M, Hatonen H, Koivunen M, Jakobsson T, Pitkanen A, et al. Design and development process of patient-centered computer-based support system for patients with schizophrenia spectrum psychosis. Inform Health Soc Care 2008 Jun;33(2):113-123. [doi: 10.1080/17538150802127207] [Medline: 18604755]
40. Gottlieb JD, Romeo KH, Penn DL, Mueser KT, Chiko BP. Web-based cognitive-behavioral therapy for auditory hallucinations in persons with psychosis: a pilot study. Schizophr Res 2013 Apr;145(1-3):82-87. [doi: 10.1016/j.schres.2013.01.002] [Medline: 23410709]
41. Vázquez-Campo M, Maroño Y, Lahera G, Mateos R, García-Caballero A. e-Motional Training: Pilot study on a novel online training program on social cognition for patients with schizophrenia. Schizophr Res Cogn Jun;4? 2016:10-17.
42. Moritz S, Köther U, Woodward TS, Veckenstedt R, Dechêne A, Stahl C. Repetition is good? An Internet trial on the illusory truth effect in schizophrenia and nonclinical participants. J Behav Ther Exp Psychiatry 2012 Dec;43(4):1058-1063. [doi: 10.1016/j.jbtep.2012.04.004] [Medline: 22683551]
43. Rus-Calafell M, Gutiérrez-Maldonado J, Ribas-Sabaté J. A virtual reality-integrated program for improving social skills in patients with schizophrenia: a pilot study. J Behav Ther Exp Psychiatry 2014 Mar;45(1):81-89. [doi: 10.1016/j.jbtep.2013.09.002] [Medline: 24063993]
44. Thomas N, Farhall J, Foley F, Rossell SL, Castle D, Ladd E, et al. Randomised controlled trial of a digitally assisted low intensity intervention to promote personal recovery in persisting psychosis: SMART-Therapy study protocol. BMC Psychiatry 2016 Sep 07;16(1):1-12 [FREE Full text] [doi: 10.1186/s12888-016-1024-1] [Medline: 27604363]

XSL•FO
RenderX

45. Spaniel F, Vohlídka P, Hrdlicka J, Kozený J, Novák T, Motlová L, et al. ITAREPS: information technology aided relapse prevention programme in schizophrenia. Schizophr Res 2008 Jan;98(1-3):312-317. [doi: 10.1016/j.schres.2007.09.005] [Medline: 17920245]
46. 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 [FREE Full text] [doi: 10.1093/schbul/sbr155] [Medline: 22080492]
47. de Leeuw JRJ, van Splunteren P, Boerema I. Personal control in rehabilitation: An internet platform for patients with schizophrenia and their caregivers. OJPsych 2012;2(4):355-361. [doi: 10.4236/ojpsych.2012.224050]
48. Bodenstein S, Niehaus D, Koen L, Wilson Z. Schizophrenia-Window-of-Hope.com? Development of a psycho-educational Internet resource for the South African setting. South Afr J Psychiatry 2010;16(2):34-38 [FREE Full text]
49. Harmell A, Palmer B, Jeste D. Preliminary study of a web-based tool for enhancing the informed consent process in schizophrenia research. Schizophr Res (2-3)? 2012;141(2-3):247-250. [Medline: 811803389]
50. Karidi MV, Vassilopoulou D, Savvidou E, Vitoratou S, Maillis A, Rabavilas A, et al. Bipolar disorder and self-stigma: A comparison with schizophrenia. J Affect Disord 2015 Sep 15;184:209-215. [doi: 10.1016/j.jad.2015.05.038] [Medline: 26112330]
51. Tsang HWH, Ching SC, Tang KH, Lam HT, Law PYY, Wan CN. Therapeutic intervention for internalized stigma of severe mental illness: A systematic review and meta-analysis. Schizophr Res 2016 May;173(1-2):45-53. [doi: 10.1016/j.schres.2016.02.013] [Medline: 26969450]
52. Karakas SA, Okanli A, Yilmaz E. The Effect of internalized stigma on the self esteem in patients with schizophrenia. Arch Psychiatr Nurs Internet Jan 2016;30(6):648-652.
53. Yilmaz E, Okanli A. The effect of internalized stigma on the adherence to treatment in patients With schizophrenia. Arch Psychiatr Nurs 2015 Oct;29(5):297-301. [doi: 10.1016/j.apnu.2015.05.006] [Medline: 26397432]
54. 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] [Medline: 26744309]
55. Thomas N, McLeod B, Jones N, Abbott J. Developing Internet interventions to target the individual impact of stigma in health conditions. Internet Interv 2015 Sep;2(3):351-358. [doi: 10.1016/j.invent.2015.01.003]
56. Spinzy Y, Nitzan U, Becker G, Bloch Y, Fennig S. Does the Internet offer social opportunities for individuals with schizophrenia? A cross-sectional pilot study. Psychiatry Res 2012 Jul 30;198(2):319-320. [doi: 10.1016/j.psychres.2012.02.022] [Medline: 22440545]
57. Bucci R, Ficarra MG, Amore R, Arzani D, Boccia S, Bruno S, et al. Vocational training in public health during medical school: a pilot study. Ig Sanita Pubbl 2015;71(1):9-20. [Medline: 25927648]
58. Ayers JW, Althouse BM, Allem J, Rosenquist JN, Ford DE. Seasonality in seeking mental health information on Google. Am J Prev Med 2013 May;44(5):520-525. [doi: 10.1016/j.amepre.2013.01.012] [Medline: 23597817]
59. van der Krieke L, Emerencia A, Aiello M, Sytema S. Usability evaluation of a web-based support system for people with a schizophrenia diagnosis. J Med Internet Res 2012;14(1):e24 [FREE Full text] [doi: 10.2196/jmir.1921] [Medline: 22311883]
60. Firth J, Torous J. Smartphone apps for schizophrenia: a systematic review. JMIR Mhealth Uhealth 2015;3(4):e102 [FREE Full text] [doi: 10.2196/mhealth.4930] [Medline: 26546039]
61. Depp CA, Mausbach B, Granholm E, Cardenas V, Ben-Zeev D, Patterson TL, et al. Mobile interventions for severe mental illness: design and preliminary data from three approaches. J Nerv Ment Dis 2010 Oct;198(10):715-721 [FREE Full text] [doi: 10.1097/NMD.0b013e3181f49ea3] [Medline: 20921861]
62. Ben-Zeev D, Scherer EA, Gottlieb JD, Rotondi AJ, Brunette MF, Achtyes ED, et al. mHealth for schizophrenia: patient engagement with a mobile phone intervention following hospital discharge. JMIR Ment Health 2016;3(3):e34 [FREE Full text] [doi: 10.2196/mental.6348] [Medline: 27465803]
63. Ben-Zeev D, Brenner CJ, Begale M, Duffecy J, Mohr DC, Mueser KT. Feasibility, acceptability, and preliminary efficacy of a smartphone intervention for schizophrenia. Schizophr Bull 2014 Nov;40(6):1244-1253. [doi: 10.1093/schbul/sbu033] [Medline: 24609454]
64. Marley J, Farooq S. Mobile telephone apps in mental health practice: uses, opportunities and challenges. BJPsych Bull 2015 Dec;39(6):288-290 [FREE Full text] [doi: 10.1192/pb.bp.114.050005] [Medline: 26755988]
65. Dragioti E, Manta M, Kotrotsiou E, Gouva M. Internet use among patients with psychotic disorder. Eur Psychiatry 2015;30:177. [Medline: 5899505008]
66. Kisely S, Ong G, Takyar A. A survey of the quality of Web based information on the treatment of schizophrenia and Attention Deficit Hyperactivity Disorder. ANP Aust N Z J Psychiatry 2003;37(1):85-91. [Medline: 5154636244]
67. Kalk NJ, Pothier DD. Patient information on schizophrenia on the internet. Psych Bull 2008 Nov 01;32(11):409-411. [doi: 10.1192/pb.bp.107.017004]
68. Christensen H, Griffiths K. The Internet and mental health literacy. Anp Australas Psychiatry 2000;34(6):975-979. [Medline: 5630245487]
69. Rickwood D, Mazzer K, Telford N. Social influences on seeking help from mental health services, in-person and online, during adolescence and young adulthood. BMC Psychiatry 2015;15. [Medline: 5812253931]

XSL•FO
RenderX

70. Bennett K, Bennett A, Griffiths K. Security considerations for e-mental health interventions. J Med Internet Res Internet 2010;12(5):e61 [FREE Full text] [doi: 10.2196/jmir.1468] [Medline: 21169173]
71. Athanasopoulou C, Hätönen H, Suni S, Lionis C, Griffiths K, Välimäki M. An analysis of online health information on schizophrenia or related conditions: a cross-sectional survey. BMC Med Inform Decis Mak 2013;13(1):11. [Medline: 5534265423]
72. Nicholas J, Proudfoot J, Parker G, Gillis I, Burckhardt R, Manicavasagar V. The ins and outs of an online bipolar education program: a study of program attrition. J Med Internet Res 2010;12(5):e57 [FREE Full text] [doi: 10.2196/jmir.1450] [Medline: 21169169]
73. Riper H, Andersson G, Christensen H, Cuijpers P, Lange A, Eysenbach G. Theme issue on e-mental health: a growing field in Internet research. J Med Internet Res 2010;12(5):e74 [FREE Full text] [doi: 10.2196/jmir.1713] [Medline: 21169177]
74. Read J. Schizophrenia, drug companies and the Internet. Soc Sci Med 2008 Jan;66(1):99-109. [doi: 10.1016/j.socscimed.2007.07.027] [Medline: 17826878]

Abbreviations

SMART: Self-Management and Recovery Technology

Edited by G Eysenbach; submitted 06.05.16; peer-reviewed by D Giacco, N Berry, S Langrial, N Bragazzi; comments to author 31.07.16; revised version received 23.10.16; accepted 25.11.16; published 03.01.17.

Please cite as:
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;4(1):e1
URL: http://mental.jmir.org/2017/1/e1/
doi:10.2196/mental.5946
PMID:28049620

©Murielle Villani, Viviane Kovess-Masfety. Originally published in JMIR Mental Health (http://mental.jmir.org), 03.01.2017. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Mental Health, is properly cited. The complete bibliographic information, a link to the original publication on http://mental.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

A Web-Disseminated Self-Help and Peer Support Program Could Fill Gaps in Mental Health Care: Lessons From a Consumer Survey

Samantha L Bernecker[1], MS; Kaitlin Banschback[2], BA; Gennarina D Santorelli[1], MS; Michael J Constantino[1], PhD

[1]Department of Psychological and Brain Sciences, University of Massachusetts, Amherst, MA, United States

[2]Division of Education, Queens College, City University of New York, Flushing, NY, United States

Corresponding Author:
Samantha L Bernecker, MS
Department of Psychological and Brain Sciences
University of Massachusetts
Tobin Hall
135 Hicks Way
Amherst, MA, 01003
United States
Phone: 1 814 574 9625
Fax: 1 413 545 0996
Email: samantha.bernecker@gmail.com

Abstract

Background: Self-guided mental health interventions that are disseminated via the Web have the potential to circumvent barriers to treatment and improve public mental health. However, self-guided interventions often fail to attract consumers and suffer from user nonadherence. Uptake of novel interventions could be improved by consulting consumers from the beginning of the development process in order to assess their interest and their preferences. Interventions can then be tailored using this feedback to optimize appeal.

Objective: The aim of our study was to determine the level of public interest in a new mental health intervention that incorporates elements of self-help and peer counseling and that is disseminated via a Web-based training course; to identify predictors of interest in the program; and to identify consumer preferences for features of Web-based courses and peer support programs.

Methods: We surveyed consumers via Amazon's Mechanical Turk to estimate interest in the self-help and peer support program. We assessed associations between demographic and clinical characteristics and interest in the program, and we obtained feedback on desired features of the program.

Results: Overall, 63.9% (378/592) of respondents said that they would try the program; interest was lower but still substantial among those who were not willing or able to access traditional mental health services. Female gender, lower income, and openness to using psychotherapy were the most consistent predictors of interest in the program. The majority of respondents, although not all, preferred romantic partners or close friends as peer counselors and would be most likely to access the program if the training course were accessed on a stand-alone website. In general, respondents valued training in active listening skills.

Conclusions: In light of the apparent public interest in this program, Web-disseminated self-help and peer support interventions have enormous potential to fill gaps in mental health care. The results of this survey can be used to inform the design of such interventions.

(JMIR Ment Health 2017;4(1):e5) doi:10.2196/mental.4751

KEYWORDS

computer-assisted instruction; eHealth; mental health; self care; self-help; peer support; social support

XSL•FO
RenderX

Introduction

The Need to Consult Consumers When Developing Web-Based Mental Health Interventions

Self-guided, Web-based health interventions have great promise in reaching consumers and improving public health. Web-based *mental health* self-help treatments may have even greater advantages in reach over traditional in-person treatments because they afford more self-reliance and privacy and they minimize stigma, circumventing common barriers to seeking mental health help from a professional [1].

However, self-guided, Web-based interventions come with their own challenge: they need to be appealing enough to motivate consumer engagement. Internet-based interventions often report low user adherence, with many users discontinuing the intervention prematurely [2-4]. On the basis of a diffusion of innovations framework, Eysenbach [2] has suggested that one factor influencing attrition rates may be "the degree to which an innovation is perceived as being consistent with the existing values, past experiences, and needs of potential adopters." In response to the low uptake of health interventions, many researchers and organizations have begun to call for an iterative development cycle in which consumers are consulted repeatedly in order to ensure that interventions are appealing to them and meet their needs [5-7].

Our Intervention: "Crowdsourcing Mental Health"

In response to these calls, our research team sought consumer input on a new intervention that is called "Crowdsourcing Mental Health" (CMH) because it distributes the task of providing mental health care among the general public. In CMH, 2 individuals who are already acquainted with each other (eg, friends, coworkers) agree to participate in the program as "partners." Both partners take an asynchronous massive open online course (MOOC) that teaches 2 sets of skills: skills for talking about stressors and skills for listening to others who are stressed. After completing the course, the partners meet weekly for peer counseling, taking turns in the "talker" and "listener" roles. This reciprocal structure allows both partners to gain the benefits of care provision [8] and care receipt, as well as to develop the intimacy that results from mutual self-disclosure [9].

Stress can precipitate the onset of, or worsen, a variety of mental illnesses (eg, [10-12]), and it has negative consequences for physical and mental health regardless of one's diagnostic status [13,14]. In order to help users manage stress, the CMH program teaches coping skills that are based on the literature on adaptive and maladaptive coping processes (eg, [15,16]). Like stress, disrupted emotion regulation has been linked to mental illness (eg, [17,18]). To improve emotion regulation, the CMH course includes psychoeducation about emotion regulation and teaches identification and labeling of emotions, which may promote adaptive responding [19-21]. Finally, the CMH program leverages the power of interpersonal relationships, both to improve well-being and to promote adherence and engagement. By "talking through" the steps of coping and emotion regulation with a supportive peer rather than on one's own, the CMH program is intended to enhance intimacy and strengthen perceived social support, which has well-established links to mental and physical health [22-24].

This Study

CMH and programs like it have the potential to improve public mental health in principle, but the success of such programs depends upon consumer interest and user adherence. In accordance with recommendations that consumer consultation be the first step in developing public health interventions [6,25], we conducted a survey to investigate the public interest in CMH and assess consumer preferences for specific elements of Web-based self-help and peer support programs, questions that remain unanswered in the existing literature (as discussed below). Addressing these questions would allow us to predict whether CMH was a viable strategy for improving public mental health and to tailor CMH to consumer preferences in order to optimize its appeal, effectiveness, and reach.

The specific research questions for this investigation were as follows. Although we had tentative hypotheses for some of these questions, this study should be viewed as exploratory, not confirmatory.

Research Question 1: Overall Interest

Is consumer interest adequate to justify investment in development of the CMH program and interventions like it?

A major goal of the survey was to gauge general public desire to participate in a program like CMH to estimate the potential reach of this program. Deciding upon a precise threshold for "adequate" interest would require knowledge of the cost-effectiveness of this program, which does not yet exist. However, we decided a priori that it would unquestionably be worthwhile to pursue the development of CMH if 30% of participants endorsed willingness to try the program. This was a conservatively high bar: even if the survey overestimated the proportion of users by 90%, this would mean about 10 million persons in the United States would try the program.

Research Question 2: Interest Among Those Not Accessing Traditional Services

Is consumer interest high enough among those who are not accessing or who do not plan to access traditional mental health care, and how does this group's level of interest compare with that of people who do access traditional care?

Common barriers to seeking mental health help from a professional include structural or practical impediments such as cost, inconvenience, and provider unavailability, as well as attitudinal barriers such as feeling that one's problem is not severe enough to warrant professional help or wanting to avoid stigma [1]. Because it is freely available on the Web, does not require interacting with a mental health professional, and is not presented as a treatment for mental illness, CMH has the potential to circumvent these barriers, so we hoped that some proportion of those who would not access traditional care would endorse willingness to try CMH. Indeed, eHealth and mHealth research suggests that technology-based interventions can reach those who have been underserved by traditional health care [26,27]. Nevertheless, CMH shares some characteristics with

XSL•FO
RenderX

traditional psychotherapy (eg, taking time each week to open up about one's problems). Because of these similarities, we hypothesized that those who were not willing to access traditional care would be less interested in CMH than those who were willing to access traditional care. We decided a priori that a 20% endorsement of willingness to try CMH within this group would be adequate to justify development of CMH.

Research Question 3: Characteristics Associated With Interest

What user characteristics are associated with interest in the program?

Characterizing the potential audience is a key step in tailoring health interventions [25]. Identifying possible "early adopters" and nonusers can inform strategies for tailoring or advertising Web-based mental health interventions to enhance their appeal to specific populations [27].

Some research has been conducted on predictors of attitudes toward mental health care or eHealth, but findings have not been consistent, and they may not apply to the nontraditional CMH program because it is intended to have broader appeal than traditional mental health services. Thus, further investigation is needed.

On the basis of current literature, one might expect females to be more interested than males [28-30], people of Asian descent to be less interested than those who are white [31-33], people with higher income [29,33,34] and more education [29,35,36] to be more interested, married or cohabiting people to be more interested than those who are not partnered [33,34,36], and past mental health care users to be more interested than those who have not accessed mental health care [29,33,37]. Findings regarding age differences in willingness to seek mental health care have been mixed [29,33,37,38], but age is inversely associated with use of eHealth [28], so one might expect that older people would be less interested in CMH because it will be disseminated via the Internet. We did not have specific expectations about the other characteristics investigated, such as psychological distress, because of contradictions or null findings in past research (eg, [33,37,39,40]).

Research Question 4: Preferred Partners

Whom would prospective users most want to have as a partner?

Most existing peer support programs have paired individuals with strangers, but to our knowledge there is no empirical justification for doing so. In fact, pairing users with individuals with whom they are already acquainted may have advantages, such as eliciting more disclosure [41], making meetings more convenient, and improving those relationships. On the other hand, users might rather not work with individuals with whom they are already close because they want to keep personal matters private from those people, because their close relationships are conflictual, or because they want the opportunity to develop a new relationship. Thus, research on consumer perspectives is necessary to differentiate among these rival possibilities.

Research Question 5: Desired Skills

Which peer counseling skills would prospective users want their partners to learn? Do these skills differ from the skills they would want to learn themselves?

We also inquired about which counseling skills people wanted to learn most, as well as which counseling skills they want their partner to learn. Delivery of appropriate social support is notoriously fraught, and the support provided is often suboptimal, mismatching the situation or the recipient's characteristics (eg, [42-44]). Perceived social support is optimized by matching the recipient's desires and goals, not the provider's [45,46]. Therefore, research is needed to clarify the type of support potential users would like to receive in CMH (ie, what skills they want their partners to learn) in order to determine what skills to teach. Investigating discrepancies between desired support provision and receipt will elucidate mismatches in what support providers want to deliver and what recipients actually want to receive; this information can then be used to educate CMH users about what types of supportive behaviors to avoid. We had no specific hypotheses about which skills would be most preferred, but we expected that, for many skills, there would be significant discrepancies between desire to learn the skill oneself versus desire for the partner to learn the skill (in light of the aforementioned potential for incongruence between support providers' and recipients' goals).

Research Question 6: Preferred Access Channels

How do 6 possible access channels compare in likelihood of use, appeal, trustworthiness, convenience, and ease of use?

Finally, we investigated the ideal access channel, offering several options for the Web-based platform and the venues through which users would learn about the program. Respondents ranked 6 options (website, app, social media, physician, community center, and school or work), then rated each channel on attributes that have been shown to predict technology and service adoption: appeal [47], ease of use [47,48], convenience [49], and trustworthiness [48,50].

Although there is evidence that these attributes are important, there is surprisingly little academic research available regarding consumer perspectives on channels of eHealth access (although it is likely that individual organizations and market research firms have collected proprietary data on related questions). With regard to Web-based platforms, we expected that respondents would report being more likely to use a stand-alone website than a mobile app or social networking site, given that a website can be accessed on a wide variety of devices; the percentage of US adults who own a laptop or desktop computer (73%) is slightly higher than those who own a smartphone (68%; [51]) and those who use social networking (65%; 76% of Internet users; [52]). We also expected that a stand-alone website would be viewed as more trustworthy than a mobile app or social networking given previous reports of user security concerns about the latter two platforms [53,54]. However, we had no hypotheses about the other attributes for these platforms or the relative merits of different organizations through which users could be alerted to the existence of health technologies.

XSL•FO
RenderX

Methods

Recruitment

Survey respondents were drawn from a convenience sample of potential health care consumers: users of Amazon's Mechanical Turk (MTurk), a work crowdsourcing website where any individual older than 18 years can complete simple tasks, including psychological experiments, for pay [55]. Although MTurk workers are not perfectly representative of the general public, they are far more demographically comparable to the US population than other Web or college student samples, and results obtained with MTurk samples are comparable to those obtained via other methods [56]. MTurk users also display rates of mental illness similar to or slightly greater than the general population [57]. Therefore, MTurk users should provide a useful approximation of potential users of our peer counseling intervention. The survey was administered in March 2014.

Eligibility

Access to the survey was limited to MTurk users with Internet protocol (IP) addresses in the United States. Users with the same IP address were prevented from completing the survey to avoid duplicate entries. We required MTurk users to have at minimum a 95% approval rate and at least 50 prior tasks completed on the MTurk website in order to access the survey.

For their data to be included in the analyses, participants need to correctly answer 3 simple comprehension questions after reading a description of the program. Because these questions were extremely straightforward (eg, "What do you learn from the training: How to speak another language, how to be helpful when listening and talking to your partner, or how to improve your memory?"), incorrect responses were indicative of inattention or gross misunderstanding of the description, rendering respondents' reactions to the program invalid.

Survey Content

Because the majority of survey content was unique to this project and therefore had not been validated in prior research, we pilot-tested and refined the survey through cognitive interviewing [58] to enhance validity. In 6 cognitive interviews conducted by the first or second author, pilot test participants completed the survey while describing their thought processes out loud and responded to a set of interviewer prompts assessing their interpretations of survey content. Survey items were altered or removed when the interviews revealed that the items were ambiguous, were not applicable to some respondents, or elicited interpretations that differed from their intended meaning.

Program Description

The survey began with a description of the program accompanied by stick figure illustrations. The description explained that, in the program, 2 people who were already acquainted would take a Web-based course in scientifically supported talking and listening skills, then would meet weekly in person to put the skills to use, and it listed a variety of potential benefits of participating. The complete description appears in Multimedia Appendix 1.

Interest in Program

Interest in the program was assessed in 3 ways. Respondents indicated intention to try the program on a dichotomous yes or no item ("Would you try the program?") and a 4-option forced-choice item. Additionally, participants responded to 12 items measuring attitudes toward the program (eg, "This program could help solve a problem I have"), including 5 reverse-scored items (eg, "This program would be a waste of my time"), rated on a 7-point Likert scale with anchors from "strongly agree" to "strongly disagree." The mean of the Likert-rated scale items was computed to create a composite continuous attitude score. This attitude scale was internally consistent (coefficient alpha=.94). Finally, we gave respondents the opportunity to provide their email addresses in order to receive more information about the program with the assumption that this, as a behavioral indicator of interest, required more commitment than a verbal claim of hypothetical willingness to try the program.

Desired Program Features

The survey also included items assessing desired features of the program. Participants were asked to rate their interest in learning 11 social support skills and in having an imagined partner learn the same skills. These skills were selected from those that, according to qualitative studies of social support, are frequently delivered by well-intentioned support providers, although they may or may not be perceived as helpful by support recipients [59-61].

Survey respondents also ranked 5 possible types of people they would prefer to have as a partner, 5 possible channels through which to meet with their partner, and 6 possible ways to access the course. They rated their perceptions of the possible ways to access the course on 4 semantic differentials: *appealing* to *unappealing*, *trustworthy* to *untrustworthy*, *convenient* to *inconvenient*, and, for the technological channels only, *easy to use* to *hard to use*.

Personal Information

Demographic characteristics and information on mental health service use were collected using straightforward, study-specific items. Rather than using total household income in subsequent analyses, we corrected for household size by dividing household income by the square root of the number of people in the household, an adjustment that assumes some economy of scale within the household, such that each additional household member costs the household less than the previous one [62].

Psychological distress was assessed using the Brief Symptom Inventory (BSI) [63], a 53-item instrument that is a shortened form of the Symptom Checklist-90-Revised. Participants rate symptoms experienced within the past week on 9 mental illness dimensions (Depression, Anxiety, Obsessive-Compulsive, Hostility, Somatization, Interpersonal Sensitivity, Paranoid Ideation, Psychoticism, and Phobic Anxiety), from which an index of total distress, the Global Severity Index, can be calculated. The Global Severity Index typically has excellent internal consistency (coefficient alpha>.90 [64]) and test-retest reliability of .90 over a 2-week interval [63]. The BSI displays both convergent validity with other measures of

XSL•FO
RenderX

psychopathology and predictive validity in correctly classifying individuals as patients [63,64]. In our sample, coefficient alpha was .97.

All surveys were approved by the University of Massachusetts Amherst Institutional Review Board and were carried out in accordance with all applicable regulations. Before consenting, participants were informed about the investigator's identity; the purpose, length, and risks and benefits of taking part in each survey; and the methods of data storage.

Statistical Analysis

We addressed missing data by using the package mice [65] for the software R (R Core Team) to generate and pool 5 multiply imputed datasets. This package implements Rubin's [66] rules for pooling, with Barnard and Rubin's [67] approximation for degrees of freedom. The fit of nested models is compared using the methods described by Meng and Rubin [68].

To identify demographic and clinical predictors of interest in the program, we conducted a series of regressions for each of the 3 outcome variables: attitude score (continuous), willingness to try the program (dichotomous), and provision of an email address (dichotomous). In the first step of these exploratory analyses, predictors were entered hierarchically in blocks. This allowed for tests of the incremental predictive effect of a group of related variables; for example, all race or ethnicity dummy codes were entered in a block, enabling a test of whether race or ethnicity significantly improved model fit, which would not have been possible if all variables were entered simultaneously. We expected that some of the predictors entered in the same block would be collinear (eg, education and income), but would act as indices of the same construct (eg, socioeconomic status or SES), and we would interpret the test of whether that block improved model fit as an indicator of whether the overall construct predicted interest in the program. The order of the blocks was based on what Cohen and colleagues [69] refer to as "causal priority." That is, variables are entered earlier when they logically cannot be caused by other variables in the model, whereas variables entered later could be caused by earlier variables. For example, gender may cause level of psychological distress, but psychological distress cannot cause gender. In cases when reciprocal causation was possible (eg, SES and psychological distress), we entered the variable that is usually evident earlier in an individual's life course first.

After conducting these hierarchical regressions with all variables, we then repeated the procedure, omitting any blocks of predictors that did not marginally improve model fit ($P<.10$). We then ran a final simultaneous regression in which we removed any individual predictors that did not approach significance when entered in order in the previous series of regressions ($P<.10$) in order to obtain estimates of the effect of each variable while controlling for all other relevant variables (including those for which reciprocal causation was possible). Retaining "marginally significant" covariates in the final model (ie, using a cutoff of $P<.10$ as opposed to $P<.05$) constitutes a more conservative test of the independent predictive ability of each variable, while eliminating those that did not approach significance in earlier models reduces noise and increases parsimony.

To compare participants' interest in their partners versus themselves learning each support skill, we conducted paired *t* tests for each skill.

To identify whether specific potential partners, meeting channels, or course access methods were ranked significantly higher than others, we compared each pair of possible choices with a Wilcoxon signed rank test, with a Bonferroni correction for multiple comparisons.

Results

Characteristics of the Sample

Of the 637 MTurk users who completed the survey, 592 (92.9%) correctly answered all 3 comprehension questions and were therefore eligible for inclusion. Missing data were relatively rare; all 592 individuals responded to the majority of items such that there were no missing values for any attitude items, mental health and distress items, gender, race, marital status, or education; the maximum number of missing values for any variable was 8 (for income).

Demographic, clinical, and service use characteristics of the sample are presented in Table 1. Of note, respondents evidenced a wide range of symptom distress, with approximately a quarter scoring above the BSI's suggested clinical cutoff (ie, their symptom severity was consistent with the presence of mental illness).

XSL•FO
RenderX

Table 1. Participant characteristics.

Characteristics	Mean (SD) or n (%) (N=592)
Age in years, mean (SD)	37.37 (13.11)
Gender, n (%)	
Male	212 (35.8)
Female	375 (63.3)
Gender nonconforming (eg, transgender, genderqueer)	5 (0.8)
Race or ethnicity, n (%)	
White, non-Hispanic	458 (77.4)
Black	44 (7.4)
Hispanic	33 (5.6)
Asian	27 (4.6)
Native American	6 (1.0)
Other race or ethnicity	24 (4.0)
Marital status, n (%)	
Married or cohabiting	275 (46.5)
Never married	256 (43.2)
Separated or divorced	50 (8.4)
Widowed	11 (1.9)
Education, n (%)	
High school or less	64 (10.8)
2-Year degree	51 (8.6)
Some college	177 (29.9)
4-Year degree	184 (31.1)
Some graduate or professional school	31 (5.2)
Graduate or professional degree	85 (14.4)
Income in US $, mean (SD)	
Median household income	42K
Income per person[1/2]	32.9K (22.7K)
Brief Symptom Inventory	
Score, mean (SD)	0.5045 (0.5985)
In “clinical” range, n (%)	142 (24.0)
Psychotherapy use, n (%)	
Currently in therapy	44 (7.4)
Ever in therapy	261 (44.1)
Would consider trying therapy	403 (68.1)
Psychiatric medication use, n (%)	
Currently prescribed medication	73 (12.3)
Ever prescribed medication	175 (29.6)
Would consider trying medication	362 (61.1)

Overall Interest in the Program

More than half the respondents (378/592, 63.9%; 95% CI 60.0% to 67.7%) indicated on the dichotomous item that they would try the program. When asked to choose from 4 options, 14.9% (88/592) indicated that they “would sign up now,” 46.5% (275/592) indicated that they “might try it in the future,” 29.2% (173/592) indicated that they “would probably not try it,” and

XSL•FO
RenderX

9.5% (56/592) indicated that they "would never try it." For the behavioral indicator of interest, approximately one-third of the respondents (193/592, 32.6%; 95% CI 28.8% to 37.8%) volunteered their email addresses in order to request more information about the program. The median score on the continuous attitude scale was 5.1 out of a possible range of 1 to 7 (mean 4.9, SD 1.1), corresponding to an anchor of "somewhat agree" on positively worded items.

To assess whether our program would appeal to those who lacked access to or interest in traditional mental health interventions, we computed the percentages of those who had not used psychotherapy or psychiatric medication but who would try our program, as well as the percentages of those who stated that they would not be willing to use those traditional interventions but who would try our program. Of those who never accessed psychotherapy, 62.5% indicated that they would try the program, compared with 65.5% of those who had used therapy, χ^2_1=0.4, *P*=.51. Of those who said that they would not be willing to use therapy if they had a problem, 51.3% indicated they would try our program, while 69.7% of those who were willing to use therapy would try our program, χ^2_1=18.1, *P*<.001. A similar pattern emerged with regard to psychiatric medication: 62.8% of those who had never taken psychiatric medication would try the program, and 66.3% of those who had ever been prescribed psychiatric medication would try the program, χ^2_1=0.5, *P*=.48. Of those who would never consider using medication if needed, 57.8% would try our program, whereas 67.7% of those who would consider using medication would try our program, χ^2_1=5.5, *P*=.02.

Predictors of Interest

In the first hierarchical linear regression predicting continuous attitude score, the blocks containing race, age, and marital status failed to improve model fit even marginally. Therefore, as planned, these blocks were removed from the subsequent analyses, and the second hierarchical regression included blocks for gender, SES, psychological symptoms, past treatment use, and hypothetical treatment use. At this stage, the following variables significantly predicted more positive attitude toward CMH (at the step in which they were entered): female gender, past use of therapy, and willingness to consider using therapy. Greater psychological symptoms marginally predicted positive attitude, and greater income was marginally associated with worse attitude. Full results of these initial analyses appear in Multimedia Appendix 2.

In a simultaneous regression, the aforementioned predictors with *P*<.10 were retained and all others were removed (Table 2). In this reduced model, the magnitude of estimated associations between attitude and gender, symptoms, and willingness to consider therapy were similar to their magnitudes in the previous model. Income became a significant predictor once education was removed, and past use of therapy became nonsignificant when entered simultaneously with willingness to consider therapy.

Table 2. Simultaneous regression predicting attitude toward the Crowdsourcing Mental Health program.

Predictor	*B*	SE *B*	95% CI *B*	*P* value
Female[a]	0.200	0.095	0.013 to 0.386	.04
Income[b]	−0.055	0.020	−0.095 to −0.016	.006
Brief Symptom Inventory	0.112	0.077	−0.039 to 0.263	.14
Ever used therapy	0.073	0.097	−0.118 to 0.263	.45
Would consider therapy	0.586	0.101	0.387 to 0.784	<.001

[a]Reference category is combined male and gender nonconforming respondents.

[b]Unit is income per household member$^{1/2}$in US $10,000 increments.

In the first hierarchical logistic regression predicting whether respondents indicated willingness to participate in the program on the dichotomous item, the following blocks failed to marginally or significantly improve model fit: gender, marital status, and past treatment use. In the next regression, in which those blocks were removed, the block in which race or ethnicity dummy codes were entered marginally improved model fit, apparently driven by Hispanic respondents' greater likelihood of indicating willingness to participate than non-Hispanic white respondents. All other blocks significantly improved model fit, and all predictors within those blocks were marginal or significant predictors of willingness to try the program except for willingness to consider taking psychiatric medication. See Multimedia Appendix 2 for detailed results of these analyses.

Therefore, for the simultaneous regression (Table 3), only willingness to consider medication was removed (the dummy codes for all race or ethnicity categories were retained so that the reference category would not change). In this analysis, individuals who were older or had higher income were less likely to indicate that they would try the program, and individuals who identified as Hispanic or who would be willing to consider using psychotherapy were more likely to state that they would try the program.

XSL•FO
RenderX

Table 3. Simultaneous regression predicting intention to try the Crowdsourcing Mental Health program.

Predictor	*B*	SE *B*	95% CI *B*	*P* value
Hispanic[a]	1.102	0.512	0.100 to 2.11	.03
Black[a]	0.221	0.356	−0.479 to 0.921	.53
Asian[a]	0.682	0.461	−0.224 to 1.587	.14
Native American[a]	−0.169	0.891	−1.918 to 1.581	.85
Other race[a]	−0.484	0.443	−1.354 to 0.386	.28
Age	−0.015	0.007	−0.029 to −0.001	.04
Income[b]	−0.087	0.041	−0.167 to −0.007	.03
Education	−0.123	0.066	−0.255 to 0.007	.06
Brief Symptom Inventory	0.292	0.165	−0.033 to 0.616	.08
Would consider therapy	0.936	0.194	0.556 to 1.317	<.001

[a]Reference category is non-Hispanic white.

[b]Unit is income per household member$^{1/2}$in US $10,000 increments.

In the first hierarchical logistic regression predicting whether participants provided an email address to request more information, blocks including gender, race, symptoms, and hypothetical treatment use significantly improved model fit; no other blocks approached significance. In the second hierarchical logistic regression, female gender, symptoms, and openness to using psychotherapy all significantly predicted provision of an email address; Asian participants were significantly less likely to provide an email address than white participants. No other predictors approached significance. The full results of these regression analyses can be found in Multimedia Appendix 2.

In the simultaneous regression predicting email provision, willingness to consider medication and the dummy code for gender nonconforming were dropped (such that the reference category for gender was now non–female-identified rather than male). In this analysis, presented in Table 4, female gender, psychological symptoms, and openness to using therapy remained significant predictors.

Table 4. Simultaneous regression predicting provision of email address.

Predictor	*B*	SE *B*	95% CI *B*	*P* value
Female[a]	0.411	0.195	0.023 to 0.794	.04
Hispanic[b]	0.180	0.387	−0.581 to 0.939	.64
Black[b]	0.466	0.337	−0.196 to 1.128	.17
Asian[b]	−1.230	0.642	−2.491 to 0.031	.06
Native American[b]	1.207	0.933	−0.626 to 3.040	.20
Other race[b]	−0.093	0.473	−1.022 to 0.836	.84
Brief Symptom Inventory	0.471	0.149	0.179 to 0.764	.002
Would consider therapy	0.929	0.217	0.503 to 1.355	<.001

[a]Reference category is combined male and gender nonconforming respondents.

[b]Reference category is non-Hispanic white.

To summarize the significant results from the final models, female gender predicted favorable attitudes and email provision; Hispanic ethnicity predicted intention to try CMH; older age was associated with lower endorsement of willingness to try CMH; lower income predicted favorable attitudes and intention to try CMH; higher psychological distress was associated with email provision; and willingness to use psychotherapy predicted all 3 dependent variables.

Preferred Partners

Table 5 lists the proportion of participants who ranked each potential partner first and second and the results of pairwise comparisons of the ranks of each partner type. Most individuals preferred a romantic partner as a first choice, with a close friend as a common second choice. A notable minority of respondents ranked a stranger as their ideal peer counselor.

XSL•FO
RenderX

Table 5. Most preferred peers.

Partner type	Ranked 1, n (%) (N=588)	Ranked 2, n (%) (N=588)	Mean rank[a]
Romantic partner or spouse	339 (57.7)	88 (15.0)	1.96
Close friend	102 (17.3)	232 (39.5)	2.39
Family member	59 (10.0)	161 (27.4)	3.01
Acquaintance	25 (4.3)	70 (11.9)	3.55
Stranger	63 (10.7)	37 (6.3)	4.08

[a]All pairwise comparisons between ranks were significantly different, $P<.005$.

Desired Counseling Skills

In order to identify the skills that consumers believe would be most valuable to learn in a peer support program, the survey listed counseling skills and asked respondents to rate how important it was to them that their peer learn that skill, as well as how important it was that they themselves learn that skill, on a 1 to 7 Likert scale from "not at all important" to "extremely important." Table 6 provides the proportion of respondents rating each skill as "very" or "extremely" important to learn, as well as the results of within-subjects *t* tests of the difference in importance between one's peer learning each skill and learning it oneself.

Table 6. Importance of learning various peer counseling skills.

Peer counseling skills	Rated skill "very" or "extremely" important, n (%) (N=592)		Mean difference in ratings	t_{591}	*P* value
	Want peer to learn	Want self to learn			
How to genuinely listen	474 (80.6)	366 (61.9)	0.58	11.06	<.001
How to pay attention	439 (74.6)	351 (59.3)	0.51	9.37	<.001
How to show understanding	416 (70.7)	377 (63.7)	0.23	4.56	<.001
How to empathize	403 (68.5)	366 (61.8)	0.28	5.28	<.001
How to avoid being judgmental	397 (67.5)	357 (60.3)	0.28	4.87	<.001
How to be compassionate	387 (65.9)	378 (63.9)	0.14	2.94	.003
How to comfort the other person	357 (60.7)	363 (64.7)	−0.05	−0.94	.35
How to help think through decisions	348 (59.1)	371 (62.6)	−0.13	−2.44	.02
How to help solve practical problems	310 (52.7)	334 (56.5)	−0.10	−1.86	.06
How to give advice	308 (52.4)	345 (58.3)	−0.11	−2.03	.04

The most highly prized skills involved simply listening attentively and taking an understanding, nonjudgmental stance. Generally, respondents considered it more important for their peer to learn each skill than themselves. However, this pattern was weaker or even reversed for skills related to intervening to resolve the other person's distress, for example, by solving problems or comforting the other person. For those "intervention-like" skills, participants wanted to learn to deliver the skills to their peers more than they wanted their peers to learn the skills.

Access Channels

To determine the method of access that would reach the most consumers, we provided respondents with a choice of 6 ways to access the peer counseling training course and intervention: through a stand-alone website, through a social networking website such as Facebook, as a mobile "app," as a program offered through a doctor's office or other health care provider, as a program offered through one's workplace or school, or as a program offered through a community center such as a public library or the YMCA (Young Men's Christian Association). Respondents were asked to indicate the way they would be most likely to access the program by rank-ordering the options. They also rated each option on several 6-point semantic differential scales: appealing-unappealing, trustworthy-untrustworthy, convenient-inconvenient, and easy to use–hard to use.

The most popular access choice by far was stand-alone website, with 51.2% (303/592) of respondents ranking it as their most likely option, with doctor's office and mobile app following (see Table 7). On the basis of the semantic differential ratings (which are summarized in Table 8), respondents viewed a website as most appealing, convenient, and easy to use and second in trustworthiness. Accessing peer counseling through a doctor's office or health care provider was seen as most trustworthy but least convenient; in contrast, mobile apps were rated as relatively convenient but less trustworthy and harder to use. Community centers were moderately trustworthy but less convenient, and work or school was moderately convenient and trustworthy. Social networking sites were the least popular option, rated low in appeal and trustworthiness, although moderate in convenience and ease of use.

XSL•FO
RenderX

Table 7. Most likely method for accessing peer counseling.

Method of access	Ranked 1, n (%) (N=588)	Ranked 2, n (%) (N=588)	Mean rank[a]
Website	301 (51.2)	111 (18.9)	2.12
Doctor's office	86 (14.6)	95 (16.2)	3.44[b]
Mobile app	68 (11.6)	138 (23.5)	3.66[b,c]
Community center	46 (7.8)	94 (16.0)	3.69[c]
Work or school	49 (8.3)	72 (12.2)	3.87[c]
Social networking site	38 (6.5)	78 (13.3)	4.22

[a]Lower mean ranks indicate greater preference.

[b]These options did not differ significantly when compared, Wilcoxon signed rank test $P<.0033$.

[c]These options did not differ significantly, Wilcoxon signed rank test $P<.0033$.

Table 8. Access methods' mean ranks on each attribute.

Method of access	Mean rank[a]			
	Appealing	Trustworthy	Convenient	Easy to use
Website	2.57	3.03[b]	2.66	1.79
Doctor's office	3.46[b]	2.55	4.18[c]	-
Mobile app	3.85[c]	4.47[c]	3.27[b]	2.15
Community center	3.44[b]	3.14[b]	4.04[c]	-
Work or school	3.74[c]	3.32	3.54[b]	-
Social networking site	3.93[c]	4.49[c]	3.30[b]	2.06

[a]Attributes not assessed for a particular access method are marked by a dash. Lower mean ranks indicate greater preference.

[b]These options did not differ significantly when compared, Wilcoxon signed rank test $P<.0033$.

[c]These options did not differ significantly, Wilcoxon signed rank test $P<.0033$.

Discussion

Overall Interest in the Program

The purpose of this investigation was to assess consumer interest in a Web-based self-help and peer support mental health intervention, to determine demographic and clinical predictors of interest in the intervention, and to evaluate consumer preferences for specific features of Web-disseminated peer support interventions.

Respondents expressed fairly high interest in the CMH program: 63.9% verbally communicated that they would try the program, and 32.6% showed behavioral evidence of interest by offering their email addresses to request more information. More than half of respondents who indicated that they would never consider seeking psychotherapy or psychiatric medication were willing to try the CMH program. This proportion was significantly lower than it was among those who were willing to access these traditional mental health services, which indicates that programs like CMH are not a panacea; they cannot reach every person who is "left out" by traditional services. However, it appears that peer counseling still appeals to a substantive portion of that population.

Predictors of Interest

Several demographic and clinical characteristics were associated with 3 different indicators of interest in the CMH program: a multi-item measure of the program's appeal (continuous), endorsement of intention to try the program (dichotomous), and provision of an email address in order to receive information about the program (dichotomous). Female gender, lower income, and openness to using psychotherapy were associated with positive attitude toward CMH while controlling for other variables. Younger age, Hispanic ethnicity, lower income, and openness to using psychotherapy predicted willingness to try the program while controlling for other variables. Female gender, higher symptom distress, and openness to using therapy were associated with provision of an email address while controlling for other variables.

Gender

We predicted that females would be more interested in the CMH program than males in light of their greater willingness to seek both eHealth and traditional mental health services [28-30], which may be related to gender differences in rates of mental illnesses as well as to lower perceived stigma among women [70]. However, the association between gender and interest remained when controlling for hypothetical use of professional mental health care, suggesting that there are other reasons

XSL•FO
RenderX

women find CMH more appealing than men do. Perhaps the prospect of reciprocal social support is attractive to women to an even greater degree than professional help. According to Taylor and colleagues' [71] "tend and befriend" theory, women are evolutionarily prepared to respond to stress with affiliative behaviors and building of social networks. Women also place higher demands upon friendships than men, expecting more reciprocity and intimacy [72]. Therefore, women may value CMH and other peer support programs' efficacy for meeting the needs of enhancing relationships and social resources.

The association between gender and interest in the program suggests that CMH and other peer support programs do not completely avoid the barriers men face to seeking mental health care. This makes sense when one considers the demands of the male gender role. CMH has the potential to reduce stigma because users do not have to identify as mentally ill; however, it still requires that users seek support from one another and disclose their personal experiences, thoughts, and feelings. Such support-seeking and vulnerability violate cultural scripts of traditional masculinity [70,73]. However, the associations between gender and interest in the program were small, suggesting that many men were still interested in CMH.

Income

The association between interest in CMH and lower income is particularly intriguing in light of previous research showing that people with lower income have more negative attitudes toward seeking professional psychological help (eg, [29]). It may be that people with lower income find professional care less appealing and instead prefer to utilize nonprofessional sources of help. A national survey found that low income was associated with seeking support for health problems from one's personal social network rather than professionals [74]. Thus, leveraging existing interpersonal relationships for delivery of health care may be an ideal way to reach low-income individuals.

Age

Older respondents were less likely to endorse willingness to try the CMH program; however, age did not predict participants' attitudes toward the program or their likelihood of requesting more information via email. Older age is associated with lower technology adoption [75], including lower use of eHealth [28]. Therefore, dissemination of Web-based interventions to older individuals might be facilitated by ensuring that interfaces are intuitive to users of all ages and by promoting programs as user-friendly. It may also be helpful to supplement Web interventions with face-to-face support or to secure endorsement from trusted individuals (eg, health care providers; [76]).

Race or Ethnicity

Respondents who identified as Hispanic were more likely to indicate that they would try the program than non-Hispanic white respondents. (Although the association between Hispanic ethnicity and attitudes did not reach significance, it was in the same direction.) This result requires replication, given that it was not consistent across outcome measures and only 33 respondents selected this ethnic category. Furthermore, there is a great deal of cultural heterogeneity among Hispanic Americans. However, one can speculate that Hispanic respondents' greater willingness to use the CMH program may be related to the value of *familismo*, which features prominently in research on Hispanic cultural psychology (eg, [77]). Hispanic individuals' strong family support systems and desire to keep family matters private have been given as reasons for limited utilization of professional mental health care among this group [78]. In contrast to traditional mental health services, programs like CMH that train individuals to improve their mental health through existing social ties may be a particularly culturally acceptable strategy for reaching individuals high in *familismo*.

No other racial or ethnic identity group differed from non-Hispanic whites in level of interest in the CMH program. For many racial or ethnic minorities, stigma around mental illness is higher than among white individuals [79], and there may be distrust of health care providers [80], which partially drives negative attitudes toward traditional mental health services among minorities [81]. Perhaps by eliminating the barrier of stigma by promoting mental health without requiring that users receive a label of "disordered" or "ill," and by enabling users to receive support from those they trust, CMH and programs like it can decrease the racial mental health disparities that persist in the United States [82].

Clinical Characteristics

Openness to using psychotherapy was the most consistent predictor of interest in CMH across the 3 outcome variables, even when controlling for all demographic and clinical characteristics. This suggests that some of the same, unmeasured factors drive willingness to access therapy and interest in CMH. On the other hand, openness to using therapy accounted for less than 6% of the variance in attitudes toward CMH, and many individuals who indicated they would not use psychotherapy endorsed willingness to try CMH. This suggests that the shared features of professional psychotherapy and Web-based self-help and peer support programs account for *some* common level of appeal but that, for the most part, these traditional and nontraditional interventions fill *separate* ecological niches in the mental health care system. Rather than focusing on disseminating a handful of traditional strategies for treating mental health problems, researchers and policy makers should consider investing effort in developing a diverse portfolio of tools in order to maximize reach and impact on public mental health.

In the hierarchical models, symptom distress was significantly or marginally associated with each index of interest such that people with more symptoms expressed more interest in the CMH program. Distress remained a significant predictor of requesting more information via email when controlling for other variables. The general positive association between distress and interest is heartening—CMH and similar programs will appeal most to those who need them most.

Preferred Partners

When asked whom they would prefer as a partner in the CMH program, respondents generally favored romantic partners or close friends, although a notable minority of respondents preferred to work with a stranger. These findings on selecting

XSL•FO
RenderX

a peer suggest that it is important for anyone creating a peer support intervention to recognize that, although such interventions have typically paired 2 strangers, most people would rather work with someone whom they already know, preferably someone with whom they are close. At the same time, some individuals—perhaps those with narrower social circles or conflictual close relationships—find disclosing to a stranger attractive. Peer support's reach might be optimized by designing interventions that are flexible enough to allow for a variety of people to act as peers and by building in processes for introducing strangers who do not want to work with friends or family.

Additionally, the popularity of a romantic partner as a peer counselor may also imply that many people are interested in strengthening their romantic relationships, a possibility corroborated by many comments in an open-ended section of the survey about desiring to improve communication with spouses. Web-based interventions for couples or spouses may present an additional opportunity to improve public mental health, given the evidence that interventions for couples can improve individual mental health in addition to relationship functioning [83].

Desired Counseling Skills

When presented with a list of counseling skills that they or their peers could learn, respondents expressed the greatest desire that their peers learn skills that involved attentive, nonjudgmental listening. Respondents generally considered it more important for their peer to learn each skill than to learn that skill themselves, perhaps because people are more invested in receiving quality support than providing it or because people tend to overestimate their own abilities [84]. This disparity was especially apparent for active listening skills, but this pattern was weaker or even reversed for skills related to resolving the other person's distress. In other words, respondents wanted to learn to "fix" stressors for their peers but just wanted their peers to learn to listen empathically.

These findings converge with several lines of work that illuminate helpful and unhelpful ways to react to others' distress. Well-intentioned peers and loved ones often respond to disclosures of distress by trying to eliminate the stressful stimulus (eg, by solving problems or giving advice) or by trying to change the discloser's emotional response (eg, by reframing the stressor in a positive light or minimizing its gravity). Yet the recipients of such "support" tend to regard it as unhelpful or even disturbing [44,59-61]. The reasons why attempts to change the stressor or the emotional response could be harmful are not yet thoroughly investigated, but such support attempts may be perceived as judgmental, make recipients feel misunderstood and more alone, or interfere with self-verification strivings (ie, a motivation to receive feedback that confirms self-conceptions) [85]. In contrast, social support recipients tend to appreciate loved ones simply being present, expressing empathy, being accepting, or validating their feelings [44,59-61].

On the basis of this literature and the corroborating results of our survey, those who hope to create new peer support interventions should consider incorporating training in attentive, nonjudgmental listening and reflection skills, as well as education about the potential dangers of common "helping" behaviors such as giving reassurance and advice. However, one must recognize that what support seekers *prefer* may not necessarily correspond with what is *effective*. Purely "supportive" psychotherapies are not as effective as those that contain more "active" ingredients [86]. If the creators of peer support training programs do plan to teach peers to administer more active problem-solving or extrinsic emotion regulation, they should make sure support providers are thoroughly trained and monitored to do so sensitively, lest the support be regarded as unhelpful or damage the relationship.

Access Channels

Selecting from 6 options for learning about and accessing the Web-based training course, the overwhelming majority of respondents indicated that they would be most likely to use the program if it took the form of a stand-alone website. A notable minority indicated that a health care provider's office or a mobile app would be the ideal point of access. A website and a mobile app were regarded as convenient, and health care providers were regarded as highly trustworthy but inconvenient. These results suggest that a training course is likely to have the greatest reach if offered via a stand-alone website. However, offering a mobile version of the course, or disseminating peer counseling resources through existing health care providers, could expand the population served, given that 11.6% and 14.6% of respondents, respectively, ranked those access options as the most likely way to reach them. Perhaps developers of Web-disseminated self-help or peer support courses could capitalize on the trustworthiness of health care providers by using doctors' offices as a first point of contact but could increase convenience by enabling users to access the course and meet with peers at any location or on any device of their choosing.

Limitations and Future Directions

The chief limitation of this study was the use of a nonprobability sample. Although diverse, MTurk users are not representative of the population, and they may be somewhat more interested in this program than the general public because of their comfort with using technology.

An additional limitation of this study is that the findings regarding interest in the program apply to the specific description of the program used in the survey. Interest may have differed if the program were presented in more detail or with other emphases. Furthermore, Web-disseminated self-help or peer support programs that include different features may engender different levels of consumer interest than the CMH program.

Future research on such programs could expand upon the foundation laid here in a variety of ways. This exploratory study established that interest exists; however, it did not explain *why* respondents were interested. It would be helpful to know which elements of this Web-based self-help and peer support training drive consumers' attraction and which elements are neutral or even unappealing. Additionally, although we found some differences in interest among demographic groups, we could only speculate on reasons for the associations between interest

XSL•FO
RenderX

and demographic characteristics. Further investigations could probe the underlying causes of these associations in order to inform how such programs could be more responsive to the values and life circumstances of diverse individuals. Finally, it may be especially fruitful to combine these two research threads and examine interactions between demographics and preferences for specific elements of such programs, thus identifying elements that are particularly desirable to certain demographic groups so that interventions can be tailored to their needs.

Conclusions

The results of this study substantiate the potential for CMH to fill gaps in mental health care. Diverse consumers would be interested in such an intervention, including those who are not already accessing services. Because they minimize stigma and utilize existing social support systems, reciprocal peer support interventions may be especially attractive to some groups who are underserved by professional mental health services.

It appears that CMH's appeal can be enhanced by allowing a variety of options for peer counselors and by teaching active listening skills. It also seems that the course will reach the greatest number of users if accessed via a website, although access through mobile apps or through health care providers' offices may also be useful options.

We hope that the results of these surveys will persuade readers of the potential utility of Web-disseminated self-help and peer support programs and will inform the creation and dissemination of other programs.

Acknowledgments

This research was supported in part by a Graduate Research Fellowship awarded to SLB by the University of Massachusetts Amherst Center for Research on Families and by an Honors Research Grant awarded to KB by the University of Massachusetts Amherst Commonwealth Honors College.

Authors' Contributions

SLB conceived the study, designed and administered the survey, conducted cognitive interviews, analyzed the data, and wrote the manuscript. KB contributed to the literature review, participated in development of the survey, conducted cognitive interviews, and participated in preliminary data analysis. GDS contributed to the literature review and revision of the manuscript. MJC collaborated on all aspects of the research design, provided laboratory resources to conduct the surveys, and edited the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The description of the program presented in the survey.

[PDF File (Adobe PDF File), 147KB - mental_v4i1e5_app1.pdf]

Multimedia Appendix 2

The results of the hierarchical linear and logistic regressions.

[PDF File (Adobe PDF File), 58KB - mental_v4i1e5_app2.pdf]

References

1. Mojtabai R, Olfson M, Sampson NA, Jin R, Druss B, Wang PS, et al. Barriers to mental health treatment: results from the National Comorbidity Survey Replication. Psychol Med 2011 Aug;41(8):1751-1761 [FREE Full text] [doi: 10.1017/S0033291710002291] [Medline: 21134315]
2. Eysenbach G. The law of attrition. J Med Internet Res 2005;7(1):e11 [FREE Full text] [doi: 10.2196/jmir.7.1.e11] [Medline: 15829473]
3. Christensen H, Griffiths KM, Farrer L. Adherence in internet interventions for anxiety and depression. J Med Internet Res 2009;11(2):e13 [FREE Full text] [doi: 10.2196/jmir.1194] [Medline: 19403466]
4. 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] [Medline: 19799804]
5. Smits R, Bryant J, Sanson-Fisher R, Tzelepis F, Henskens F, Paul C, et al. Tailored and integrated Web-based tools for improving psychosocial outcomes of cancer patients: the DoTTI development framework. J Med Internet Res 2014;16(3):e76 [FREE Full text] [doi: 10.2196/jmir.2849] [Medline: 24641991]
6. van Gemert-Pijnen JE, Nijland N, van Limburg M, 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;13(4):e111 [FREE Full text] [doi: 10.2196/jmir.1672] [Medline: 22155738]

XSL•FO
RenderX

7. Onken LS, Carroll KM, Shoham V, Cuthbert BN, Riddle M. Reenvisioning clinical science: unifying the discipline to improve the public health. Clin Psychol Sci 2014 Jan 1;2(1):22-34 [FREE Full text] [doi: 10.1177/2167702613497932] [Medline: 25821658]
8. Brown SL, Nesse RM, Vinokur AD, Smith DM. Providing social support may be more beneficial than receiving it: results from a prospective study of mortality. Psychol Sci 2003 Jul;14(4):320-327. [Medline: 12807404]
9. Laurenceau JP, Barrett LF, Pietromonaco PR. Intimacy as an interpersonal process: the importance of self-disclosure, partner disclosure, and perceived partner responsiveness in interpersonal exchanges. J Pers Soc Psychol 1998 May;74(5):1238-1251. [Medline: 9599440]
10. Michl LC, McLaughlin KA, Shepherd K, Nolen-Hoeksema S. Rumination as a mechanism linking stressful life events to symptoms of depression and anxiety: longitudinal evidence in early adolescents and adults. J Abnorm Psychol 2013 May;122(2):339-352 [FREE Full text] [doi: 10.1037/a0031994] [Medline: 23713497]
11. Middeldorp CM, Cath DC, Beem AL, Willemsen G, Boomsma DI. Life events, anxious depression and personality: a prospective and genetic study. Psychol Med 2008 Nov;38(11):1557-1565. [doi: 10.1017/S0033291708002985] [Medline: 18294422]
12. Liu RT, Alloy LB. Stress generation in depression: a systematic review of the empirical literature and recommendations for future study. Clin Psychol Rev 2010 Jul;30(5):582-593 [FREE Full text] [doi: 10.1016/j.cpr.2010.04.010] [Medline: 20478648]
13. Rusli BN, Edimansyah BA, Naing L. Working conditions, self-perceived stress, anxiety, depression and quality of life: a structural equation modelling approach. BMC Public Health 2008;8:48 [FREE Full text] [doi: 10.1186/1471-2458-8-48] [Medline: 18254966]
14. Seeman TE, McEwen BS, Rowe JW, Singer BH. Allostatic load as a marker of cumulative biological risk: MacArthur studies of successful aging. Proc Natl Acad Sci U S A 2001 Apr 10;98(8):4770-4775 [FREE Full text] [doi: 10.1073/pnas.081072698] [Medline: 11287659]
15. Kashdan TB, Barrios V, Forsyth JP, Steger MF. Experiential avoidance as a generalized psychological vulnerability: comparisons with coping and emotion regulation strategies. Behav Res Ther 2006 Sep;44(9):1301-1320. [doi: 10.1016/j.brat.2005.10.003] [Medline: 16321362]
16. Bonanno GA, Burton CL. Regulatory flexibility: an individual differences perspective on coping and emotion regulation. Perspect Psychol Sci 2013 Nov;8(6):591-612. [doi: 10.1177/1745691613504116] [Medline: 26173226]
17. Aldao A. Introduction to the special issue: emotion regulation as a transdiagnostic process. Cogn Ther Res 2016 Mar 15;40(3):257-261. [doi: 10.1007/s10608-016-9764-2]
18. Sheppes G, Suri G, Gross JJ. Emotion regulation and psychopathology. Annu Rev Clin Psychol 2015;11:379-405. [doi: 10.1146/annurev-clinpsy-032814-112739] [Medline: 25581242]
19. Barrett LF, Gross JJ. Emotion representation and regulation: a process model of emotional intelligence. In: Mayne TJ, Bonanno GA, editors. Emotions: Current Issues and Future Directions. New York, NY: Guilford Press; 2001:286-310.
20. Izard C, Stark K, Trentacosta C, Schultz D. Beyond emotion regulation: emotion utilization and adaptive functioning. Child Dev Perspect 2008 Dec;2(3):156-163 [FREE Full text] [doi: 10.1111/j.1750-8606.2008.00058.x] [Medline: 19956781]
21. Kircanski K, Lieberman MD, Craske MG. Feelings into words: contributions of language to exposure therapy. Psychol Sci 2012 Oct 1;23(10):1086-1091 [FREE Full text] [doi: 10.1177/0956797612443830] [Medline: 22902568]
22. Cacioppo JT, Hawkley LC, Thisted RA. Perceived social isolation makes me sad: 5-year cross-lagged analyses of loneliness and depressive symptomatology in the Chicago Health, Aging, and Social Relations Study. Psychol Aging 2010 Jun;25(2):453-463 [FREE Full text] [doi: 10.1037/a0017216] [Medline: 20545429]
23. Fuhrer R, Stansfeld SA, Chemali J, Shipley MJ. Gender, social relations and mental health: prospective findings from an occupational cohort (Whitehall II study). Soc Sci Med 1999 Jan;48(1):77-87. [Medline: 10048839]
24. Luo Y, Hawkley LC, Waite LJ, Cacioppo JT. Loneliness, health, and mortality in old age: a national longitudinal study. Soc Sci Med 2012 Mar;74(6):907-914 [FREE Full text] [doi: 10.1016/j.socscimed.2011.11.028] [Medline: 22326307]
25. Lefebvre RC. Social Marketing and Social Change: Strategies and Tools for Improving Health, Well-Being, and the Environment. San Francisco, CA: Jossey-Bass; 2013.
26. Crilly JF, Keefe RH, Volpe F. Use of electronic technologies to promote community and personal health for individuals unconnected to health care systems. Am J Public Health 2011 Jul;101(7):1163-1167. [doi: 10.2105/AJPH.2010.300003] [Medline: 21566023]
27. Montague E, Perchonok J. Health and wellness technology use by historically underserved health consumers: systematic review. J Med Internet Res 2012;14(3):e78 [FREE Full text] [doi: 10.2196/jmir.2095] [Medline: 22652979]
28. 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] [Medline: 25048379]
29. Mojtabai R. Americans' attitudes toward mental health treatment seeking: 1990-2003. Psychiatr Serv 2007 May;58(5):642-651. [doi: 10.1176/appi.ps.58.5.642] [Medline: 17463345]

XSL•FO
RenderX

30. Nam SK, Chu HJ, Lee MK, Lee JH, Kim N, Lee SM. A meta-analysis of gender differences in attitudes toward seeking professional psychological help. J Am Coll Health 2010;59(2):110-116. [doi: 10.1080/07448481.2010.483714] [Medline: 20864437]
31. Kim BSK, Omizo MM. Asian cultural values, attitudes toward seeking professional psychological help, and willingness to see a counselor. Couns Psychol 2003;31(3):343-361. [doi: 10.1177/0011000003031003008]
32. Loya F, Reddy R, Hinshaw SP. Mental illness stigma as a mediator of differences in Caucasian and South Asian college students' attitudes toward psychological counseling. J Counseling Psych 2010;57(4):484-490. [doi: 10.1037/a0021113]
33. Masuda A, Anderson PL, Twohig MP, Feinstein AB, Chou Y, Wendell JW, et al. Help-seeking experiences and attitudes among African American, Asian American, and European American college students. Int J Adv Couns 2009 May 29;31(3):168-180. [doi: 10.1007/s10447-009-9076-2]
34. ten Have M, de Graaf R, Ormel J, Vilagut G, Kovess V, Alonso J, ESEMeD/MHEDEA 2000 Investigators. Are attitudes towards mental health help-seeking associated with service use? Results from the European Study of Epidemiology of Mental Disorders. Soc Psychiatry Psychiatr Epidemiol 2010 Feb;45(2):153-163 [FREE Full text] [doi: 10.1007/s00127-009-0050-4] [Medline: 19381427]
35. Hammer JH, Vogel DL, Heimerdinger-Edwards SR. Men's help seeking: examination of differences across community size, education, and income. Psych Men Masc 2013;14(1):65-75. [doi: 10.1037/a0026813]
36. Villatoro AP, Morales ES, Mays VM. Family culture in mental health help-seeking and utilization in a nationally representative sample of Latinos in the United States: The NLAAS. Am J Orthopsychiatry 2014 Jul;84(4):353-363 [FREE Full text] [doi: 10.1037/h0099844] [Medline: 24999521]
37. Hoyt DR, Conger RD, Valde JG, Weihs K. Psychological distress and help seeking in rural America. Am J Community Psychol 1997 Aug;25(4):449-470. [Medline: 9338954]
38. Currin JB, Hayslip B, Temple JR. The relationship between age, gender, historical change, and adults' perceptions of mental health and mental health services. Int J Aging Hum Dev 2011;72(4):317-341. [Medline: 21977677]
39. Nam SK, Chu HJ, Lee MK, Lee JH, Kim N, Lee SM. A meta-analysis of gender differences in attitudes toward seeking professional psychological help. J Am Coll Health 2010;59(2):110-116. [doi: 10.1080/07448481.2010.483714] [Medline: 20864437]
40. Komiya N, Good GE, Sherrod NB. Emotional openness as a predictor of college students' attitudes toward seeking psychological help. Journal Counsel Psych 2000;47(1):138-143. [doi: 10.1037/0022-0167.47.1.138]
41. Rime B. Emotion elicits the social sharing of emotion: theory and empirical review. Emotion Review 2009 Jan 01;1(1):60-85. [doi: 10.1177/1754073908097189]
42. Feeney BC, Collins NL. A new look at social support: a theoretical perspective on thriving through relationships. Pers Soc Psychol Rev 2015 May;19(2):113-147. [doi: 10.1177/1088868314544222] [Medline: 25125368]
43. Ingram KM, Betz NE, Mindes EJ, Schmitt MM, Smith NG. Unsupportive responses from others concerning a stressful life event: development of the Unsupportive Social Interactions Inventory. J Soc Clin Psychol 2001 Jun;20(2):173-207. [doi: 10.1521/jscp.20.2.173.22265]
44. Marigold DC, Cavallo JV, Holmes JG, Wood JV. You can't always give what you want: the challenge of providing social support to low self-esteem individuals. J Pers Soc Psychol 2014 Jul;107(1):56-80. [doi: 10.1037/a0036554] [Medline: 24956314]
45. Cutrona CE, Shaffer PA, Wesner KA, Gardner KA. Optimally matching support and perceived spousal sensitivity. J Fam Psychol 2007 Dec;21(4):754-758. [doi: 10.1037/0893-3200.21.4.754] [Medline: 18179347]
46. Horowitz LM, Krasnoperova EN, Tatar EG, Hansen MB, Person EA, Galvin KL, et al. The way to console may depend on the goal: experimental studies of social support. J Exp Soc Psychol 2001;37(1):61. [doi: 10.1006/jesp.2000.1435]
47. Schepers J, Wetzels M. A meta-analysis of the technology acceptance model: investigating subjective norm and moderation effects. Info Mgmt 2007 Jan;44(1):90-103. [doi: 10.1016/j.im.2006.10.007]
48. Featherman MS, Pavlou PA. Predicting e-services adoption: a perceived risk facets perspective. Int J Human-Comp Stud 2003 Oct;59(4):451-474. [doi: 10.1016/S1071-5819(03)00111-3]
49. Meuter ML, Ostrom AL, Roundtree RI, Bitner MJ. Self-service technologies: understanding customer satisfaction with technology-based service encounters. J Marketing 2000 Jul;64(3):50-64. [doi: 10.1509/jmkg.64.3.50.18024]
50. Bahmanziari T, Pearson J, Crosby L. Is trust important in technology adoption? A policy capturing approach. J Comp Info Systems 2003;43(4):46-54. [doi: 10.1080/08874417.2003.11647533]
51. Anderson M. Technology Device Ownership: 2015. Pew Research Center. 2015 Oct 29. URL: http://www.pewinternet.org/files/2015/10/PI_2015-10-29_device-ownership_FINAL.pdf [accessed 2016-05-20] [WebCite Cache ID 6heBX0TJ6]
52. Perrin A. Social Media Usage: 2005-2015. Pew Research Center. 2015 Oct 08. URL: http://www.pewinternet.org/files/2015/10/PI_2015-10-08_Social-Networking-Usage-2005-2015_FINAL.pdf [accessed 2016-05-20] [WebCite Cache ID 6heBchv2c]
53. Chin E, Felt A, Sekar V, Wagner D. Measuring user confidence in smartphone security and privacy. In: Proceedings of the Eighth Symposium on Usable Privacy and Security. 2012 Presented at: Symposium on Usable Privacy and Security; 2012; Washington, DC p. 1-16 URL: https://cups.cs.cmu.edu/soups/2012/proceedings/a1_Chin.pdf [doi: 10.1145/2335356.2335358]

XSL•FO
RenderX

54. Debatin B, Lovejoy J, Horn A, Hughes B. Facebook and online privacy: attitudes, behaviors, and unintended consequences. J Comp-Mediated Comm 2008;15(1):83-108. [doi: 10.1111/j.1083-6101.2009.01494.x]
55. Mturk. Amazon Mechanical Turk. URL: https://www.mturk.com/mturk/welcome [accessed 2015-05-20] [WebCite Cache ID 6YegV2iHN]
56. Buhrmester M, Kwang T, Gosling SD. Amazon's Mechanical Turk: a new source of inexpensive, yet high-quality, data? Perspect Psychol Sci 2011 Feb 03;6(1):3-5. [doi: 10.1177/1745691610393980]
57. Shapiro DN, Chandler J, Mueller PA. Using Mechanical Turk to study clinical populations. Clin Psychol Sci 2013 Jan 31;1(2):213-220. [doi: 10.1177/2167702612469015]
58. Willis GB. Cognitive Interviewing: A Tool for Improving Questionnaire Design. Thousand Oaks, CA: Sage; 2004.
59. Dakof GA, Taylor SE. Victims' perceptions of social support: what is helpful from whom? J Pers Soc Psychol 1990 Jan;58(1):80-89. [Medline: 2308075]
60. Dunkel Schetter C. Social support and cancer: findings based on patient interviews and their implications. J Soc Issues 1984;40:77-98. [doi: 10.1111/j.1540-4560.1984.tb01108.x]
61. Lehman DR, Ellard JH, Wortman CB. Social support for the bereaved: recipients' and providers' perspectives on what is helpful. J Consult Clin Psychol 1986;54(4):438-446. [doi: 10.1037/0022-006X.54.4.438]
62. Buhmann B, Rainwater L, Schmaus G, Smeeding TM. Equivalence scales, well-being, inequality and poverty: sensitivity estimates across ten countries using the Luxembourg Income Study database. Rev Income Wealth 1988;34(2):115-142. [doi: 10.1111/j.1475-4991.1988.tb00564.x]
63. Derogatis LR. BSI, Brief Symptom Inventory: Administration, Scoring, and Procedures Manual. Bloomington, MN: PsychCorp; 1993.
64. Müller JM, Postert C, Beyer T, Furniss T, Achtergarde S. Comparison of eleven short versions of the Symptom Checklist 90-Revised (SCL-90-R) for use in the assessment of general psychopathology. J Psychopathol Behav Assess 2009 Jun 9;32(2):246-254. [doi: 10.1007/s10862-009-9141-5]
65. van Buuren S, Groothuis-Oudshoorn K. mice: multivariate imputation by chained equations in R. J Stat Softw 2011;45(3). [doi: 10.18637/jss.v045.i03]
66. Rubin D. Multiple Imputation For Nonresponse In Surveys. Hoboken, NJ: Wiley; 1987.
67. Barnard J, Rubin DB. Miscellanea. Small-sample degrees of freedom with multiple imputation. Biometrika 1999 Dec 01;86(4):948-955. [doi: 10.1093/biomet/86.4.948]
68. Meng XL, Rubin DB. Performing likelihood ratio tests with multiply-imputed data sets. Biometrika 1992;79(1):103-111. [doi: 10.1093/biomet/79.1.103]
69. Cohen J, Cohen P, West SG, Aiken LS. Applied Multiple Regression/Correlation Analysis for the Behavioral Sciences. Mahwah, NJ: L. Erlbaum Associates; 2003.
70. Vogel DL, Wester SR, Larson L. Avoidance of counseling: psychological factors that inhibit seeking help. J Couns Devel 2007;85:410-422. [doi: 10.1002/j.1556-6678.2007.tb00609.x]
71. Taylor SE, Klein LC, Lewis BP, Gruenewald TL, Gurung RA, Updegraff JA. Biobehavioral responses to stress in females: tend-and-befriend, not fight-or-flight. Psychol Rev 2000 Jul;107(3):411-429. [Medline: 10941275]
72. Hall JA. Sex differences in friendship expectations: a meta-analysis. J Soc Persl Relat 2010 Dec 29;28(6):723-747. [doi: 10.1177/0265407510386192]
73. Good GE, Robertson JM, O'Neil JM, Fitzgerald LF, Stevens M, DeBord KA, et al. Male gender role conflict: psychometric issues and relations to psychological distress. J Counsel Psychol 1995;42(1):3-10. [doi: 10.1037/0022-0167.42.1.3]
74. Ybarra ML, Suman M. Help seeking behavior and the Internet: a national survey. Int J Med Inform 2006 Jan;75(1):29-41. [doi: 10.1016/j.ijmedinf.2005.07.029] [Medline: 16129659]
75. Czaja SJ, Charness N, Fisk AD, Hertzog C, Nair SN, Rogers WA, et al. Factors predicting the use of technology: findings from the Center for Research and Education on Aging and Technology Enhancement (CREATE). Psychol Aging 2006 Jun;21(2):333-352 [FREE Full text] [doi: 10.1037/0882-7974.21.2.333] [Medline: 16768579]
76. James DCS, Harville C, Whitehead N, Stellefson M, Dodani S, Sears C. Willingness of African American women to participate in e-health/m-health research. Telemed E-health 2016;22(3):191-197. [doi: 10.1089/tmj.2015.0071]
77. Sabogal F, Marin G, Otero-Sabogal R, Marin BV, Perez-Stable EJ. Hispanic familism and acculturation: what changes and what doesn't? Hisp J Behav Science 1987;9:397-412. [doi: 10.1177/07399863870094003]
78. Kouyoumdjian H, Zamboanga BL, Hansen DJ. Barriers to community mental health services for Latinos: treatment considerations. Clin Psychol Sci Prac 2003;10(4):394-422. [doi: 10.1093/clipsy.bpg041]
79. Clement S, Schauman O, Graham T, Maggioni F, Evans-Lacko S, Bezborodovs N, et al. What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. Psychol Med 2015 Jan;45(1):11-27. [doi: 10.1017/S0033291714000129] [Medline: 24569086]
80. Townes DL, Chavez-Korell S, Cunningham NJ. Reexamining the relationships between racial identity, cultural mistrust, help-seeking attitudes, and preference for a Black counselor. J Counsel Psych 2009;56(2):330-336. [doi: 10.1037/a0015449]
81. Conner KO, Copeland VC, Grote NK, Koeske G, Rosen D, Reynolds CF, et al. Mental health treatment seeking among older adults with depression: the impact of stigma and race. Am J Geriatr Psychiatry 2010 Jun;18(6):531-543 [FREE Full text] [doi: 10.1097/JGP.0b013e3181cc0366] [Medline: 20220602]

XSL•FO
RenderX

82. Ault-Brutus AA. Changes in racial-ethnic disparities in use and adequacy of mental health care in the United States, 1990–2003. Psychiatr Serv 2012 Jun;63(6):531-540. [doi: 10.1176/appi.ps.201000397] [Medline: 22422014]
83. Barbato A, D'Avanzo B. Efficacy of couple therapy as a treatment for depression: a meta-analysis. Psychiatr Q 2008 Jun;79(2):121-132. [doi: 10.1007/s11126-008-9068-0] [Medline: 18259866]
84. Dunning D, Heath C, Suls J. Flawed self-assessment: implications for health, education, and the workplace. Psychol Sci Public Interest 2004;5(3):69-106. [doi: 10.1111/j.1529-1006.2004.00018.x]
85. Swann WB. Self-Traps: The Elusive Quest for Higher Self-Esteem. New York, NY: Freeman; 1996.
86. Barth J, Munder T, Gerger H, Nüesch E, Trelle S, Znoj H, et al. Comparative efficacy of seven psychotherapeutic interventions for patients with depression: a network meta-analysis. PLoS Med 2013;10(5):e1001454 [FREE Full text] [doi: 10.1371/journal.pmed.1001454] [Medline: 23723742]

Abbreviations

BSI: Brief Symptom Inventory
CMH: Crowdsourcing Mental Health
IP: Internet protocol
MOOC: massive open online course
MTurk: Mechanical Turk
SES: socioeconomic status
YMCA: Young Men's Christian Association

Edited by G Eysenbach; submitted 25.05.15; peer-reviewed by B Carron-Arthur, M Nguyen; comments to author 24.01.16; revised version received 20.05.16; accepted 03.01.17; published 19.01.17.

Please cite as:
Bernecker SL, Banschback K, Santorelli GD, Constantino MJ
A Web-Disseminated Self-Help and Peer Support Program Could Fill Gaps in Mental Health Care: Lessons From a Consumer Survey
JMIR Ment Health 2017;4(1):e5
URL: http://mental.jmir.org/2017/1/e5/
doi:10.2196/mental.4751
PMID:28104578

©Samantha L Bernecker, Kaitlin Banschback, Gennarina D Santorelli, Michael J Constantino. Originally published in JMIR Mental Health (http://mental.jmir.org), 19.01.2017. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Mental Health, is properly cited. The complete bibliographic information, a link to the original publication on http://mental.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Social Skills Training for Adolescents With Autism Spectrum Disorder Using Facebook (Project Rex Connect): A Survey Study

McLeod Frampton Gwynette[1], MD; Danielle Morriss[2], MD; Nancy Warren[1], PhD; James Truelove[1], MSW; Jennifer Warthen[1], MSW; Charles Paul Ross[3], BS; George Mood[4], BA; Charlotte Anne Snook[5], BS; Jeffrey Borckardt[1,6,7], PhD

[1]Department of Psychiatry and Behavioral Sciences, Medical University of South Carolina, Charleston, SC, United States

[2]Brown University, Providence, RI, United States

[3]Department of Psychology, Loyola University of Maryland, Baltimore, MD, United States

[4]College of Charleston, Charleston, SC, United States

[5]Clemson University, Clemson, SC, United States

[6]Department of Anesthesia and Perioperative Medicine, Medical University of South Carolina, Charleston, SC, United States

[7]Ralph H. Johnson VAMC, Charleston, SC, United States

Corresponding Author:
McLeod Frampton Gwynette, MD
Department of Psychiatry and Behavioral Sciences
Medical University of South Carolina
67 President Street
5th Floor, South Tower, Room 509
Charleston, SC, 29425
United States
Phone: 1 843 792 9162
Fax: 1 843 792 4190
Email: gwynette@musc.edu

Abstract

Background: Adolescents with autism spectrum disorder (ASD) spend more time using electronic screen media than neurotypical peers; preliminary evidence suggests that computer-assisted or Web-based interventions may be beneficial for social skills acquisition. The current generation of adolescents accesses the Internet through computers or phones almost daily, and Facebook is the most frequently used social media platform among teenagers. This is the first research study to explore the use of Facebook as a therapeutic tool for adolescents with ASD.

Objective: To study the feasibility and clinical impact of using a Web-based social platform in combination with social skills training for adolescents with ASD.

Methods: This pilot study enrolled 6 participants (all males; mean age 14.1 years) in an online social skills training group using Facebook. Data was collected on the participants' social and behavioral functioning at the start and conclusion of the intervention. Outcome measures included the Social Responsiveness Scale-2, the Social Skills Improvement System Rating Scale, and the Project Rex Parent Survey. Participants were surveyed at the conclusion of the intervention regarding their experience.

Results: No statistically significant differences in measurable outcomes were observed. However, the online addition of Facebook was well received by participants and their parents. The Facebook intervention was able to be executed with a careful privacy protocol in place and at minimal safety risk to participants.

Conclusions: The utilization of Facebook to facilitate delivery of social skills training for adolescents with ASD appears to be feasible, although the clinical impact of such an addition is still unclear. It is important to note that social difficulties of participants persisted with the addition of the online platform and participants still required assistance to engage with peers in an online environment. A Web-based intervention such as the one utilized in this study has the potential to reach a mass number of patients with ASD and could address disparities in access to in-person treatment services. However, the complexity and evolving nature of Facebook's website and privacy settings leads to a number of unique online safety concerns that may limit its clinical utility. Issues encountered in our study support the development of an alternative and closed Web-based social platform designed specifically for the target audience with ASD; this platform could be a safer and more easily moderated setting for aiding in social

XSL•FO
RenderX

skills development. Despite a small sample size with no statistically significant improvements of target symptoms, the use of electronic screen media as a therapeutic tool for adolescents with ASD is still a promising area of research warranting further investigation. Our study helps inform future obstacles regarding feasibility and safety.

(JMIR Ment Health 2017;4(1):e4) doi:10.2196/mental.6605

KEYWORDS

autism; social media; social skills

Introduction

Autism spectrum disorder (ASD) affects 1 in 68 children in the United States and is characterized by deficits in social communication; impaired social interactions; and repetitive and/or restricted interests, behaviors, and activities [1,2]. Adolescence is a time of particular risk and opportunity for patients and families affected by ASD, as the presence or absence of effective interventions can profoundly influence a successful transition into adulthood. These services often include group social skills training (SST), an intervention with demonstrated effectiveness in improving core ASD symptoms and social deficits in high-functioning adolescents [3-6].

Currently, SST groups are run in person, usually weekly over a 2-4-month period. However, access to traditional SST programs is limited, mirroring existing gaps for other ASD services that are often related to geographic and socioeconomic disparities [7]. Multiple published studies of interventions using Facebook have demonstrated the social media platform's capability to reach other underserved patient populations [8-10], indicating that Facebook may also be a viable modality for reaching patients with ASD.

Interventions utilizing Facebook technology have been demonstrated to be effective in treating numerous other mental health conditions [11-19]. A recent study found 92% of US teens go online daily [20] and 71% of teens ages 13-17 use Facebook [21]. Research of adolescents with ASD reflects a similarly high amount of use [22], so Web-based care has the potential to be desirable to adolescents with ASD, which could improve interest or time spent utilizing a therapeutic tool. Studies of social media use by adolescents with ASD also demonstrate they most often interact online with acquaintances they previously met in person [23] and may improve social interactions [22], leading to support of its use in conjunction with SST.

For these reasons, the investigators hypothesized that utilization of Facebook to deliver SST for adolescents with ASD would be feasible and acceptable to participants and possibly improve clinical outcomes. We define feasibility as a capability of being executed and we define acceptability as favorable ratings on participant satisfaction surveys. This pilot study is unique as there are no other published studies to date that augment face-to-face social skills instruction with a social networking site (SNS) component or curriculum.

Methods

Participants

Participants were recruited offline from within the Project Rex clinic, an SST program at the Medical University of South Carolina serving adolescents with ASD along with their families [24]. A survey of Project Rex parents indicated most would be interested in having their child use a Web-based social network to build social skills and keep in contact with friends. Enrolled participants consisted of 6 males ranging from 12 to 19 years of age (mean 14.1 years), with a previous diagnosis of ASD and an IQ in the normal range.

Pre- and posttreatment surveys of participants, parents, and teachers (or other responsible adult) were administered via REDCap [25], a Web-based survey and data collection platform. Outcome measures included the Social Responsiveness Scale-2 (SRS-2) [26]; the Social Skills Improvement System Rating Scale (SSiS-RS) [27]; the Project Rex Parent Survey, a 12-item Likert scale measuring utilization of various social skills in the past 2 weeks; and the Project Rex Connect Participant Survey, a 10-item *yes/no* survey on the participants' opinions about the treatment received.

Procedures

Participants were recruited from the Project Rex clinical program and were followed for a period of 8 weeks. The participants were enrolled in a closed, invite-only *group* within Facebook facilitated by the investigators for 8 weeks. Online groups within Facebook provide a platform where users can post comments, pictures, and videos and have discussions. Each participant was directly aided by investigators to set up their account with a deidentified username and specific privacy settings. Participants were previously acquainted with each other from prior participation in the live Project Rex SST, which they had completed 2 weeks prior to study enrollment. The Facebook group curriculum included weekly shared topics and encouraged the use of social skills taught in the Project Rex SST, such as starting conversations, exchanging information with peers, and giving compliments.

To maximize the likelihood of safe and appropriate Facebook use, participants and their parents were provided with education and training on use of the account, online etiquette, and maintenance of privacy settings. Inappropriate use included adverse messaging, inappropriate friend requests, and cyberbullying. The participants were informed of the study rule that any sharing of photos or videos from a private collection or from the Internet would require parental approval prior to the participant posting it. All group settings were placed on Facebook's option of *secret group* to minimize the risk of a

XSL•FO
RenderX

breach in confidentiality (see Figure 1), which meant information posted by participants was not publicly available. Participants were also unable to invite new group members due to privacy settings. Investigators and participants were Facebook *friends* with one another and no one else, further limiting access of individuals outside the study (see Figure 2).

The participants were free to use Facebook as they desired within the study guidelines. In an attempt to encourage social engagement, participants were asked to log onto their accounts for a minimum of 6 days a week with a minimum time frame of 15 minutes per Facebook session. The investigators provided a weekly topic of discussion and also posted general reminders drawn from the Project Rex curriculum on how to initiate and maintain a conversation.

Following safety protocols, a study investigator reviewed all posts on a daily basis. Investigators maintained sole access to each account's email address and had shared access to passwords, allowing access to intervene if any participant posted inappropriate material or attempted to obtain friends outside of Project Rex. Due to account settings, Facebook would automatically send an email if there were any attempts at changing the account password or accepting friend requests from outside members. All participant email accounts were checked on a daily basis.

Figure 1. Screenshot of Facebook group privacy setting utilized in this study.

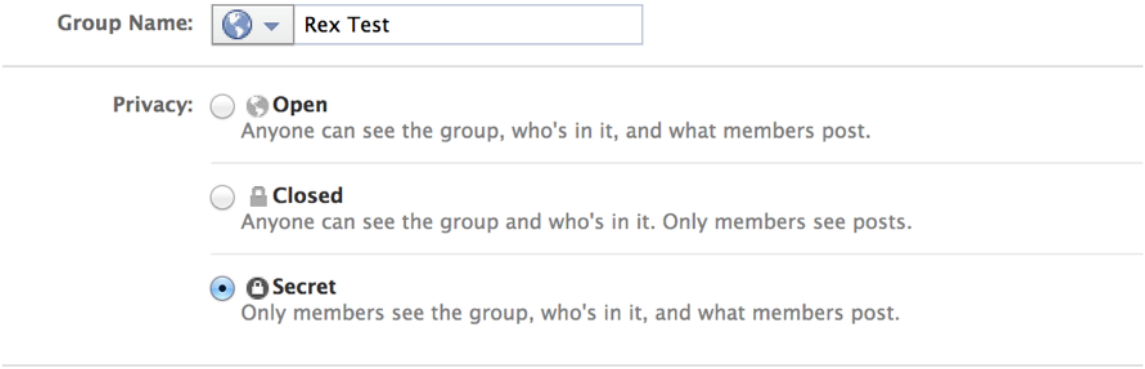
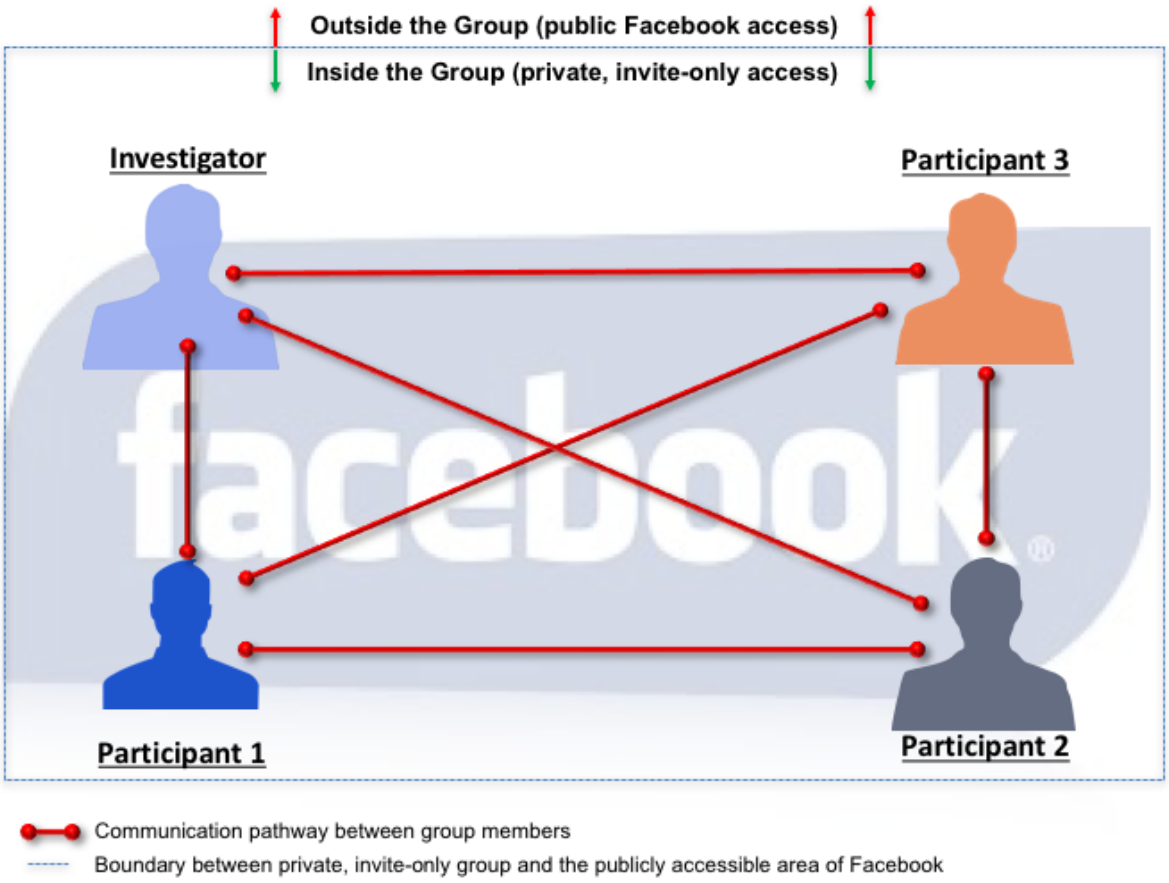


Figure 2. Overview of the secret, private Facebook group utilized in this study.



XSL•FO
RenderX

Results

Upon the conclusion of the study, there were no statistically significant differences in pretreatment and posttreatment measures according to the parent- and teacher-completed SRS-2; the parent-, teacher-, and participant-completed SSiS-RS; or the Project Rex Parent Survey. Outcome measures of this study were limited by the small sample size. Results of the participant experience survey indicate high satisfaction and acceptability rates. A total of 80%-100% of participants (N=5) selected "yes," indicating complete satisfaction, for each item. One participant did not complete the participant survey (see Table 1).

Table 1. Results of the participant satisfaction survey (N=5).

Question	Participants replying "yes," n (%)
I enjoyed my participation in this group.	4 (80)
I practiced introducing myself to others in this group.	4 (80)
I practiced my "starting a conversation" skills in this group.	5 (100)
I practiced my listening skills in this group.	4 (80)
I practiced my "asking a question" skills in this group.	4 (80)
I practiced my "having a conversation" skills in this group.	4 (80)
I believe my social skills improved from my participation in this group.	5 (100)
I believe I have made friends from this group experience.	4 (80)
I will keep in contact with the other group members.	4 (80)
I would repeat this group.	4 (80)
I would recommend the Project Rex program to my peers or friends.	4 (80)

There were no adverse events during the course of this study, including breaches of confidentiality, cyberbullying, or inappropriate contact with individuals outside of the Facebook group. One participant did join a fan club and required multiple redirections, twice by Facebook message and once by telephone, in order to comply with the study protocol. Participants tolerated the intervention well and they all completed the study protocol.

Discussion

This is the first research study to explore the use of Facebook as a therapeutic tool for adolescents with ASD. The results of this pilot study show that the utilization of Facebook to facilitate delivery of social skills training for adolescents with ASD appears to be feasible, although the clinical impact of such an addition is still unclear. Our study was conducted safely and confidentially, with the execution of many privacy measures not typical of community Facebook use. While there were no statistically significant effects of the Facebook intervention, it is very likely that this pilot study was significantly underpowered by having only 6 participants.

There were several interesting observations gathered from this pilot study that should influence follow-up studies of a similar nature. Investigators found participants' impaired social functioning was observable even in an online environment. That is, computers and Web-based social media did not *mask* the symptoms of ASD in this study. Future studies could potentially begin with a basic training session aimed at the participants' core deficits and ways to generalize skills acquired from the live groups to the online environment. For example, investigators noted participants in the Facebook group frequently posted material of interest to them, but not necessarily to others. In future studies, it may be beneficial to teach participants to consider what others may be interested in viewing. In this way, researchers could potentially address deficits in the ability of individuals with ASD to experience the world through the perspective of another person, a core deficit related to "theory of mind" [28,29]. Although not utilized in this study, collecting data on the frequency and quality of participants' posts while online could help further characterize patterns of social media usage in individuals with ASD, assist in measuring potential response to Web-based social skills training, and serve as a useful feedback tool for the participants. Also not investigated in this study was observer-expectancy effect. It is likely that investigators' monitoring techniques had some effect on subjects' behavioral reactivity, although whether this positively or negatively impacted subject satisfaction and participation warrants further exploration.

The privacy restraints used in this study represent a potential trade-off between the engagement and use of Facebook by the participants and security and confidentiality. The privacy restrictions allowed participants to have a more controlled and supported online experience versus the opportunity to practice newly acquired skills in a more anonymous virtual platform. Given the extensive privacy features used during this study, Facebook's evolving privacy policies, and the utility of having a closed system designed as an adjunct for SST, it may be beneficial to develop a new, self-contained SNS geared specifically toward ASD youth and adults. This would provide the opportunity for more secure interactions between participants as it would lessen the risk of *public* posting of information that could happen with Facebook use. If a private site was utilized, investigators would also have increased ability to moderate the online environment if inappropriate posting did occur.

A direction suggested by multiple participants was a gaming component of the online experience. It may be beneficial from an engagement standpoint to incorporate gaming into an online

XSL•FO
RenderX

social group for patients with ASD. Evidence suggests patients with ASD most frequently visit websites related to gaming [22] and the potential research directions for therapeutic gaming is largely unexplored. This would represent another benefit of developing a self-contained SNS geared specifically toward ASD youth and adults, as a gaming component could be specifically targeted to maximize opportunities for social interaction.

Given its potential to reach a vast number of patients with ASD, especially those who are underserved, the feasibility and effectiveness of using an SNS to enhance social functioning warrants further investigation. Potential benefits of adding such a component include the increased ability to engage and attract youth with ASD and that the nature of social networking allows for an extended reach to additional populations who may not typically be able to access SST. Ideally, an SNS platform could be used to reinforce new friendships established with SST peers and serve as a virtual training ground or "dress rehearsal" for the development of live friendships outside of the clinical realm. If successfully implemented, an SNS platform can be a powerful modality both for the delivery of SST and for addressing disparities in access to clinical services for patients and families affected by ASD.

Acknowledgments

The investigators wish to thank the Medical University of South Carolina Interprofessional Institute who funded the work reported in this article, making this project possible. In addition, the investigators extend their thanks to Teri Lynn Herbert, research librarian at the Medical University of South Carolina, and Dr Michael Madson in the Medical University of South Carolina Writing Center.

Conflicts of Interest

None declared.

References

1. Christensen DL, Baio J, Van Naarden Braun K, Bilder D, Charles J, Constantino JN, Centers for Disease Control and Prevention (CDC). Prevalence and characteristics of autism spectrum disorder among children aged 8 years--Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012. MMWR Surveill Summ 2016 Apr 1;65(3):1-23. [doi: 10.15585/mmwr.ss6503a1] [Medline: 27031587]
2. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edition. Arlington, VA: American Psychiatric Publishing; 2013.
3. Laugeson EA, Frankel F, Gantman A, Dillon AR, Mogil C. Evidence-based social skills training for adolescents with autism spectrum disorders: The UCLA PEERS program. J Autism Dev Disord 2012 Jun;42(6):1025-1036. [doi: 10.1007/s10803-011-1339-1] [Medline: 21858588]
4. Laugeson EA, Frankel F, Mogil C, Dillon AR. Parent-assisted social skills training to improve friendships in teens with autism spectrum disorders. J Autism Dev Disord 2009 Apr;39(4):596-606. [doi: 10.1007/s10803-008-0664-5] [Medline: 19015968]
5. Yoo H, Bahn G, Cho I, Kim E, Kim J, Min J, et al. A randomized controlled trial of the Korean version of the PEERS(®) parent-assisted social skills training program for teens with ASD. Autism Res 2014 Feb;7(1):145-161. [doi: 10.1002/aur.1354] [Medline: 24408892]
6. Rao PA, Beidel DC, Murray MJ. Social skills interventions for children with Asperger's syndrome or high-functioning autism: A review and recommendations. J Autism Dev Disord 2008 Feb;38(2):353-361. [doi: 10.1007/s10803-007-0402-4] [Medline: 17641962]
7. Elder JH, Brasher S, Alexander B. Identifying the barriers to early diagnosis and treatment in underserved individuals with autism spectrum disorders (ASD) and their families: A qualitative study. Issues Ment Health Nurs 2016 Jun;37(6):412-420. [doi: 10.3109/01612840.2016.1153174] [Medline: 27070190]
8. Martinez O, Wu E, Shultz AZ, Capote J, López RJ, Sandfort T, et al. Still a hard-to-reach population? Using social media to recruit Latino gay couples for an HIV intervention adaptation study. J Med Internet Res 2014;16(4):e113 [FREE Full text] [doi: 10.2196/jmir.3311] [Medline: 24763130]
9. Pedrana A, Hellard M, Gold J, Ata N, Chang S, Howard S, et al. Queer as F**k: Reaching and engaging gay men in sexual health promotion through social networking sites. J Med Internet Res 2013;15(2):e25 [FREE Full text] [doi: 10.2196/jmir.2334] [Medline: 23391459]
10. Prescott TL, Phillips IG, DuBois LZ, Bull SS, Mustanski B, Ybarra ML. Reaching adolescent gay, bisexual, and queer men online: Development and refinement of a national recruitment strategy. J Med Internet Res 2016;18(8):e200 [FREE Full text] [doi: 10.2196/jmir.5602] [Medline: 27492781]
11. Cheung YT, Chan CH, Lai CJ, Chan WF, Wang MP, Li HC, et al. Using WhatsApp and Facebook online social groups for smoking relapse prevention for recent quitters: A pilot pragmatic cluster randomized controlled trial. J Med Internet Res 2015;17(10):e238 [FREE Full text] [doi: 10.2196/jmir.4829] [Medline: 26494159]

XSL•FO
RenderX

12. Cole-Lewis H, Perotte A, Galica K, Dreyer L, Griffith C, Schwarz M, et al. Social network behavior and engagement within a smoking cessation Facebook page. J Med Internet Res 2016;18(8):e205 [FREE Full text] [doi: 10.2196/jmir.5574] [Medline: 27485315]
13. Duke JC, Hansen H, Kim AE, Curry L, Allen J. The use of social media by state tobacco control programs to promote smoking cessation: A cross-sectional study. J Med Internet Res 2014;16(7):e169 [FREE Full text] [doi: 10.2196/jmir.3430] [Medline: 25014311]
14. Ramo DE, Thrul J, Chavez K, Delucchi KL, Prochaska JJ. Feasibility and quit rates of the Tobacco Status Project: A Facebook smoking cessation intervention for young adults. J Med Internet Res 2015;17(12):e291 [FREE Full text] [doi: 10.2196/jmir.5209] [Medline: 26721211]
15. Struik LL, Baskerville NB. The role of Facebook in Crush the Crave, a mobile- and social media-based smoking cessation intervention: Qualitative framework analysis of posts. J Med Internet Res 2014;16(7):e170 [FREE Full text] [doi: 10.2196/jmir.3189] [Medline: 25016998]
16. Thrul J, Klein AB, Ramo DE. Smoking cessation intervention on Facebook: Which content generates the best engagement? J Med Internet Res 2015;17(11):e244 [FREE Full text] [doi: 10.2196/jmir.4575] [Medline: 26561529]
17. Crosier BS, Brian RM, Ben-Zeev D. Using Facebook to reach people who experience auditory hallucinations. J Med Internet Res 2016;18(6):e160 [FREE Full text] [doi: 10.2196/jmir.5420] [Medline: 27302017]
18. Flaudias V, de Chazeron I, Zerhouni O, Boudesseul J, Begue L, Bouthier R, et al. Preventing alcohol abuse through social networking sites: A first assessment of a two-year ecological approach. J Med Internet Res 2015;17(12):e278 [FREE Full text] [doi: 10.2196/jmir.4233] [Medline: 26681577]
19. Park S, Lee SW, Kwak J, Cha M, Jeong B. Activities on Facebook reveal the depressive state of users. J Med Internet Res 2013;15(10):e217 [FREE Full text] [doi: 10.2196/jmir.2718] [Medline: 24084314]
20. Duggan M, Ellison NB, Lampe C, Lenhart A, Madden M. Pew Research Center's Internet & American Life Project. Washington, DC: Pew Research Center; 2015 Jan 09. Social media update 2014 URL: http://www.pewinternet.org/2015/01/09/social-media-update-2014/ [accessed 2016-01-09] [WebCite Cache ID 6jatE5FZD]
21. Lenhart A. Pew Research Center's Internet & American Life Project. Washington, DC: Pew Research Center; 2015 Apr 09. Teens, social media and technology overview 2015 URL: http://www.pewinternet.org/2015/04/09/teens-social-media-technology-2015/ [accessed 2016-08-10] [WebCite Cache ID 6jf5QwHFH]
22. Kuo MH, Orsmond GI, Coster WJ, Cohn ES. Media use among adolescents with autism spectrum disorder. Autism 2014 Nov;18(8):914-923. [doi: 10.1177/1362361313497832] [Medline: 24142797]
23. Reich SM, Subrahmanyam K, Espinoza G. Friending, IMing, and hanging out face-to-face: Overlap in adolescents' online and offline social networks. Dev Psychol 2012 Mar;48(2):356-368. [doi: 10.1037/a0026980] [Medline: 22369341]
24. Project Rex. URL: https://www.projectrex.org/ [accessed 2017-01-13] [WebCite Cache ID 6nUHhA67S]
25. Project REDCap. 2016. URL: https://projectredcap.org [accessed 2016-09-02] [WebCite Cache ID 6kEJqRIAB]
26. Constantino JM. The Social Responsiveness Scale, Second Edition (SRS-2) Manual. Los Angeles, CA: Western Psychological Services; 2012.
27. Gresham FM, Elliott SN. Social Skills Improvement System (SSiS) Rating Scales. Minneapolis, MN: NCS Pearson; 2008.
28. Baron-Cohen S, Leslie AM, Frith U. Does the autistic child have a “theory of mind?”. Cognition 1985 Oct;21(1):37-46. [Medline: 2934210]
29. Bauminger N, Kasari C. Brief report: Theory of mind in high-functioning children with autism. J Autism Dev Disord 1999 Feb;29(1):81-86. [Medline: 10097997]

Abbreviations

ASD: autism spectrum disorder
SNS: social networking site
SRS-2: Social Responsiveness Scale-2
SSiS-RS: Social Skills Improvement System Rating Scale
SST: social skills training

Edited by J Torous; submitted 13.09.16; peer-reviewed by N Nazneen, D Ben-Zeev; comments to author 27.09.16; revised version received 20.12.16; accepted 04.01.17; published 23.01.17.

Please cite as:
Gwynette MF, Morriss D, Warren N, Truelove J, Warthen J, Ross CP, Mood G, Snook CA, Borckardt J
Social Skills Training for Adolescents With Autism Spectrum Disorder Using Facebook (Project Rex Connect): A Survey Study
JMIR Ment Health 2017;4(1):e4
URL: http://mental.jmir.org/2017/1/e4/
doi:10.2196/mental.6605
PMID:28115297

XSL•FO
RenderX

©McLeod Frampton Gwynette, Danielle Morriss, Nancy Warren, James Truelove, Jennifer Warthen, Charles Paul Ross, George Mood, Charlotte Anne Snook, Jeffrey Borckardt. Originally published in JMIR Mental Health (http://mental.jmir.org), 23.01.2017. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Mental Health, is properly cited. The complete bibliographic information, a link to the original publication on http://mental.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Using Real-Time Social Media Technologies to Monitor Levels of Perceived Stress and Emotional State in College Students: A Web-Based Questionnaire Study

Sam Liu[1], PhD; Miaoqi Zhu[1], PhD; Dong Jin Yu[2], MCompSc; Alexander Rasin[3], PhD; Sean D Young[1], PhD

[1]Institute for Prediction Technology, Department of Family Medicine, University of California, Los Angeles, CA, United States

[2]Department of Computer Science, University of California, Los Angeles, CA, United States

[3]College of Computing and Digital Media, DePaul University, Chicago, IL, United States

Corresponding Author:
Sam Liu, PhD
Institute for Prediction Technology
Department of Family Medicine
University of California
10880 Wilshire Blvd Suite 1800
Los Angeles, CA, 90064
United States
Phone: 1 424 346 4485
Fax: 1 424 346 4485
Email: samliu@mednet.ucla.edu

Abstract

Background: College can be stressful for many freshmen as they cope with a variety of stressors. Excess stress can negatively affect both psychological and physical health. Thus, there is a need to find innovative and cost-effective strategies to help identify students experiencing high levels of stress to receive appropriate treatment. Social media use has been rapidly growing, and recent studies have reported that data from these technologies can be used for public health surveillance. Currently, no studies have examined whether Twitter data can be used to monitor stress level and emotional state among college students.

Objective: The primary objective of our study was to investigate whether students' perceived levels of stress were associated with the sentiment and emotions of their tweets. The secondary objective was to explore whether students' emotional state was associated with the sentiment and emotions of their tweets.

Methods: We recruited 181 first-year freshman students aged 18-20 years at University of California, Los Angeles. All participants were asked to complete a questionnaire that assessed their demographic characteristics, levels of stress, and emotional state for the last 7 days. All questionnaires were completed within a 48-hour period. All tweets posted by the participants from that week (November 2 to 8, 2015) were mined and manually categorized based on their sentiment (positive, negative, neutral) and emotion (anger, fear, love, happiness) expressed. Ordinal regressions were used to assess whether weekly levels of stress and emotional states were associated with the percentage of positive, neutral, negative, anger, fear, love, or happiness tweets.

Results: A total of 121 participants completed the survey and were included in our analysis. A total of 1879 tweets were analyzed. A higher level of weekly stress was significantly associated with a greater percentage of negative sentiment tweets (beta=1.7, SE 0.7; *P*=.02) and tweets containing emotions of fear (beta=2.4, SE 0.9; *P*=.01) and love (beta=3.6, SE 1.4; *P*=.01). A greater level of anger was negatively associated with the percentage of positive sentiment (beta=–1.6, SE 0.8; *P*=.05) and tweets related to the emotions of happiness (beta=–2.2, SE 0.9; *P*=.02). A greater level of fear was positively associated with the percentage of negative sentiment (beta=1.67, SE 0.7; *P*=.01), particularly a greater proportion of tweets related to the emotion of fear (beta=2.4, SE 0.8; *P*=.01). Participants who reported a greater level of love showed a smaller percentage of negative sentiment tweets (beta=–1.3, SE 0.7; *P*=0.05). Emotions of happiness were positively associated with the percentage of tweets related to the emotion of happiness (beta=–1.8, SE 0.8; *P*=.02) and negatively associated with percentage of negative sentiment tweets (beta=–1.7, SE 0.7; *P*=.02) and tweets related to the emotion of fear (beta=–2.8, SE 0.8; *P*=.01).

Conclusions: Sentiment and emotions expressed in the tweets have the potential to provide real-time monitoring of stress level and emotional well-being in college students.

XSL•FO
RenderX

(JMIR Ment Health 2017;4(1):e2) doi:10.2196/mental.5626

KEYWORDS

social media; twitter messaging, stress; monitoring

Introduction

Background

College can be stressful for many freshmen as they cope with a variety of academic, personal, and social pressures [1]. Although not all stress is negative, a certain level of stress can be beneficial to help improve performance. However, too much stress can adversely affect health [2]. In the annual survey of the American Freshman, the number of students reported feeling overwhelmed and stressed has increased steadily in the last decade [3]. Over 50% of college students suffer significant levels of stress during a typical college semester [4].

High levels of stress is known to negatively impact a person's emotional well-being by increasing the degree of negative emotions (eg, anger, fear) and decreasing the levels of positive emotions (eg, love, happiness) [5]. Increased levels of stressful life events have been shown to be associated with anxiety, depression, and suicidal ideation in college students [6-8]. Excess stress can also negatively affect physical health, such as increased sleep disturbances, decreased immune function, and loss of appetite [9-11]. Consequently, there is a need to find innovative and cost-effective strategies to help identify those students experiencing high levels of stress and negative emotions early on so that they can receive the appropriate treatment in order to prevent future mental illnesses [4].

Social media use, such as Twitter and Facebook, has been rapidly growing, and research has already shown that data from these technologies can be used for novel approaches to public health surveillance [12-15]. Twitter usage among young adults has increased 16% from 2012 to 2014. Currently, 32% of adults of the ages 18-29 years use Twitter, and the usage is expected to increase steadily in the future [12-15].

People often have the need to share their emotions and experiences [16]. Researchers have theorized that emotional sharing may fulfill a socio-affective need by eliciting attention, affection, and social support. Consequently, this may help individuals cope with their emotions and provide an immediate relief [16]. Users often share their thoughts, feelings, and opinions on these social media platforms, and as a result, social media data may be used to provide real-time monitoring of stress and emotional state among college students [17]. Previous studies have shown that Twitter data can be used to monitor a wide range of health outcomes, such as detecting human immunodeficiency virus infection outbreaks and predicting an individual's risk of depression [12,18]. For example, De Choudhury et al conducted one of the first studies that used an individual's tweets to predict the risk of depression [18]. The authors found that certain features extracted from a person's tweets collected over a 1-year period were highly associated with the risk of depression in adults, such as raised negative sentiment in the tweets, frequent mentions of antidepressant medication, and greater expression of religious involvement. Currently, no studies have examined whether Twitter data can be used to monitor stress level and emotional state among college students. Studying this topic is important because the large amount of social media data from college students' frequent use of social media can be used to help university officials and researchers monitor and reduce stress among college students [19].

Objectives

The primary objective of our study, therefore, was to investigate whether students' perceived levels of stress were associated with the sentiment and emotions of their tweets. The secondary objective was to explore whether students' emotional state was associated with the sentiment and emotions of their tweets. Because of the high level of stress among incoming freshman students, we decided to study this population in their first quarter of school. We hypothesized that higher levels of stress, anger, and fear would be associated with a greater proportion of tweets with negative sentiment and emotions (anger and fear). Conversely, we hypothesized that higher levels of love and happiness would be associated with a greater proportion of tweets with positive sentiment and emotions (love and happiness).

Methods

Overview

This was a longitudinal observational study that took place during the fall semester of 2015. A total of 181 first-year undergraduate freshman students at University of California, Los Angeles (UCLA) were recruited. In order to be eligible for the study, participants were required to be freshmen, have a Twitter account, post at least two tweets per week, and be willing to share their Twitter handle. Data collected between November 2 and November 8, 2015, were extracted for analysis. Ethics approval was obtained from the UCLA Research Ethics Board.

Recruitment and Study Protocol

Participants were informed about the study through flyers on social media websites and on UCLA campus between September 14 and October 12, 2015. Participants who provided consent were asked to complete a Web-based questionnaire that assessed their levels of stress and emotional state for the last 7 days. Psychometric measures of stress were constructed to assess the extent to which individuals find their lives to be overloaded. Participants were to identify their overall levels of stress and sources of stress for the last 7 days on a 1-5 Likert scale (1=not at all stress, 2=low stress, 3=average stress, 4=high stress, 5=extremely high stress). Previous research has identified basic human emotions, which included feelings of anger, fear, love, and happiness [20,21]. Participants were asked to rate their emotional state (feelings of anger, fear, love, and happiness) for the last 7 days on a 1-5 Likert scale (1=extremely low,

XSL•FO
RenderX

2=low, 3=somewhat, 4=strong, 5=extremely strong). All questionnaires were completed within a 48-hour period. Demographic information was collected, including age, gender, ethnicity, and students' area of study. All tweets posted by the participants from that week (November 2 to 8, 2015) were mined and manually categorized based on their sentiment (positive, negative, neutral) and emotion (anger, fear, love, happiness) expressed. Participants were rewarded with a US $5 gift card for completing the survey.

Twitter Sentiment and Emotion Analysis

All participants' tweets were extracted using a Twitter streaming application programming interface. To ensure the accuracy of the coding, a random subset of the tweets (n=100) was selected first. These tweets were then coded independently by 2 domain experts (SL and SY) based on the tweets' sentiment and emotions. The interrater reliability was .83. In the event of conflicting opinions, resolution was achieved by consensus. The domain expert (SL) then manually coded the remainder of the tweets.

The tweets were first coded as expressing positive, negative, and neutral sentiments. To ensure the quality of the coding, a publicly available set of labeled tweets (n=150) by workers on Amazon's Mechanical Turk was used as a reference prior to sentiment labeling [22]. The tweets were then categorized into 4 primary emotions of anger, fear, love, and happiness in order to reflect the emotional state that the students felt during the week. Based on previous work by Ekman's list of basic emotions [21] and Parrots' classification of emotions [23], we created a coding scheme to categorize other emotions that led to or could be included in the 4 primary emotions of anger, fear, love, and happiness. For example, (1) emotion of love also included emotions of affection, kindness, passion, and longing; (2) emotion of happiness also included emotions of joy, cheerfulness, and excitement; (3) emotion of anger also included emotions of disgust, torment, and judgment; (4) emotion of fear also included emotions of nervousness, stress, and sadness. Ambiguous tweets that could not be understood were labeled as unknown. Retweets were excluded from the analysis, as it was a challenge to interpret the sentiment and emotions. For example, it was unclear whether the participants were retweeting because they shared the sentiment of the person who originally tweeted it or they were retweeting for support toward that person.

Statistical Analysis

Descriptive statistics were used to summarize baseline demographic characteristics, levels of stress, emotional well-being, and the number of positive, neutral, negative, anger, fear, love, and happiness tweets. Ordinal regressions were used to assess whether weekly levels of stress and emotional states (anger, fear, love, happiness) were associated with the percentage of positive, neutral, negative, anger, fear, love, or happiness tweets. Due to the small number of participants who scored either 1 (extremely low) or 5 (extremely high) on the Likert scales for weekly levels of stress and emotional well-being, it is common to combine the cells [24]. We combined scores of 1 (extremely low) with 2 (low) and 5 (extremely high) with 4 (high). As result, the dependent variable in the ordinal regression for self-report levels of stress and emotional state contained 3 levels (low, average, and high). In order to account for the differences in the number of tweets people posted, we calculated the percentage of tweets expressing positive, negative, and neutral sentiments, and emotions of anger, fear, love, and happiness to be included in the regression analyses. Based on previous research, all models were adjusted for covariates including age, ethnicity, and gender [25-28]. In assessing overall model fit, the goodness-of-fit measure (–2 log likelihood) was used. Smaller values of the –2 log likelihood measure indicated better model fit [29]. Data were analyzed using SPSS version 21 (IBM Corp). Data were reported as mean (SD), and statistical significance was assumed at $P \leq .05$.

Results

Participants

A total of 121 participants completed the survey and were included in our analysis. Baseline participant characteristics are presented in Table 1. The prevalence of white and Asian ethnic groups in this study were underrepresented, whereas African American and Latino ethnic groups were overrepresented in the distribution in UCLA [30]. This may be due to the popularity of Twitter usage among African Americans and Latinos [19].

Stress Level and Emotional State

The distribution of stress level and emotional state is displayed in Table 2. The majority of participants (~80%) reported average or high levels of stress. The most commonly reported stressors by students were related to attending class, completing homework, and dealing with self-image. Overall, the majority of participants (~50%-70%) reported lower to average levels of anger and fear, and average to higher levels of love and happiness. Stress was significantly correlated with anger (r=.17, P=.05) and fear (r=.51, P<.001). Emotions of anger were also positively correlated with fear (r=.41, P<.001). Meanwhile, emotions of happiness were significantly correlated with love (r=.52, P<.001).

XSL•FO
RenderX

Table 1. Baseline characteristics.

Characteristic (N=121)	Mean (SD) or n (%)
Age	18.14 (SD 0.49)
Gender	
Female	76 (62.8%)
Ethnicity	
White	25 (20.7%)
African American	13 (10.7%)
Latino	35 (28.9%)
Asian	33 (27.3%)
Other	15 (12.4%)
Areas of study	
Health science	55 (45.4%)
Business	10 (8.3%)
Math or engineering	15 (12.4%)
Social science or arts	24 (19.8%)
Undeclared	17 (14.0%)

Table 2. Summary levels of stress and emotions.

Stress levels and emotions	Low, n (%)	Average, n (%)	High, n (%)
Overall stress	26 (21.5%)	48 (39.7%)	47 (38.8%)
Emotions of anger	68 (56.1%)	32 (26.4%)	21 (17.4%)
Emotions of fear	61 (50.4%)	31 (25.6%)	29 (24.0%)
Emotions of love	38 (31.4%)	34 (28.1%)	49 (40.5%)
Emotions of happiness	20 (16.5%)	38 (31.4%)	63 (52.1%)

Sentiment and Emotional Analysis of the Tweets

A total of 1879 tweets were included in our analysis. Out of these tweets, there were 490 (26.08%) positive sentiment tweets, 410 (21.82%) negative sentiment tweets, 590 (31.40%) neutral tweets, and 389 (20.70%) unknown tweets. Of the positive sentiment tweets, 201 tweets expressed emotions of love, kindness, support, inspiration, or longing, for example, “Blessed At The End Of Every Day”; “Lord do I have such amazing and supportive friends”; and 289 tweets expressed emotions of happiness, joy, or excitement, for example, “Finally done wit midterms”; “I just ate next to Zaza Pachulia at In N Out’s westwood!!!” Of the negative sentiment tweets, 124 tweets expressed emotions of anger, insult, dogma, or judgment, for example, “I swear these people just stare at me it annoying”; “I hate essays with a passion … ”; and 286 tweets expressed emotions of either fear, stress, or sadness, for example, “College is just too stressful”; “I chose Netflix and sleep over studying and now 1 hour before my test I hate myself.” The participants posted on average 14 (SD 23, range 2-144) tweets during the 7-day period. The average number of tweets per person that contain positive, negative, and neutral sentiments were 3.7 (SD 3.4, range 0-35), 3.1 (SD 5.9, range 0-43), and 4.5 (SD 8.2, range 0-52), respectively. The mean number of tweets per person containing emotion of anger was 1.1 (SD 1.9, range 0-10), and the mean number of tweets containing emotion of fear was 2.2 (SD 4.3, range 0-33).

The relationship between individuals’ stress level, emotional state, and sentiment and emotions expressed in tweets is shown in Table 3. In our ordinal regression analysis, we found that a higher level of weekly stress was significantly associated with a greater percentage of negative sentiment tweets, tweets containing fear, and tweets containing love. The best-fitting model for predicting weekly levels of stress was using tweets related to the emotions of fear (–2 log likelihood=181.3; χ^2_7=21.2; *P*=.004). A greater level of anger was negatively associated with the percentage of positive sentiment and tweets related to the emotions of happiness. The best-fitting model for predicting weekly levels of anger was using tweets related to the emotions of happiness (–2 log likelihood=161.3; χ^2_7=7.1; *P*=.03). A greater level of fear was positively associated with the percentage of negative sentiments, particularly a greater proportion of tweets containing the emotion of fear. The best-fitting model for predicting weekly levels of fear was using tweets related to the emotions of fear (–2 log likelihood=180.0; χ^2_7=18.2; *P*=.01). Participants who reported a greater level of love showed a smaller percentage of negative sentiment tweets (–2 log likelihood=217.8; χ^2_7=15.1; *P*=.03). Finally, emotions

XSL•FO
RenderX

of happiness were positively associated with the percentage of tweets related to the emotion of happiness and negatively associated with the percentage of negative sentiment tweets and tweets related to the emotion of fear. The best-fitting model for predicting weekly emotions of happiness was using tweets related to the emotions of fear (–2 log likelihood 179.0; χ^2_7 20.1; *P*=.005).

Table 3. The relationship between individuals' stress level, emotional state, and sentiment and emotions expressed in tweets (model adjusted for age, gender, and ethnicity).

Tweet sentiments and emotions	Stress		Anger		Fear		Love		Happiness	
	Beta (SE)	*P*	Beta (SE)	*P*	Beta (SE)	*P*	Beta (SE)	*P*	Beta (SE)	*P*
Percent of negative sentiment	1.72 (0.74)	.02	0.85 (0.70)	.22	1.67 (0.73)	.02	–1.3 (0.70)	.05	–1.69 (0.70)	.02
Percent of positive sentiment	0.10 (0.71)	.89	–1.60 (0.80)	.05	–0.78 (0.72)	.28	0.54 (0.71)	.45	1.24 (0.72)	.09
Percent of neutral sentiment	–0.42 (0.69)	.54	–0.27 (0.72)	.71	0.26 (0.69)	.70	–0.05 (0.70)	.95	–0.92 (0.69)	.18
Percent of tweets related to the emotion of anger	–0.03 (1.06)	.98	0.35 (1.1)	.75	0.19 (1.1)	.86	0.62 (1.1)	.55	1.37 (1.17)	.24
Percent of tweets related to the emotion of fear	2.37 (0.90)	.01	0.90 (0.79)	.25	2.11 (0.83)	.01	–1.42 (0.80)	.07	–2.8 (0.84)	.01
Percent of tweets related to the emotion of love	3.60 (1.44)	.01	0.88 (1.35)	.51	2.55 (1.38)	.06	–0.94 (1.3)	.48	–1.70 (1.31)	.20
Percent of tweets related to the emotion of happiness	–0.92 (0.73)	.21	–2.22 (0.94)	.02	–1.54 (0.80)	.06	0.93 (0.75)	.21	1.79 (0.79)	.02

Discussion

Principal Findings

The main finding of this study was that tweet sentiment was associated with participants' future survey about their emotions and stress. Specifically, higher levels of stress and emotion of fear were associated with a greater percentage of negative sentiments and percentage of tweets related to fear. Meanwhile, emotions of love and happiness were negatively associated with the percentage of negative sentiments and percentage of tweets related to the emotion of fear. Interestingly, perceived level of stress was also positively associated with the percentage of tweets with love and hope. Overall, these findings provide evidence that real-time social media data may be used to monitor the psychological health of college students.

There have been previous studies showing that content of geo-tagged tweets (eg, frequency of keywords) can be extracted to predict disease outbreaks at a population level [12,15,18]. However, there is a lack of studies that have examined whether the content of social media data can be used to monitor psychological health at an individual level. In this study, we have built on previous study methods of analyzing the tweets [12,31]. To our knowledge, this is one of the first studies that (1) categorized the tweets with increased degree of granularity of emotional state (eg, anger, fear, love, happiness) and (2) found that certain emotions expressed in individuals' tweets were better predictors of stress level and emotional state. An interesting finding in this study, contrary to our hypothesis, was that when individuals experienced a higher level of stress, they were more likely to post tweets related to both fear and love or hope. A possible explanation for this is that individuals may post tweets related to love and hope as a coping mechanism and may find it to be comforting while experiencing a higher levels of stress [18,32].

The results from this study have several research implications. First, these findings have furthered our understanding of the types of information that can be extracted from social media data and used to monitor individuals' levels of stress and emotional well-being. Second, our results suggest that it may be possible to create a new public health surveillance tool to monitor and predict stress level and emotional state among college students. This new tool can help school administrators implement targeted health interventions for those individuals at risk for high levels of psychological distress. Consequently, this can help improve students' overall health and enhance their academic experience. Finally, the findings from this study can help create a new area of research, and the methods learned can be applied to other population groups (eg, individuals at risk for heart disease).

Limitations

A limitation of this study was limited sample size and that only freshman college students were included. It may be possible that participants may change their Web-based behavior when they know they are part of the study (ie, Hawthorne effect). Personality and characteristic differences may also influence the frequency and the types of content posted on social media. Overall these factors may limit the ability to generalize our findings. Another limitation was that the psychometric

XSL•FO
RenderX

questionnaires used have not been previously validated. We also excluded retweets and only included a week of tweets in our analysis. It may be possible that individuals may have expressed their levels of stress and their emotional state in their retweets or outside the time frame that the tweets were captured. Thus, future studies need to examine the methods to analyze retweets and the optimal time frame that the tweets need to be captured in order to provide accurate predictions of individuals' levels of stress and emotional well-being. Furthermore, the tweets in this study were manually categorized into 4 types of emotions. In order to scale tweets both as a cost-effective surveillance method and as a tool for developing insights into individuals' health, natural language processing and machine-learning techniques need to be developed to accurately label the tweets into various emotional categories. Finally, levels of stress and emotional state were measured at only one time point in this study. Future research needs to examine how observed changes in the measures of emotions extracted from Twitter data predict changes in the levels of stress and emotional well-being. We plan to pursue this in future studies by collecting Twitter data and psychological measures of college students in a longitudinal study.

Conclusions

The ability to use real-time social media data to provide health surveillance has a significant public health application. The results of this study suggest that sentiment and emotions expressed in the tweets have the potential to provide real-time monitoring of stress level and emotional well-being in college students. Future studies can build on the methods used in this study to further refine the ways of utilizing real-time social media data for monitoring the levels of stress and emotional well-being.

Acknowledgments

This work was funded by support from the National Institutes of Mental Health (Young: 1R01MH106415), National Human Genome Research Institute (Young, Condie, Wang: 1U01HG008488) and the University of California, Office of the President (Young: CA-15-329077).

Conflicts of Interest

None declared.

References

1. Deckro GR, Ballinger KM, Hoyt M, Wilcher M, Dusek J, Myers P, et al. The evaluation of a mind/body intervention to reduce psychological distress and perceived stress in college students. J Am Coll Health 2002 May;50(6):281-287. [doi: 10.1080/07448480209603446] [Medline: 12701653]
2. Folkman SJ. Stress, Positive Emotion, and Coping. Curr Dir Psychol Sci 2000;9(4):115-118. [doi: 10.1111/1467-8721.00073]
3. Eagan K, Stolzenberg EB, Ramirez JJ, Aragon MC, Suchard MR, Hurtado S. The American freshman: National norms fall 2014. Los Angeles: Higher Education Research Institute, UCLA; 2014.
4. Robotham DC, Julian C. Stress and the higher education student: a critical review of the literature. J Furth High Educ 2006 May;30(2):107-117. [doi: 10.1080/03098770600617513]
5. Lazarus R. Stress and emotion: a new synthesis. New York, NY: Springer; 1999.
6. Andrews B, Wilding JM. The relation of depression and anxiety to life-stress and achievement in students. Br J Psychol 2004 Nov;95(Pt 4):509-521. [doi: 10.1348/0007126042369802] [Medline: 15527535]
7. Rawson HE, Bloomer K, Kendall A. Stress, anxiety, depression, and physical illness in college students. J Genet Psychol 1994 Sep;155(3):321-330. [doi: 10.1080/00221325.1994.9914782] [Medline: 7964658]
8. Kassel JD, Bornovalova M, Mehta N. Generalized expectancies for negative mood regulation predict change in anxiety and depression among college students. Behav Res Ther 2007 May;45(5):939-950. [doi: 10.1016/j.brat.2006.07.014] [Medline: 17010932]
9. Dhabhar FS. Effects of stress on immune function: the good, the bad, and the beautiful. Immunol Res 2014 May;58(2-3):193-210. [doi: 10.1007/s12026-014-8517-0] [Medline: 24798553]
10. Kandiah JM, Yake M, Jones J, Meyer M. Stress influences appetite and comfort food preferences in college women. Nutr Res 2006 Mar;26(3):118-123. [doi: 10.1016/j.nutres.2005.11.010]
11. Hirotsu C, Tufik S, Andersen ML. Interactions between sleep, stress, and metabolism: from physiological to pathological conditions. Sleep Sci 2015 Nov;8(3):143-152 [FREE Full text] [doi: 10.1016/j.slsci.2015.09.002] [Medline: 26779321]
12. Young SD, Rivers C, Lewis B. Methods of using real-time social media technologies for detection and remote monitoring of HIV outcomes. Prev Med 2014 Jun;63:112-115 [FREE Full text] [doi: 10.1016/j.ypmed.2014.01.024] [Medline: 24513169]
13. Gore RJ, Diallo S, Padilla J. You are what you tweet: connecting the geographic variation in America's obesity rate to Twitter content. PLoS One 2015;10(9):e0133505 [FREE Full text] [doi: 10.1371/journal.pone.0133505] [Medline: 26332588]
14. Broniatowski DA, Paul MJ, Dredze M. National and local influenza surveillance through Twitter: an analysis of the 2012-2013 influenza epidemic. PLoS One 2013;8(12):e83672 [FREE Full text] [doi: 10.1371/journal.pone.0083672] [Medline: 24349542]

XSL•FO
RenderX

15. Bodnar T, Salathé M. Validating models for disease detection using twitter. In: In Proceedings of the 22nd International Conference on World Wide Web. 2013 Presented at: ACM; May 13–17, 2013; Rio de Janeiro, Brazil p. 699-702.
16. Luminet O, Bouts P, Delie F, Manstead A, Rimé B. Social sharing of emotion following exposure to a negatively valenced situation. Cogn Emot 2000 Sep;14(5):661-688. [doi: 10.1080/026999300501176666]
17. Young SD, Jaganath D. Feasibility of using social networking technologies for health research among men who have sex with men: a mixed methods study. Am J Mens Health 2014 Jan;8(1):6-14 [FREE Full text] [doi: 10.1177/1557988313476878] [Medline: 23407600]
18. De Choudhury M, Gamon M, Counts S, Horvitz E. Predicting Depression via Social Media. In: Association for the Advancement of Artificial Intelligence. 2013 Presented at: ICWSM; July 8, 2013; Cambridge, Massachusetts p. 2.
19. Duggan M, Ellison N, Lampe C, Lenhart A, Madden M. Pew Research Center. 2014. Social Media Update 2014. Pew Research Center. 2014. URL: http://www.pewinternet.org/2015/01/09/social-media-update-2014/ [accessed 2016-12-14] [WebCite Cache ID 6mkjVYBje]
20. Ekman P. An argument for basic emotions. Cogn Emot 1992 May 1;6(3):169-200. [doi: 10.1080/02699392084110688]
21. Dalgleish T, Power M. Basic emotions. In: Handbook of cognition and emotion. Chichester, England: Wiley; 1999.
22. QCRI. Sentiment Analysis in Twitter. 2016. URL: http://alt.qcri.org/semeval2016/task4/ [accessed 2016-12-14] [WebCite Cache ID 6mkjooo2s]
23. Emotions in social psychology: essential readings. Philadelphia, Pa: Psychology Press; 2001.
24. Agresti A. Categorical Data Analysis (Wiley Series in Probability and Statistics). New Jersey: Wiley; 2012.
25. Pomerantz E, Altermatt R, Saxon J. Making the grade but feeling distressed: gender differences in academic performance and internal distress. J Educ Psychol 2002;94(2):396-404. [doi: 10.1037/0022-0663.94.2.396]
26. Rudolph K, Hammen C. Age and gender as determinants of stress exposure, generation, and reactions in youngsters: a transactional perspective. Child Dev 1999;70(3):660-677. [Medline: 10368914]
27. Smedley B, Myers H, Harrell S. Minority-status stresses and the college adjustment of ethnic minority freshmen. J Higher Educ 1993 Jul;64(4):434-452. [doi: 10.2307/2960051]
28. Folkman S, Lazarus RS, Pimley S, Novacek J. Age differences in stress and coping processes. Psychol Aging 1987 Jun;2(2):171-184. [Medline: 3268206]
29. Hair J, Black W, Babin B, Anderson R. Multivariate data analysis. Upper Saddle River, NJ: Prentice Hall; 2010.
30. Universityofcalifornia.edu.: University of California Los Angeles Fall enrollment at a glance. Los Angeles, California, USA: University of California Los Angeles; 2015. URL: https://www.universityofcalifornia.edu/infocenter/fall-enrollment-glance [accessed 2016-12-14] [WebCite Cache ID 6mkkteBRT]
31. Signorini A, Segre AM, Polgreen PM. The use of Twitter to track levels of disease activity and public concern in the US during the influenza A H1N1 pandemic. PLoS One 2011 May 04;6(5):e19467 [FREE Full text] [doi: 10.1371/journal.pone.0019467]
32. McCullough M, Larson D. Religion and depression: a review of the literature. Twin res 2012 Feb 21;2(02):126-136. [doi: 10.1375/twin.2.2.126]

Abbreviations

UCLA: University of California, Los Angeles

Edited by G Eysenbach; submitted 09.02.16; peer-reviewed by D Broniatowski, A Benis, M Hart, DC Ferguson RN PhD, J Apolinário-Hagen; comments to author 06.04.16; revised version received 31.05.16; accepted 11.06.16; published 10.01.17.

Please cite as:
Liu S, Zhu M, Yu DJ, Rasin A, Young SD
Using Real-Time Social Media Technologies to Monitor Levels of Perceived Stress and Emotional State in College Students: A Web-Based Questionnaire Study
JMIR Ment Health 2017;4(1):e2
URL: http://mental.jmir.org/2017/1/e2/
doi:10.2196/mental.5626
PMID:28073737

©Sam Liu, Miaoqi Zhu, Dong Jin Yu, Alexander Rasin, Sean D Young. Originally published in JMIR Mental Health (http://mental.jmir.org), 10.01.2017. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Mental Health, is properly cited. The complete bibliographic

XSL•FO
RenderX

information, a link to the original publication on http://mental.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Applying Computerized Adaptive Testing to the Four-Dimensional Symptom Questionnaire (4DSQ): A Simulation Study

Tessa Magnée[1], MSc (Psych); Derek P de Beurs[1], PhD; Berend Terluin[2], MD, PhD; Peter F Verhaak[1,3], PhD

[1]Netherlands Institute for Health Services Research (NIVEL), Utrecht, Netherlands

[2]EMGO Institute for Health and Care Research, Department of General Practice and Elderly Care Medicine, VU University Medical Center, Amsterdam, Netherlands

[3]Groningen University, University Medical Center Groningen, Department of General Practice, Groningen, Netherlands

Corresponding Author:
Tessa Magnée, MSc (Psych)
Netherlands Institute for Health Services Research (NIVEL)
Otterstraat 118-114
Utrecht, 3500BN
Netherlands
Phone: 31 302729854
Fax: 31 302729729
Email: t.magnee@nivel.nl

Abstract

Background: Efficient screening questionnaires are useful in general practice. Computerized adaptive testing (CAT) is a method to improve the efficiency of questionnaires, as only the items that are particularly informative for a certain responder are dynamically selected.

Objective: The objective of this study was to test whether CAT could improve the efficiency of the Four-Dimensional Symptom Questionnaire (4DSQ), a frequently used self-report questionnaire designed to assess common psychosocial problems in general practice.

Methods: A simulation study was conducted using a sample of Dutch patients visiting a general practitioner (GP) with psychological problems (n=379). Responders completed a paper-and-pencil version of the 50-item 4DSQ and a psychometric evaluation was performed to check if the data agreed with item response theory (IRT) assumptions. Next, a CAT simulation was performed for each of the four 4DSQ scales (distress, depression, anxiety, and somatization), based on the given responses as if they had been collected through CAT. The following two stopping rules were applied for the administration of items: (1) stop if measurement precision is below a predefined level, or (2) stop if more than half of the items of the subscale are administered.

Results: In general, the items of each of the four scales agreed with IRT assumptions. Application of the first stopping rule reduced the length of the questionnaire by 38% (from 50 to 31 items on average). When the second stopping rule was also applied, the total number of items could be reduced by 56% (from 50 to 22 items on average).

Conclusions: CAT seems useful for improving the efficiency of the 4DSQ by 56% without losing a considerable amount of measurement precision. The CAT version of the 4DSQ may be useful as part of an online assessment to investigate the severity of mental health problems of patients visiting a GP. This simulation study is the first step needed for the development a CAT version of the 4DSQ. A CAT version of the 4DSQ could be of high value for Dutch GPs since increasing numbers of patients with mental health problems are visiting the general practice. In further research, the results of a real-time CAT should be compared with the results of the administration of the full scale.

(JMIR Ment Health 2017;4(1):e7) doi:10.2196/mental.6545

KEYWORDS

item response theory; Four-Dimensional Symptom Questionnaire; computerized adaptive testing; mental health; general practice

XSL•FO
RenderX

Introduction

General practitioners (GPs) are often the first point of contact for persons with mental health problems, and they make important decisions about treatment and referrals. However, GPs vary in their ability to detect mental problems in patients during consultations [1] and may have difficulties distinguishing between "normal" psychological distress and psychopathology [2]. Moreover, time pressure in general practice is increasing.

Using a short, good quality screener to distinguish between mild psychological symptoms and severe disorders has become of particular importance for Dutch GPs, as they have been restricted to refer only patients with a Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV) disorder [3] to mental health care professionals.

The Four-Dimensional Symptom Questionnaire (4DSQ; Multimedia Appendix 1) is a frequently used self-report questionnaire designed to assess common psychosocial problems in general practice [4]. It consists of four subscales measuring distress, depression, anxiety, and somatization. The 4DSQ is available in Dutch, English, and several other languages and has been widely used and validated in clinical practice. The full version of the 4DSQ comprises 50 items. It has been found that most responders need 7 minutes to complete the full version and 75% of all responders complete the 4DSQ within 10 minutes [4]. Responses to the questionnaire can be used to distinguish between patients with "normal" psychological distress and patients with psychopathology [5-7]. This is of increasing importance for GPs who have to make crucial decisions about the triage of patients with mental health problems.

Computerized adaptive testing (CAT) is a method to reduce patient burden of traditional questionnaires, by letting a computer dynamically select only the items that give new information about the patient. Based on a patient's answer to a single first item, a responders underlying trait (eg, level of depression) is estimated. In addition, an automated algorithm selects the next item that is most appropriate or informative for this responder. The benefit of using CAT is the reduction in items without a loss in reliability or precision in measurement [8].

CAT relies on item response theory (IRT) [9]. A CAT version of the Center for Epidemiologic Studies-Depression (CES-D) scale, one of the most widely used depression screeners, provided only marginally different outcomes with a decreased number of items compared to the full version [10]. CAT has also been applied successfully to other mental health questionnaires, such as the Beck Depression Inventory [11], the Beck Scale for Suicide Ideation [12], and the 90-item Mood and Anxiety Symptom Questionnaire [13] and seems more accurate than a simple short-form version of an assessment [14]. It is not clear yet if the efficiency of screening for common mental health problems in general practice can be increased by developing an adaptive version of the 4DSQ.

The aims of this simulation study were (1) to investigate if responses of a clinical sample to a paper-and-pencil version of the 4DSQ meet the psychometric requirements needed for IRT; and (2) to determine if a simulated adaptive version of the 4DSQ would yield inferences similar to those based on the full version of the 4DSQ. This simulation study is the first step necessary for the development of a CAT version of the 4DSQ.

Methods

Participants

We used data collected in the baseline measurement of a study evaluating triage decisions in general practice. All patients with mental health problems visiting a GP working in a primary care center in the northern part of the Netherlands between January 1 and December 31, 2014 were included in the study (N=408). All included participants provided informed consent. Participants filled in the Dutch paper-and-pen version of the 4DSQ and only patients with complete data were included in the analyses (92.9%, 379/408). As a result, our final sample consisted of 379 participants with a mean age of 44.8 years (SD 16.5, range 16 to 87). Of the participants, 66.8% (253/379) were female. No significant differences in age (P=.715) or sex (P=.205) were found between responders with complete and without complete data.

Psychometric Evaluation

Since all four of the 4DSQ scales are used and interpreted separately, we performed the psychometric evaluation and our analyses for each of the four scales separately. We followed the five steps described in the analysis plan used for the PROMIS study, which was aimed at improving patient-reported outcome instruments [8].

Step 1: Descriptive Statistics

Descriptive statistics were calculated for each single item (Multimedia Appendix 2). The 4DSQ consists of questions about complaints and symptoms that occurred during the previous week, such as "During the past week, did you feel tense?" Responders indicated how often they experienced these symptoms by answering "no," "sometimes," "regularly," "often," or "very often or constantly." According to the scoring protocol, responses were coded as 0 (no), 1 (sometimes), 2 (regularly, often, or very often/constantly). The four 4DSQ scales vary in the total number of items: 16 items for distress, 6 for depression, 12 for anxiety, and 16 for somatization. A total score was calculated for each scale by adding up all item scores. To examine internal consistency, Cronbach alpha was calculated for each scale, with .8 as the acceptable minimum. We analyzed whether removing any of the items changed the internal consistency of a scale.

Step 2: Evaluate Item Response Theory Assumptions

Within IRT, data have to agree with three basic assumptions: unidimensionality, local independency, and monotonicity [8].

Unidimensionality means that a person's response to an item is accounted for by his or her level on the underlying trait and not by any other factor. A confirmatory factor analysis (CFA) with ordinal data was performed to study unidimensionality for each scale. The model's fit was assessed using four frequently used fit indices: comparative fit index (CFI) greater than 0.95 for good fit, root mean square error of approximation (RMSEA)

XSL•FO
RenderX

less than 0.06 for good fit, Tucker Lewis index (TLI) greater than 0.95 for good fit, and standardized root mean residuals (SRMR) less than 0.08 for good fit.

Local independence means that there should be no significant association among item responses, except for the association controlled for by the underlying trait. This assumption was checked by inspecting residual correlations between item pairs within the CFA. Items with high residual correlations (greater than 0.2) were considered as possibly locally dependent.

The assumption of monotonicity means that an item response related to a higher level of the trait should increase with the level of the trait. This assumption was studied by plotting trace lines. In addition, we studied scalability coefficients of IRT probability curves (greater than 0.3 indicates monotonicity).

Step 3: Graded Response Model Fit

Within IRT, several models are commonly used; however, because of the ordered-response categories of the 4DSQ, a graded response model (GRM) was preferred for our data [15]. This model estimates at which levels of an underlying trait (θ), such as depression, a person is likely to choose one of the response options of an item. For each single item, several GRM parameters are estimated. The discrimination parameter (α) represents the extent to which an item discriminates between different trait levels. An item with a high alpha is strongly associated with the measured construct. Two difficulty or threshold parameters ($ß_1$ and $ß_2$) were also estimated. A category response curve (CRC), based on the estimated parameters, was plotted for each item to evaluate the fit of the model to the data.

Step 4: Differential Item Functioning

An item displays differential item functioning (DIF) if persons with different characteristics (eg, males and females) respond differently to an item, despite equivalent levels of the underlying trait [8]. Items showing DIF may bias CAT outcomes. To check for DIF (uniform and non-uniform), GRM estimates of each item were compared between subgroups varying in gender (male or female) and age (R^2 less than .03 indicating no DIF).

Step 5: Simulated Computerized Adaptive Testing

The GRM parameter estimates from Step 3 were used for a CAT simulation. As no information on a subject is available before the first item is administered, θ is initially set at 0. After the first item is answered, the choice for the next item is based on the GRM parameters of all potential next items in relation to the response to the item that was answered first. All optimal next items are selected based on the maximum Fisher estimation method. The CAT selects new items until a pre-defined stopping rule is reached. A stopping rule is based on either a maximum number of items administered or on a pre-specified level of measurement precision [10-13].

We combined the two following stopping rules: (1) stop when the standard error of the trait is similar to the standard error of the full lengths scale, or (2) stop when half the number of the full scale is administered. We compared CAT outcomes with the first stopping rule only and with both stopping rules. Regarding the first stopping rule, we inspected varying levels of standard error (from 0.2 to 0.8). The pre-defined standard error of theta that corresponded with the standard error of the full scale was used as a reference point. Correlations were calculated between trait levels based on CAT and on the scores from the full version of the 4DSQ. We added a second stopping rule because questionnaires in mental health often are most informative for patients with relatively high levels of clinical outcomes [10,16,17]. For patients with a low level of the assessed outcome (eg, patients with low levels of depression), many items provide little (additional) information. Ironically, as the CAT algorithm finds it difficult to estimate the standard error when items offer little information, patients with a low trait level often have to answer all items, even though they provide no new information.

Software

The descriptive statistics and the estimation of the GRM parameters were done in STATA 14.0. The CFA model was estimated using the lavaan package in R [18,19]. Monotonicity was checked using the R mokken package [20] and DIF with the R lordif package [21]. The CAT simulation was done with the CatIRT package in R [22].

Results

Step 1: Descriptive Statistics

The sample's mean total score on the 4DSQ distress scale was 18.6 (SE 0.43, range 0-32, median 20), with an overall Cronbach alpha of .92. The mean depression score was 3.4 (SE 0.20, range 0-12, median 2), with a Cronbach alpha of .90. The mean score for anxiety was 5.5 (SE 0.27, range 0-23, median 4), with a Cronbach alpha of .87. Finally, for the somatization scale, the sample scored 11.6 on average (SE 0.35, range 0-32, median 11), with a Cronbach alpha of .85. These results were comparable to other studies [4,7]. The descriptive statistics of the single items on the four scales are shown in Multimedia Appendix 2. Removing any one of the items did not change the internal consistency of any of the four scales.

Step 2: Checking Item Response Theory Assumptions

Regarding the first assumption, unidimensionality, we concluded that the items of the anxiety scale showed a good model fit for all four fit indices of the CFA. The items of the distress and depression scales showed a good fit for three of the four indices, but not for RMSEA, although they nearly did. For good fit, RMSEA should be lower than 0.06, but it was 0.08 (distress) and 0.07 (depression). The items of the somatization scale showed good fit for two out of four indices, but not for RMSEA (0.07 instead of less than 0.06) and TLI (0.94 instead of greater than 0.95).

Regarding the second assumption, out of 321 items pairs within the four scales (equation 1), two item pairs with a residual correlation above 0.2 were observed, indicating local independency. They were items 20 and 39 (sleep-related), and items 47 and 48 (trauma-related), all from the distress scale.

$$321=(½)(6)(5) + (½)(16)(15) + (½)(12)(11) + (½)(16)(15) \quad (1)$$

The scalability coefficient of all items was higher than 0.3, indicating that all items met the third assumption of monotonicity.

XSL•FO
RenderX

Step 3: Graded Response Model Fit

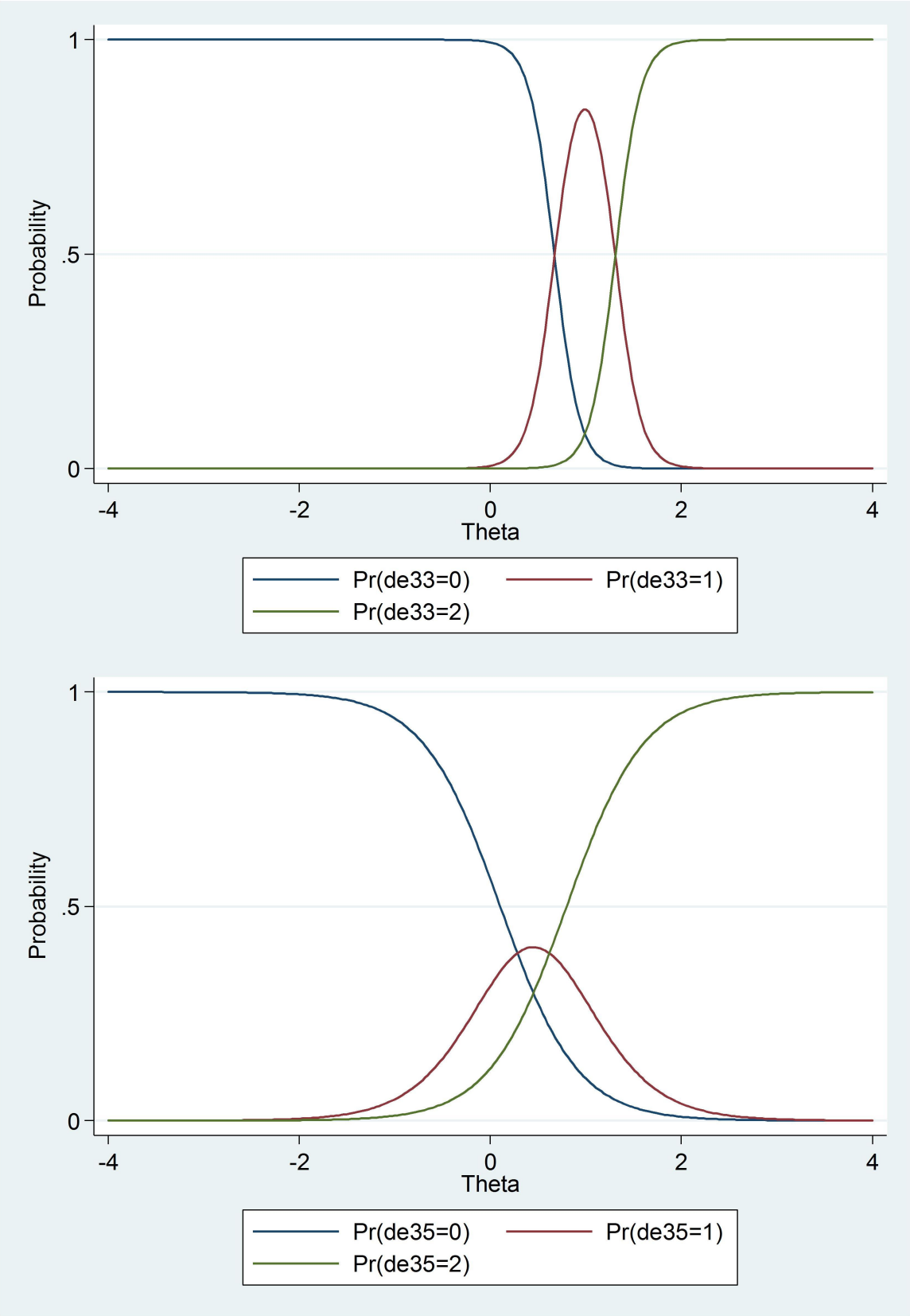
The parameter estimates of the GRM for all items of the four scales are shown in Multimedia Appendix 3. Item 33 ("would be better off dead") of the depression scale showed the highest alpha (7.377) and discriminates best between persons with low and high levels of depression. For the three other scales, the highest alphas were observed for item 37 (3.483, distress, "no longer feel like doing anything"), item 27 (5.527, anxiety, "feel frightened"), and item 16 (1.855, somatization, "pain in the chest"). All other items showed an alpha above 1, except for items 47 and 48 (distress), item 50 (anxiety), and items 6 and 8 (somatization).

It was found that 43 items showed CRCs as expected. Five items on the anxiety scale (40, 42, 43, 49, and 50) and two items on the somatization scale (5 and 14) did not show CRCs as expected. For those items, the probability to answer "sometimes" was always lower than the probability for one of the other responses, regardless of the trait level.

As an example, Figure 1 shows the CRCs of the items with the highest (item 33; α=7.377, $ß_1$=0.688, $ß_2$=1.349) and lowest (item 35; α=2.457, $ß_1$=0.119, $ß_2$=0.828) discrimination parameter (α) of the depression scale. The higher discrimination parameter of item 33 indicates an ability to demarcate fine gradations between persons with similar levels of depression. This can be observed in Figure 1, which shows steep curves for different answer categories for item 33. Item 35 (no escape from situation) is more easily endorsed than item 33 in general (would be better off dead), which is indicated by the location of the curves more on the left side of the graph. Persons with a high depression level are most likely to answer "sometimes" to item 33, and to answer "regularly", "often," or "very often or constantly" to item 35.

XSL•FO
RenderX

Figure 1. Category response curves of items 33 and 35 of the Four-Dimensional Symptom Questionnaire depression scale. The probability (y-axis) represents the chance on a certain response (0=never; 1=sometimes; 2=regularly, often, very often, or constantly) given a certain level of theta. Theta (x-axis) represents the underlying trait level; in this figure, depression. The abbreviation Pr is probability.



Step 4: Differential Item Functioning

For the depression, anxiety, and somatization subscales, no items showed DIF. The only item that showed significant and relevant uniform and non-uniform DIF was item 41 (“I quickly get emotional”) from the distress scale for the covariate gender.

XSL•FO
RenderX

Step 5: Simulated Computerized Adaptive Testing

The characteristics of the simulated CAT under different levels of measurement precision (allowing the standard error of the estimated underlying trait to gradually increase; stopping rule 1) are shown in Table 1. For each scale, the standard error of theta that was equal to the standard error of the full version scale is indicated. For example, the standard error of the full version scale of distress was 0.4. When allowing the standard error of theta to be maximal 0.4, the mean number of items administered could be decreased from 16 to 6.3. The correlation between the distress level based on 6.3 items and the distress level based on all items was high (0.96). Comparable results were found for the three other scales. With the first stopping rule, we were able to reduce the mean number of items administered to 5 for depression (from 6), to 8.3 for anxiety (from 12), and to 12.9 for somatization (from 16), while correlations between CAT and full test scores remained high. Applying CAT with the first stopping rule to all four scales could reduce the total number of 4DSQ items from 50 to, on average, 34 items.

Table 1. Mean number of items administered under varying levels of measurement precision and correlations between computerized adaptive testing scores and full version scores of the Four-Dimensional Symptom Questionnaire.

Stopping rule	Distress		Depression		Anxiety		Somatization	
	Number of items, mean (SD)	Correlation[a]	Number of items, mean (SD)	Correlation[a]	Number of items, mean (SD)	Correlation[a]	Number of items, mean (SD)	Correlation[a]
None	16	1.00	6	1.00	12	1.00	16	1.00
SE[b] (θ)<0.2	15.7 (0.8)	1	5.7 (0.9)[c]	1[c]	12 (0)	1	16 (0)	1
SE (θ)<0.3	8.8 (4.5)	0.98	5.4 (1.2)	0.99	8.7 (4.3)[c]	0.97[c]	14 (0)	0.97
SE (θ)<0.4	6.3 (4.3)[c]	0.96[c]	5.0 (1.3)	0.99	8.3 (4.3)	0.97	12.9 (2.1)[c]	0.95[c]
SE (θ)<0.5	4.9 (3.8)	0.92	4.9 (1.4)	0.99	8.1 (4.4)	0.97	11.2 (4.9)	0.95
SE (θ)<0.6	4.1 (2.6)	0.86	4.6 (1.4)	0.99	5.9 (4.2)	0.94	7.5 (4.6)	0.86
SE (θ)<0.7	3.8 (2.5)	0.84	3.9 (1.3)	0.97	5.9 (4.1)	0.94	4.6 (3.4)	0.73
SE (θ)<0.8	3.7 (2.3)	0.79	3.9 (1.3)	0.97	5.6 (4.0)	0.93	4.6 (3.4)	0.73

[a]Correlation between CAT θ and complete test θ.

[b]SE: standard error.

[c]The standard error of theta (θ) is equal to the standard error of the full version scale.

The results of combining the first stopping rule with the second stopping rule are shown in Table 2. For distress, the average number of items could be further decreased from 6.3 to 5, but the correlation also decreased from 0.96 to 0.79. Therefore, we did not apply the second stopping rule to this scale. For the three other scales, the number of average items could be decreased, while the correlation remained high. Overall, when applying the CAT with both stopping rules (except for distress), the 4DSQ could be reduced from 50 to 22 items.

Table 2. Mean number of items administered and correlation with total estimated theta under one or two stopping rules.

Stopping rule	Distress		Depression		Anxiety		Somatization	
	Number of items, mean (SD)	Correlation[a]	Number of items, mean (SD)	Correlation[a]	Number of items, mean (SD)	Correlation[a]	Number of items, mean (SD)	Correlation[a]
None	16	1.00	6	1.00	12	1.00	16	1.00
SE[b] (θ) = SE (full)	6.3 (4.3)	0.96	5.4 (1.2)	0.99	8.7 (4.3)	0.97	12.9 (2.1)	0.95
Maximum items[c]	5.0 (2.1)	0.79	3.0 (0)	0.96	4.9 (1.4)	0.92	7.9 (0.3)	0.92

[a]Correlation between CAT θ and complete test θ.

[b]SE: standard error.

[c]Maximum items are determined by dividing the number of items by 2.

XSL•FO
RenderX

Discussion

Principal Findings

In summary, when applying CAT to the 4DSQ and applying two stopping rules to the subscales of anxiety, depression, somatization, and one stopping rule to the subscale distress, the total number of items on the 4DSQ could be reduced by 56% on average (from 50 to 22 items), without losing a considerable amount of measurement precision.

Interpretation

Our simulation study showed that CAT may increase the efficiency of the 4DSQ and could reduce responders' burden by more than 50%. These results were also found in other CAT studies, such as on the *Center for Epidemiological Studies-Depression Scale* (CES-D), where the total scale of 20 items could be reduced to 7 items [23].

Some CATs to measure anxiety and depression have already been used and evaluated in clinical (specialist) care [24-26]. These CATs appeared to be useful for longitudinal monitoring of symptoms, since they were as reliable over time as traditional questionnaires [27].

A CAT version of the 4DSQ seems especially useful in general practices, for example, as part of a broad online assessment to investigate the severity of psychological problems of patients. As the number of patients visiting their GP with mental health problems is increasing [28], there is a growing need for an efficient screener for mental health problems. Many Dutch GPs already use the 4DSQ. An efficient, shortened 4DSQ could be combined with other mental health questionnaires, while keeping responders' burden as low as possible. GPs have only a limited time and often have to make important decisions about referring patients with mental health problems. An online severity assessment, ideally preceding the first consultation, could be helpful as a first quick evaluation on which to base further (treatment) decisions. Some GPs use the 4DSQ as an agenda-setting tool to talk about the psychological problems of their patients. An online assessment could fulfill the same agenda-setting function.

However, some obstacles for the successful implementation of a CAT version of the 4DSQ in general practice exist. First, current information and communication technology (ICT) possibilities in general practices are insufficient for the implementation of CAT, which requires sophisticated statistical software. Second, it is not clear to what extent GPs are willing to implement a CAT version of the 4DSQ. GPs may use responses from individual 4DSQ items, such as item 47 or 48 on traumatic events, for a quick clinical evaluation, and this information may be lost when applying CAT. Lastly, it is not clear if CAT is appropriate for all patients. Previous research on CAT after inpatient rehabilitation suggests that it might only be feasible to collect (complete) data for a specific subset of patients [29]. Some patients may prefer a paper-and-pencil version of a questionnaire to an online assessment. Although a CAT version of the 4DSQ might not be immediately available for use in clinical practice, some studies have already shown that CAT versions of traditional questionnaires can be used in a clinical setting [24-26] and are well accepted by patients [25]. Recently developed, free-to-use online CAT platforms [30,31] are likely to enable the development of new CAT questionnaires. Moreover, some Dutch GPs already have been using an online screener to assess mental health problems, so application of a CAT version of the 4DSQ in clinical practice may be within reach.

Strengths and Limitations

As this was a simulation study, we used responses to a paper-and-pencil version of the 4DSQ. In reality, responders might behave differently when receiving a computerized adaptive assessment. For example, we do not know if the actual computer administration might influence responses or what effect differences in the item order may have. However, a previous study showed that differences between results from a simulation CAT and a real CAT were small [32]. We used data from a sample from a northern region of the Netherlands, but parameter estimates based on data from different regions and countries might also differ.

Regarding the psychometric evaluation, our data showed some weaknesses. For most items of the four subscales of the 4DSQ, the assumptions for an IRT analysis were met. The assumption of unidimensionality was not met perfectly for all four scales, although it nearly was. Moreover, some items showed other limitations, such as correlations between item pairs or differential item functioning. These items might be left out in future (real-time) CAT versions of the 4DSQ. As in other studies, we found relevant DIF for the item "emotionality" on the distress scale. Women tend to more easily agree with this item compared to men, even when they have a similar underlying level of distress. When looking at the individual responses to the CAT of the distress scale, the item "emotionality" was only administered to participants with a very low level of distress. This indicates that the DIF on this item does not bias the CAT outcomes, as this item is not informative enough to be included in the final CAT. When looking at the distribution and the CRC of some items of the anxiety and somatization scales, participants either endorse option 0 or option 1 to 2. Patients apparently have difficulties differentiating between response categories 1 and 2. This might be solved in future studies by grouping response options 1 and 2 for certain items, making them dichotomous.

Conclusions

Data from this simulation study in general agreed with assumptions needed for CAT. CAT seems useful for improving the efficiency of the 4DSQ by 56%, without losing a considerable amount of measurement precision. Of course, this simulation study is only the first step towards a CAT version of the 4DSQ that could be implemented in clinical practice and it should be followed by a study on a real-time CAT and eventually by an evaluation of the developed CAT version in a clinical setting.

XSL•FO
RenderX

Acknowledgments

We would like to thank Marjolein Jansen and Thomas de Kok for their contributions to data collection.

Authors' Contributions

TM, DB, and PFV designed the study. TM and DB analyzed the data. All authors contributed to and approved the final manuscript.

Conflicts of Interest

BT is the copyright owner of the 4DSQ and receives copyright fees from companies that use the 4DSQ on a commercial basis (the 4DSQ is freely available for non-commercial use in health care and research). BT received fees from various institutions for workshops on the application of the 4DSQ in primary care settings.

Multimedia Appendix 1

English version of the Four-Dimensional Symptom Questionnaire.

[PDF File (Adobe PDF File), 247KB - mental_v4i1e7_app1.pdf]

Multimedia Appendix 2

Descriptive statistics of items of the Four-Dimensional Symptom Questionnaire.

[PDF File (Adobe PDF File), 518KB - mental_v4i1e7_app2.pdf]

Multimedia Appendix 3

Graded response model parameter estimates of the Four-Dimensional Symptom Questionnaire.

[PDF File (Adobe PDF File), 525KB - mental_v4i1e7_app3.pdf]

References

1. Zantinge EM, Verhaak PF, Kerssens JJ, Bensing JM. The workload of GPs: consultations of patients with psychological and somatic problems compared. Br J Gen Pract 2005 Aug;55(517):609-614 [FREE Full text] [Medline: 16105369]
2. Hyde J, Evans J, Sharp D, Croudace T, Harrison G, Lewis G, et al. Deciding who gets treatment for depression and anxiety: a study of consecutive GP attenders. Br J Gen Pract 2005 Nov;55(520):846-853 [FREE Full text] [Medline: 16282000]
3. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. Washington, DC: American Psychiatric Association; 2013.
4. Terluin B, van Marwijk HW, Adèr HJ, de Vet HC, Penninx BW, Hermens ML, et al. The Four-Dimensional Symptom Questionnaire (4DSQ): a validation study of a multidimensional self-report questionnaire to assess distress, depression, anxiety and somatization. BMC Psychiatry 2006 Aug 22;6:34 [FREE Full text] [doi: 10.1186/1471-244X-6-34] [Medline: 16925825]
5. Geraghty AW, Stuart B, Terluin B, Kendrick T, Little P, Moore M. Distinguishing between emotional distress and psychiatric disorder in primary care attenders: A cross sectional study of the four-dimensional symptom questionnaire (4DSQ). J Affect Disord 2015 Sep 15;184:198-204. [doi: 10.1016/j.jad.2015.05.064] [Medline: 26099254]
6. Terluin B, Brouwers EP, van Marwijk HW, Verhaak PF, van der Horst H. Detecting depressive and anxiety disorders in distressed patients in primary care; comparative diagnostic accuracy of the Four-Dimensional Symptom Questionnaire (4DSQ) and the Hospital Anxiety and Depression Scale (HADS). BMC Fam Pract 2009 Aug 23;10:58 [FREE Full text] [doi: 10.1186/1471-2296-10-58] [Medline: 19698153]
7. Terluin B, Oosterbaan DB, Brouwers EP, van Straten A, van de Ven PM, Langerak W, et al. To what extent does the anxiety scale of the Four-Dimensional Symptom Questionnaire (4DSQ) detect specific types of anxiety disorder in primary care? A psychometric study. BMC Psychiatry 2014 Apr 24;14:121 [FREE Full text] [doi: 10.1186/1471-244X-14-121] [Medline: 24761829]
8. Reeve BB, Hays RD, Bjorner JB, Cook KF, Crane PK, Teresi JA, et al. Psychometric evaluation and calibration of health-related quality of life item banks: plans for the Patient-Reported Outcomes Measurement Information System (PROMIS). Med Care 2007 May;45(5 Suppl 1):S22-S31. [doi: 10.1097/01.mlr.0000250483.85507.04] [Medline: 17443115]
9. van der Linden WJ, Hambleton RK, editors. Handbook of Modern Item Response Theory. New York: Springer; 1997.
10. Smits N, Cuijpers P, van Straten A. Applying computerized adaptive testing to the CES-D scale: a simulation study. Psychiatry Res 2011 Jun 30;188(1):147-155 [FREE Full text] [doi: 10.1016/j.psychres.2010.12.001] [Medline: 21208660]
11. Gardner W, Shear K, Kelleher KJ, Pajer KA, Mammen O, Buysse D, et al. Computerized adaptive measurement of depression: a simulation study. BMC Psychiatry 2004 May 06;4:13 [FREE Full text] [doi: 10.1186/1471-244X-4-13] [Medline: 15132755]

XSL•FO
RenderX

12. De Beurs DP, de Vries AL, de Groot MH, de Keijser J, Kerkhof AJ. Applying computer adaptive testing to optimize online assessment of suicidal behavior: a simulation study. J Med Internet Res 2014 Sep 11;16(9):e207 [FREE Full text] [doi: 10.2196/jmir.3511] [Medline: 25213259]
13. Flens G, Smits N, Carlier I, van Hemert AM, de Beurs E. Simulating computer adaptive testing with the Mood and Anxiety Symptom Questionnaire. Psychol Assess 2016 Aug;28(8):953-962. [doi: 10.1037/pas0000240] [Medline: 26691506]
14. Gardner W, Kelleher KJ, Pajer KA. Multidimensional adaptive testing for mental health problems in primary care. Med Care 2002 Sep;40(9):812-823. [doi: 10.1097/01.MLR.0000025436.30093.77] [Medline: 12218771]
15. Samejima F. Estimation of Latent Ability Using a Response Pattern of Graded Scores. Richmond, VA: Psychometric Society; 1969. URL: http://www.psychometricsociety.org/sites/default/files/pdf/MN17.pdf [accessed 2017-02-11] [WebCite Cache ID 6oCHoFl4P]
16. Embretson SE, Reise SP. Item Response Theory for Psychologists. Hove, UK: Psychology Press; 2000.
17. Young MA, Halper I, Clark D, Scheftner W, Fawcett J. An item-response theory evaluation of the Beck Hopelessness Scale. Cogn Ther Res 1992 Oct;16(5):579-587. [doi: 10.1007/BF01175143]
18. The Comprehensive R Archive Network. 2009. URL: http://cran.r-project.org/ [accessed 2017-02-11] [WebCite Cache ID 6oCI04qc1]
19. Rosseel Y. lavaan: An R package for structural euation modeling. J Stat Softw 2012;48(2) [FREE Full text]
20. Van der Ark LA. Mokken scale analysis in R. J Stat Softw 2007;20(11) [FREE Full text]
21. Choi SW, Gibbons LE, Crane PK. lordif: An R package for detecting differential item functioning using iterative hybrid ordinal logistic regression/item response theory and Monte Carlo simulations. J Stat Softw 2011 Mar 01;39(8):1-30 [FREE Full text] [Medline: 21572908]
22. Nydick SW. Package CATIRT. 2014 Apr 02. URL: http://cran.r-project.org/web/packages/catIrt/catIrt.pdf [accessed 2017-02-11] [WebCite Cache ID 6oCIO742h]
23. Smits N, Zitman FG, Cuijpers P, den Hollander-Gijsman ME, Carlier IV. A proof of principle for using adaptive testing in routine outcome monitoring: the efficiency of the Mood and Anxiety Symptoms Questionnaire -Anhedonic Depression CAT. BMC Med Res Methodol 2012 Jan 10;12:4 [FREE Full text] [doi: 10.1186/1471-2288-12-4] [Medline: 22233260]
24. Becker J, Fliege H, Kocalevent R, Bjorner JB, Rose M, Walter OB, et al. Functioning and validity of a Computerized Adaptive Test to measure anxiety (A-CAT). Depress Anxiety 2008;25(12):E182-E194. [doi: 10.1002/da.20482] [Medline: 18979458]
25. Fliege H, Becker J, Walter OB, Rose M, Bjorner JB, Klapp BF. Evaluation of a computer-adaptive test for the assessment of depression (D-CAT) in clinical application. Int J Methods Psychiatr Res 2009;18(1):23-36. [doi: 10.1002/mpr.274] [Medline: 19194856]
26. Walter OB, Becker J, Bjorner JB, Fliege H, Klapp BF, Rose M. Development and evaluation of a computer adaptive test for 'Anxiety' (Anxiety-CAT). Qual Life Res 2007;16 Suppl 1:143-155. [doi: 10.1007/s11136-007-9191-7] [Medline: 17342455]
27. Devine J, Fliege H, Kocalevent R, Mierke A, Klapp BF, Rose M. Evaluation of Computerized Adaptive Tests (CATs) for longitudinal monitoring of depression, anxiety, and stress reactions. J Affect Disord 2016 Jan 15;190:846-853. [doi: 10.1016/j.jad.2014.10.063] [Medline: 25481813]
28. Magnée T, de Beurs DP, de Bakker DH, Verhaak PF. Consultations in general practices with and without mental health nurses: an observational study from 2010 to 2014. BMJ Open 2016 Jul 18;6(7):e011579 [FREE Full text] [doi: 10.1136/bmjopen-2016-011579] [Medline: 27431902]
29. Wong AW, Heinemann AW, Miskovic A, Semik P, Snyder TM. Feasibility of computerized adaptive testing for collection of patient-reported outcomes after inpatient rehabilitation. Arch Phys Med Rehabil 2014 May;95(5):882-891. [doi: 10.1016/j.apmr.2013.12.024] [Medline: 24440363]
30. Psychometrics Centre. Concerto Adaptive Testing Platform. Cambridge: University of Cambridge; 2013. URL: http://www.psychometrics.cam.ac.uk/newconcerto [accessed 2017-02-11] [WebCite Cache ID 6oCHXdFO6]
31. PROMIS Assessment Center. URL: https://www.assessmentcenter.net/ [accessed 2017-02-11] [WebCite Cache ID 6oCHetK5j]
32. Kocalevent R, Rose M, Becker J, Walter OB, Fliege H, Bjorner JB, et al. An evaluation of patient-reported outcomes found computerized adaptive testing was efficient in assessing stress perception. J Clin Epidemiol 2009 Mar;62(3):278-87, 287.e1. [doi: 10.1016/j.jclinepi.2008.03.003] [Medline: 18639439]

Abbreviations

4DSQ: Four-Dimensional Symptom Questionnaire
CAT: computerized adaptive testing
CRC: category response curve
CFA: confirmatory factor analysis
DIF: differential item functioning
GP: general practitioner

XSL•FO
RenderX

GRM: graded response model
IRT: item response theory
RMSEA: root mean square error of approximation

Edited by G Eysenbach; submitted 26.08.16; peer-reviewed by W Gardner, A Geraghty; comments to author 05.12.16; revised version received 22.12.16; accepted 30.01.17; published 21.02.17.

Please cite as:
Magnée T, de Beurs DP, Terluin B, Verhaak PF
Applying Computerized Adaptive Testing to the Four-Dimensional Symptom Questionnaire (4DSQ): A Simulation Study
JMIR Ment Health 2017;4(1):e7
URL: http://mental.jmir.org/2017/1/e7/
doi:10.2196/mental.6545
PMID:28223264

©Tessa Magnée, Derek P de Beurs, Berend Terluin, Peter F Verhaak. Originally published in JMIR Mental Health (http://mental.jmir.org), 21.02.2017. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Mental Health, is properly cited. The complete bibliographic information, a link to the original publication on http://mental.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Virtual Reality for Management of Pain in Hospitalized Patients: Results of a Controlled Trial

Vartan C Tashjian[1*], MD; Sasan Mosadeghi[1], MD; Amber R Howard[1*], MPH; Mayra Lopez[1], MPH; Taylor Dupuy[1], BS; Mark Reid[1], PhD; Bibiana Martinez[1], MPH; Shahzad Ahmed[1], MD; Francis Dailey[1], MD; Karen Robbins[1], MD; Bradley Rosen[1], MD; Garth Fuller[1], MS; Itai Danovitch[1], MBA, MD; Waguih IsHak[1], MD; Brennan Spiegel[1], MSHS, MD

Cedars-Sinai Medical Center, Health Services Research, Los Angeles,CA, CA, United States

[*]these authors contributed equally

Corresponding Author:
Brennan Spiegel, MSHS, MD
Cedars-Sinai Medical Center
Health Services Research
8700 Beverly Blvd
Los Angeles,CA, CA, 90048
United States
Phone: 1 310 423 6239
Fax: 1 310 423 1802
Email: brennan.spiegel@cshs.org

Abstract

Background: Improvements in software and design and reduction in cost have made virtual reality (VR) a practical tool for immersive, three-dimensional (3D), multisensory experiences that distract patients from painful stimuli.

Objective: The objective of the study was to measure the impact of a onetime 3D VR intervention versus a two-dimensional (2D) distraction video for pain in hospitalized patients.

Methods: We conducted a comparative cohort study in a large, urban teaching hospital in medical inpatients with an average pain score of ≥3/10 from any cause. Patients with nausea, vomiting, dementia, motion sickness, stroke, seizure, and epilepsy and those placed in isolation were excluded. Patients in the intervention cohort viewed a 3D VR experience designed to reduce pain using the Samsung Gear Oculus VR headset; control patients viewed a high-definition, 2D nature video on a 14-inch bedside screen. Pre- and postintervention pain scores were recorded. Difference-in-difference scores and the proportion achieving a half standard deviation pain response were compared between groups.

Results: There were 50 subjects per cohort (N=100). The mean pain reduction in the VR cohort was greater than in controls (−1.3 vs −0.6 points, respectively; *P*=.008). A total of 35 (65%) patients in the VR cohort achieved a pain response versus 40% of controls (*P*=.01; number needed to treat=4). No adverse events were reported from VR.

Conclusions: Use of VR in hospitalized patients significantly reduces pain versus a control distraction condition. These results indicate that VR is an effective and safe adjunctive therapy for pain management in the acute inpatient setting; future randomized trials should confirm benefit with different visualizations and exposure periods.

Trial Registration: Clinicaltrials.gov NCT02456987; https://clinicaltrials.gov/ct2/show/NCT02456987 (Archived by WebCite at http://www.webcitation.org/6pJ1P644S)

(JMIR Ment Health 2017;4(1):e9) doi:10.2196/mental.7387

KEYWORDS

pain; virtual reality; inpatients; hospitalization

XSL•FO
RenderX

Introduction

Hospitalized patients frequently experience physical, emotional, and social distress that is exacerbated by a radical change in living environment, loss of customary rights and privileges, and a high prevalence of pain [1]. Nearly half of hospitalized patients experience pain, of which a quarter is considered "unbearable" [2]. In order to care for the whole patient, hospital clinicians must consider not only the physical impact of illness, but also the psychosocial impact. However, the dynamic nature of hospital medicine, coupled with limited time to spend with individual patients, poses challenges to offering holistic inpatient care.

Treatment of pain in the acute care setting is often focused on pharmacological management, which can yield inconsistent and suboptimal pain control [3]. However, extensive data reveal that adjunctive nonpharmacological techniques, such as cognitive behavioral therapy and relaxation techniques, can modify cognitions and behaviors that influence the perception of pain [4].

Virtual reality (VR) technology provides an immersive, multisensory, and three-dimensional (3D) environment that enables users to have modified experiences of reality by creating a sense of "presence" [5,6]. To date, VR has been used in numerous clinical settings to help treat anxiety disorders, control pain, support physical rehabilitation, and distract patients during wound care [5-13]. For example, VR coupled with medication is effective in decreasing pain during bandage changes for severe burns [7,11,14,15]. Similarly, VR reduces pain and provides positive distraction during routine procedures such as intravenous line placements [10] and dental procedures [8,16]. Other studies reveal that VR helps manage chronic pain conditions such as complex regional pain syndrome [17] and chronic neck pain [18]. By stimulating the visual, auditory, and proprioception senses, VR acts as a distraction to limit the user's processing of nociceptive stimuli [6].

However, the evidence to date supporting VR for inpatient care has shortcomings. In a recent meta-analysis of randomized controlled trials of VR for medical inpatients, we found 11 previous studies testing VR versus control conditions [19]. Although VR was effective and well tolerated in most studies, the trials were generally small, of variable methodological quality, limited to one indication at a time (eg, physical trauma, stroke rehabilitation, brain injury, cancer pain), and not focused on the acute care setting. It remains unclear if VR is superior to conventional means of pain distraction, such as viewing two-dimensional (2D) images, particularly in diverse populations of hospitalized, acute care patients suffering from varying types of pain. We have previously published data evaluating the feasibility and initial qualitative experience of using VR in hospitalized patients [20] but have not evaluated its impact on patient perception versus a control condition in hospitalized patients. In this study, we measured the impact of a 3D VR pain distraction experience versus a 2D pain distraction video in a diverse group of hospitalized patients with varying types of somatic and visceral pain.

Methods

Participants

We conducted a nonrandomized, comparative cohort study over a 6-month period to compare a 3D VR pain distraction experience (administered during the first 3-month recruitment period) with a 2D high-definition nature video on a 14-in screen placed in easy viewing proximity (administered during the second 3-month period), described further below. In both cohorts, we recruited adults (18+ years) admitted to the Inpatient Specialty Program at Cedars-Sinai Medical Center, a large, urban, tertiary care medical center. We excluded patients who could not consent, who were placed in contact isolation, or who had head wounds or bandages that interfere with the VR headset. In addition, because VR may cause motion sickness in some users [21], we excluded patients with a history of motion sickness and vertigo and anyone experiencing active nausea or vomiting. Patients with a history of seizures or epilepsy were also excluded to limit the theoretical risk of inducing seizures with VR (Samsung Gear user manual cites a 0.025% risk from pediatric data). Patients with an average pain score of ≥3 out of 10 during the 24 hours preceding patient screening were selected to participate in the study. We applied the same inclusion and exclusion criteria for both cohorts and approached all eligible patients in order of service admission.

Interventions

Virtual Reality Pain Distraction Experience

We administered VR using the Samsung (Ridgefield Park, NJ 07660) Gear Occulus headset fitted with a Samsung Galaxy S7 phone that delivers VR images and sound (Figure 1). We selected the Samsung Gear because it is commercially available, widely used, relatively inexpensive, has minimal visual latency, and offers a generally positive patient experience based on our previous research [20]. Higher-end tethered headsets, such as the Oculus Rift, are currently more expensive and onerous to use at scale in an inpatient setting. We used disposable sanitary covers and foam backing on each headset between patient uses and sanitized the equipment using the protocol we described in previous research [20]. Patients watched a 15-minute VR experience called Pain RelieVR, specifically designed to treat pain in patients who are bedbound or have limited mobility (AppliedVR, Los Angeles, CA, USA; Figure 2). Pain RelieVR is an immersive, 360-degree, game experience that takes place in a fantasy world where the user attempts to shoot balls at a wide range of moving objects by maneuvering his or her head toward the targets. This engaging, medium-intensity activity is free of interruption, offering the user a distracting experience designed to reduce the perception of pain. Pain RelieVR is a nonviolent and noncompetitive game that incorporates motivational music and features positively reinforcing sounds, animation, and direct messages to patients. Forward-facing action allows bedbound patients to engage without having to turn backward or contort into potentially uncomfortable positions. Figure 3 shows example patients using the Samsung Gear headsets (used with written patient permission).

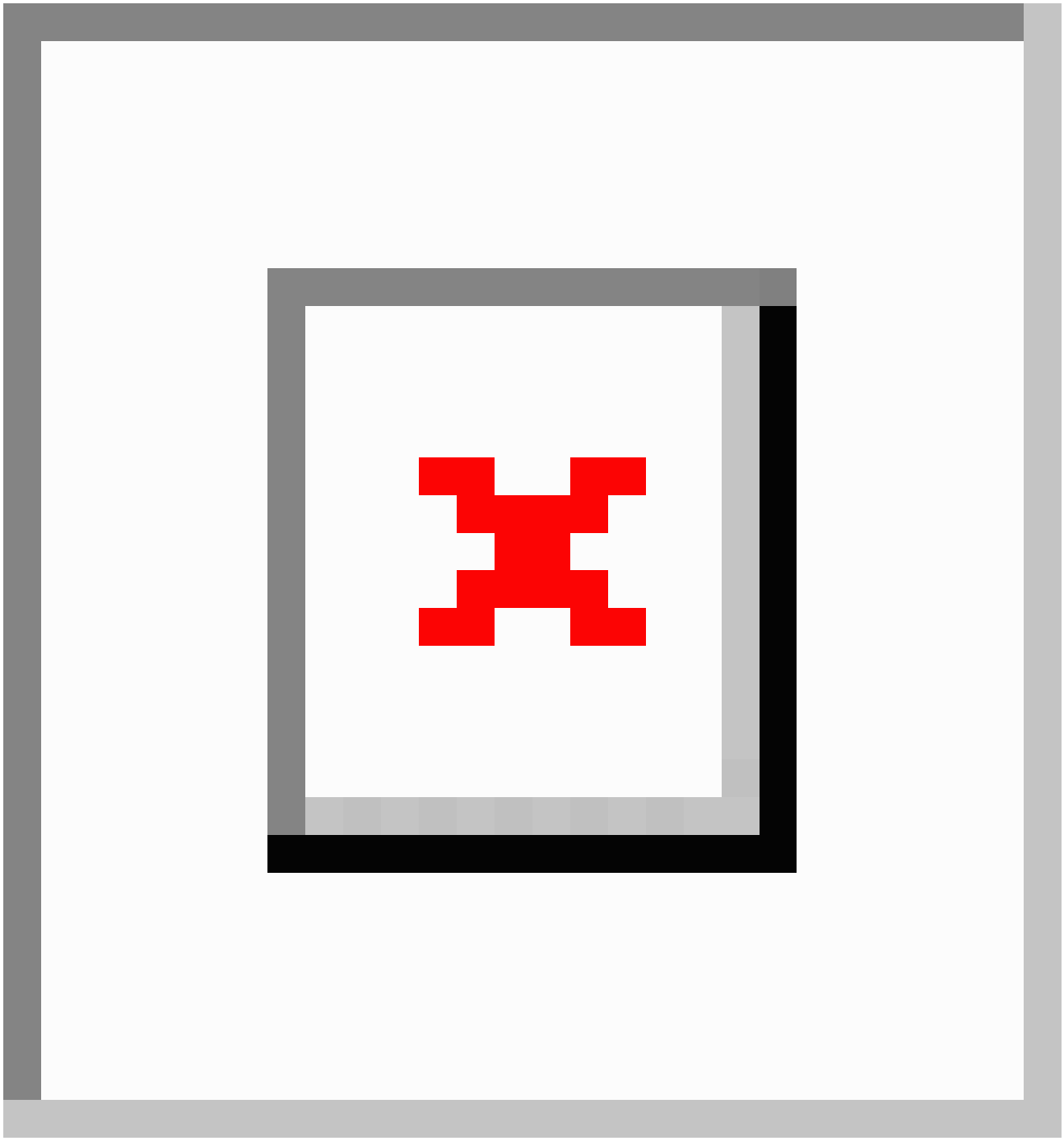
XSL•FO
RenderX

Figure 1. Samsung Gear virtual reality headset.



XSL•FO
RenderX

Figure 2. Screenshots of Pain RelieVR immersive pain distraction experience.



XSL•FO
RenderX

Figure 3. Hospitalized patients using Samsung Gear headsets (with written patient permission).



Two-Dimensional Pain Distraction Experience

During the control period, we administered a 2D high-definition (1080p) video depicting relaxing nature scenes, including mountain lakes and running streams from Patagonian vistas presented with an audio track featuring Native American Shaman music. We selected this video because of its high-definition images, positively reinforcing music, and emotionally calming content. Patients watched the video on a 14-in high-definition computer screen placed in easy viewing proximity on a bedside or chairside table. We ran the video for its first 15 minutes—the same duration as the VR intervention.

Study Procedures

Patients in both study periods were informed that researchers were testing the effect of a distraction experience on the perception of pain. Because it was important for the research staff to exhibit equipoise when describing the potential benefits

XSL•FO
RenderX

of the study intervention (ie, VR in cohort 1, nature video in cohort 2), we prepared a script that used neutral language regarding the study intervention. Once consented, patients rated their current pain using a standard 11-point numeric rating scale (NRS), ranging from 0 (no pain) to 10 ("the worst pain of your life"). The NRS is a validated measure of pain widely employed in clinical practice based on its ease of use, high compliance rates, and responsiveness to detect meaningful changes in pain [22]. Although predominantly tested for somatic pain, we have previously demonstrated psychometric validity of the NRS for visceral pain [23]. Patients in both groups repeated the NRS assessment 2 minutes after completion of the intervention. In addition, because VR has potential for adverse events, we evaluated for dizziness, vertigo, nausea, vomiting, and seizures. We also measured changes in blood pressure and heart rate in the VR group.

Statistical Analysis and Sample Size

We calculated descriptive statistics for key demographic and clinical characteristics between groups, including age, sex, race and ethnicity, primary reason for hospitalization, and baseline pain scores. We performed bivariate analysis to evaluate for significant differences between groups, including two-sample *t* tests for continuous parametric variables and chi-square tests for categorical variables.

We next compared pre- and postintervention pain scores within subjects (using paired *t* tests) and then compared difference-in-difference (DID) pain scores between cohorts (using the rank sum test given nonparametric DID distributions). In addition, we classified each individual patient as a responder or nonresponder using the criterion standard of achieving an effect size of ≥0.5 standard deviation on the pain scale, a "medium" effect size using the rule of Cohen, and a value corresponding to the minimum clinically important difference (MCID) using the rule of Norman [24]. We compared the proportion responding between groups using chi-square test and calculated the number needed to treat (NNT) between groups.

Because the study used a mixed factorial design, we used a repeated-measures analysis of variance (ANOVA), which incorporated both a between-subjects and within-subject factor (pretest-posttest). The *F* ratio of interest in the analysis was the interaction between the 2 factors, representing the treatment main effect. After estimation, we calculated eta squared (η^2), which can be interpreted as how much of the variation in the sample can be explained by the interaction.

Finally, to adjust for potential differences in patient characteristics between groups, we performed multivariable linear regression analysis to test the independent effect of VR on pain reduction, adjusting for demographic and clinical variables. To support a regression model with 5 covariates, and assuming at least 20 subjects per covariate, we required a total sample size of 100 patients. All analyses were conducted using Stata 14 (StataCorp).

Approval

The Cedars-Sinai Institutional Review Board approved this study (Cedars IRB Pro00039751).

Results

Patient Characteristics

There were 50 patients in each group (N=100). Table 1 provides baseline demographic and clinical characteristics. There were no significant differences between groups for age, sex, race, or ethnicity. The reasons for admission between groups were similar except for the proportion admitted for pulmonary reasons (higher in control group) and orthopedic reasons (higher in VR group). The mean baseline pain score was the same (5.4 points) in both groups.

XSL•FO
RenderX

Table 1. Patient characteristics.

Patient characteristics	VR[a] group (n=50), n (%)	Controls (n=50), n (%)	*P* value[b]
Age in years, mean (SD)	54.48 (17.9)	47.7 (15.2)	.10
Sex, female	30 (60)	23 (46)	
Sex, male	20 (40)	27 (54)	.16
Race/ethnicity			.73
Non-Hispanic white	25 (50)	26 (52)	.94
Black	11 (22)	14 (28)	.55
Asian	2 (4)	2 (4)	>.99
Hispanic	10 (20)	8 (16)	.64
Other	2 (4)	0	.15
Reason for hospitalization			.007
Gastrointestinal	9 (18)	19 (38)	.08
Cardiac	8 (16)	3 (6)	.17
Pain control	7 (14)	2 (4)	.91
Infectious disease	6 (12)	4 (8)	.08
Hematological/oncological	1 (2)	4 (8)	.25
Neurological	1 (2)	2 (4)	.58
Postsurgical	8 (16)	4 (8)	.27
Pulmonary	4 (8)	0	.04
Orthopedic	0	6 (12)	.01
Other	6 (12)	6 (12)	>.99

[a]VR: virtual reality.

[b]We used *t* tests for continuous variable bivariate analyses and chi-square tests for categorical analyses (when differences were found, a test of proportions was used).

Difference in Pain Scores

When focusing on within-subject changes in pain, there was a significant drop in pain in both the patients in the VR group (pre-VR mean 5.4, SD 2.6; post-VR mean 4.1, SD 2.7; delta=1.3; *P*<.001; percent reduction=24%) and the control patients (preintervention mean 5.4, SD 2.6; postintervention mean 4.8, SD 2.7; delta=0.6; *P*<.001; percent reduction=13.2%), with a larger drop in the VR group than controls (Table 2). When comparing *between* groups, the DID of −0.7 points was highly significant in favor of VR (*P*=.008). Using a binary responder definition of a ≥0.5 standard deviation drop in pain, there was a higher proportion of responders in the VR group (65%) versus the control group (40%; *P*=.01, absolute difference=25%, NNT=4). In the repeated-measures ANOVA, results showed that VR elicited a statistically significant difference in pain scores following treatment, $F_{1,97}$=7.45, *P*<.001. The calculated η^2 was .07, which Cohen considers equivalent to an effect size slightly greater than medium. In multivariable regression analysis adjusting for age, race, ethnicity, sex, and reason for hospitalization, VR remained a significant predictor of pain reduction (beta coefficient=−0.65 point, 95% CI −1.3 to 0, *P*=.05). There were no differences in the effect of VR by age, race, ethnicity, sex, or reason for hospitalization.

Table 2. Results on pain.

Group	Preintervention pain score, mean (SD)	Postintervention pain score, mean (SD)	Difference (% drop)	*P* value
Virtual reality	5.4 (2.6)	4.1 (2.7)	1.3 (24)	<.001
Control	5.4 (2.6)	4.8 (2.7)	0.6 (13.2)	<.001
Between-group difference			0.7	.008

XSL•FO
RenderX

Virtual Reality Adverse Event Monitoring

All patients in the VR group completed the Pain RelieVR experience in its entirety and reported no adverse outcomes. There was no statistically significant difference between pre-VR and post-VR systolic blood pressure, diastolic blood pressure, and heart rate measurements (P>.05; Table 3).

Table 3. Effect of virtual reality on blood pressure and heart rate.

Outcome	Pre-VR[a]	Post-VR	*P* value
Systolic blood pressure, mm Hg (n=50)			.32
Mean	119.8	118.6	
SD	17.4	16.9	
Range	83-175	84-152	
95% CI	115.4-124.2	114.37-122.93	
Diastolic blood pressure, mm Hg (n=50)			.18
Mean	66.8	69.5	
SD	11.7	11.2	
Range	46-99	48-97	
95% CI	63.85-69.75	65.7-71.4	
Heart rate, beats per minute (n=50)			.88
Mean	77.9	77.8	
SD	16.2	16.8	
Range	46-118	49-122	
95% CI	73.82-82.04	73.53-82.03	

[a]VR: virtual reality.

Discussion

Although VR has been studied in a variety of conditions including wound care, rehabilitation, and anxiety, its effectiveness for managing pain in hospitalized patients has not been fully examined. In this study, we found that use of a 15-minute VR intervention in a diverse group of hospitalized patients resulted in statistically significant and clinically relevant (NNT=4) improvements in pain versus a control distraction video without triggering adverse events or altering vital signs. These results indicate that VR may be an effective adjunctive therapy to complement traditional pain management protocols in hospitalized patients.

Whereas previous VR research has traditionally focused on specific types of pain [6-10,12,25,26], our study is unique for evaluating VR across a wide range of somatic and visceral pain conditions. In multivariable regression analysis, we found the effect of VR was independent of the reason for hospitalization or primary cause of pain, suggesting that VR has benefits across wide groups of inpatients. Because this study is focused on a single pain distraction visualization, future research should evaluate whether and how to tailor VR content for specific pain syndromes, as this may have incremental benefits over a single, generic VR intervention. Similarly, future research should investigate active VR interventions, such as mindful meditation visualizations, in addition to passive distraction experiences. Nonetheless, the finding that a single intervention improved pain across diverse conditions suggests a common mechanism for the pain benefits of VR.

It remains unknown exactly how VR works to reduce pain perception across conditions. Most proposed mechanisms attribute the benefit to simple distraction [6]. When the mind is deeply engaged in an immersive experience, it becomes difficult, if not impossible, to perceive stimuli outside of the field of attention [27]. By “hijacking” the auditory, visual, and proprioception senses, VR is thought to create an immersive distraction that restricts the mind from processing pain [6]. Additional research should evaluate the neurobiological mechanisms of VR across pain conditions and measure whether its benefits in hospitalized patients, in particular, extend beyond the immediate VR treatment period.

Our study has several important limitations. First, although we compared results between 2 well-characterized groups in this early phase VR study, this was not a randomized controlled trial. Nonetheless, we performed multivariable regression analysis to adjust for variations between groups and still found that exposure to VR was a significant predictor of reduced pain. Future research should randomize patients in a larger, prospective comparison trial. Second, the VR intervention was only 15 minutes long and included only one visualization; it is possible that pain may rebound after VR and/or longer-term benefits require more sustained and repeated exposure to varying content. Future research should evaluate the effect of altering the duration, intensity, frequency, and content of VR compared with control conditions. Third, because this was a onetime intervention we did not measure the impact of VR on use of pain medications, hospital length of stay, or postdischarge satisfaction scores. Nonetheless, this study is, to our knowledge, the first to measure the impact of VR on pain management

XSL•FO
RenderX

versus a control condition among a diverse group of hospitalized patients. Fourth, it is impossible to know whether the greater effectiveness of the VR condition was due to presenting a 3D virtual environment (vs a 2D environment) or playing a highly involving, active game versus a passive distraction experience. It is not possible from this experimental design to determine definitively if the observed effect in pain reduction was due to the 3D versus 2D experience, active versus passive components, variations in visual and audio between conditions, or other attributes that measurably vary between arms. Our pragmatic trial is a first step along a path of additional investigations; future research should test other control conditions and visualization to understand whether there are unique benefits of the 3D VR experience over other control conditions. Finally, our protocol did not track the characteristics and reasons for patient ineligibility or refusal to use VR. However, our previous research found that many hospitalized patients are not eligible to use VR for various reasons, including active neurological symptoms, ongoing nausea or vomiting, injury to the face or neck, epilepsy, too frail or debilitated, or receiving mechanical ventilation. Moreover, we found that among those who are medically eligible to use VR, up to two-thirds are unwilling to try the technology, particularly older individuals. Taken together, these findings reveal barriers to widespread use of VR in hospitalized patients. Future research should study whether adoption rates are increasing and whether using VR is cost-effective for hospitals given variable patient uptake.

These results indicate that VR is an effective, safe, and feasible intervention to aid with pain management among diverse hospitalized patients. Larger randomized clinical trials are needed to better characterize its impact on longer-term pain perception, resource utilization, and postdischarge outcomes.

Acknowledgments

All aspects of the study design, performance, analysis, data interpretation, and writing were independently conducted by the investigators using medical center funding.

Conflicts of Interest

VR devices and software were provided in kind by AppliedVR. There was no external funding for this research study.

References

1. Henderson AR. Psychology of hospitalized patients. J Natl Med Assoc 1976 Sep;68(5):378-383. [Medline: 1003569]
2. Helfand M, Freeman M. Assessment and management of acute pain in adult medical inpatients: a systematic review. Pain Med 2009 Oct;10(7):1183-1199. [doi: 10.1111/j.1526-4637.2009.00718.x] [Medline: 19818030]
3. Turk DC, Wilson HD, Cahana A. Treatment of chronic non-cancer pain. Lancet 2011 Jun 25;377(9784):2226-2235. [doi: 10.1016/S0140-6736(11)60402-9] [Medline: 21704872]
4. Okifuji A, Ackerlind S. Behavioral medicine approaches to pain. Anesthesiol Clin 2007 Dec;25(4):709-19, v.12. [doi: 10.1016/j.anclin.2007.07.009] [Medline: 18054141]
5. Malloy K, Milling L. The effectiveness of virtual reality distraction for pain reduction: a systematic review. Clin Psychol Rev 2010 Dec;30(8):1011-1018. [doi: 10.1016/j.cpr.2010.07.001] [Medline: 20691523]
6. Li A, Montaño Z, Chen VJ, Gold JI. Virtual reality and pain management: current trends and future directions. Pain Manag 2011 Mar;1(2):147-157 [FREE Full text] [doi: 10.2217/pmt.10.15] [Medline: 21779307]
7. Carrougher GJ, Hoffman HG, Nakamura D, Lezotte D, Soltani M, Leahy L, et al. The effect of virtual reality on pain and range of motion in adults with burn injuries. J Burn Care Res 2009;30(5):785-791 [FREE Full text] [Medline: 19692911]
8. Furman E, Jasinevicius TR, Bissada NF, Victoroff KZ, Skillicorn R, Buchner M. Virtual reality distraction for pain control during periodontal scaling and root planing procedures. J Am Dent Assoc 2009 Dec;140(12):1508-1516. [Medline: 19955069]
9. Garrett B, Taverner T, Masinde W, Gromala D, Shaw C, Negraeff M. A rapid evidence assessment of immersive virtual reality as an adjunct therapy in acute pain management in clinical practice. Clin J Pain 2014 Dec;30(12):1089-1098. [doi: 10.1097/AJP.0000000000000064] [Medline: 24535053]
10. Gold JI, Kim SH, Kant AJ, Joseph MH, Rizzo AS. Effectiveness of virtual reality for pediatric pain distraction during i.v. placement. Cyberpsychol Behav 2006 Apr;9(2):207-212. [doi: 10.1089/cpb.2006.9.207] [Medline: 16640481]
11. Hoffman HG, Doctor JN, Patterson DR, Carrougher GJ, Furness TA. Virtual reality as an adjunctive pain control during burn wound care in adolescent patients. Pain 2000 Mar;85(1-2):305-309. [Medline: 10692634]
12. Hoffman HG, Garcia-Palacios A, Patterson DR, Jensen M, Furness 3rd T, Ammons Jr WF. The effectiveness of virtual reality for dental pain control: a case study. Cyberpsychol Behav 2001 Aug;4(4):527-535. [doi: 10.1089/109493101750527088] [Medline: 11708732]
13. Morris LD, Louw QA, Crous LC. Feasibility and potential effect of a low-cost virtual reality system on reducing pain and anxiety in adult burn injury patients during physiotherapy in a developing country. Burns 2010 Aug;36(5):659-664. [doi: 10.1016/j.burns.2009.09.005] [Medline: 20022431]
14. Hoffman HG, Patterson DR, Carrougher GJ. Use of virtual reality for adjunctive treatment of adult burn pain during physical therapy: a controlled study. Clin J Pain 2000 Sep;16(3):244-250. [Medline: 11014398]

XSL•FO
RenderX

15. Hoffman HG, Patterson DR, Seibel E, Soltani M, Jewett-Leahy L, Sharar SR. Virtual reality pain control during burn wound debridement in the hydrotank. Clin J Pain 2008 May;24(4):299-304. [doi: 10.1097/AJP.0b013e318164d2cc] [Medline: 18427228]
16. Hoffman HG, Patterson DR, Carrougher GJ, Sharar SR. Effectiveness of virtual reality-based pain control with multiple treatments. Clin J Pain 2001 Sep;17(3):229-235. [Medline: 11587113]
17. Sato K, Fukumori S, Matsusaki T, Maruo T, Ishikawa S, Nishie H, et al. Nonimmersive virtual reality mirror visual feedback therapy and its application for the treatment of complex regional pain syndrome: an open-label pilot study. Pain Med 2010 Apr;11(4):622-629. [doi: 10.1111/j.1526-4637.2010.00819.x] [Medline: 20202141]
18. Sarig-Bahat H, Weiss PL, Laufer Y. Neck pain assessment in a virtual environment. Spine (Phila Pa 1976) 2010 Feb 15;35(4):E105-E112. [doi: 10.1097/BRS.0b013e3181b79358] [Medline: 20110842]
19. Dascal J, Reid M, Ishak WW, Spiegel B, Recacho J, Rosen B, et al. Virtual reality and medical inpatients: a systematic review of randomized controlled trials. Innov Clin Neurosci 2017;14(1-2):14-21 (forthcoming).
20. Mosadeghi S, Reid MW, Martinez B, Rosen BT, Spiegel BM. Feasibility of an immersive virtual reality intervention for hospitalized patients: an observational cohort study. JMIR Ment Health 2016 Jun 27;3(2):e28 [FREE Full text] [doi: 10.2196/mental.5801] [Medline: 27349654]
21. Nichols S, Patel H. Health and safety implications of virtual reality: a review of empirical evidence. Appl Ergon 2002 May;33(3):251-271. [Medline: 12164509]
22. Hjermstad MJ, Fayers PM, Haugen DF, Caraceni A, Hanks GW, Loge JH, European Palliative Care Research Collaborative (EPCRC). Studies comparing numerical rating scales, verbal rating scales, and visual analogue scales for assessment of pain intensity in adults: a systematic literature review. J Pain Symptom Manage 2011 Jun;41(6):1073-1093. [doi: 10.1016/j.jpainsymman.2010.08.016] [Medline: 21621130]
23. Spiegel B, Bolus R, Harris LA, Lucak S, Naliboff B, Esrailian E, et al. Measuring irritable bowel syndrome patient-reported outcomes with an abdominal pain numeric rating scale. Aliment Pharmacol Ther 2009 Dec 01;30(11-12):1159-1170 [FREE Full text] [doi: 10.1111/j.1365-2036.2009.04144.x] [Medline: 19751360]
24. Norman GR, Sloan JA, Wyrwich KW. Interpretation of changes in health-related quality of life: the remarkable universality of half a standard deviation. Med Care 2003 May;41(5):582-592. [doi: 10.1097/01.MLR.0000062554.74615.4C] [Medline: 12719681]
25. Schmitt YS, Hoffman HG, Blough DK, Patterson DR, Jensen MP, Soltani M, et al. A randomized, controlled trial of immersive virtual reality analgesia, during physical therapy for pediatric burns. Burns 2011 Feb;37(1):61-68 [FREE Full text] [doi: 10.1016/j.burns.2010.07.007] [Medline: 20692769]
26. van Twillert B, Bremer M, Faber AW. Computer-generated virtual reality to control pain and anxiety in pediatric and adult burn patients during wound dressing changes. J Burn Care Res 2007;28(5):694-702. [doi: 10.1097/BCR.0B013E318148C96F] [Medline: 17667488]
27. McCaul KD, Malott JM. Distraction and coping with pain. Psychol Bull 1984 May;95(3):516-533. [Medline: 6399756]

Abbreviations

ANOVA: analysis of variance
DID: difference-in-difference
NNT: number needed to treat
NRS: numeric rating scale
3D: three-dimensional
2D: two-dimensional
VR: virtual reality

Edited by J Torous; submitted 26.01.17; peer-reviewed by W Greenleaf, J Firth, B Garrett; comments to author 15.02.17; revised version received 16.02.17; accepted 21.02.17; published 29.03.17.

Please cite as:
Tashjian VC, Mosadeghi S, Howard AR, Lopez M, Dupuy T, Reid M, Martinez B, Ahmed S, Dailey F, Robbins K, Rosen B, Fuller G, Danovitch I, IsHak W, Spiegel B
Virtual Reality for Management of Pain in Hospitalized Patients: Results of a Controlled Trial
JMIR Ment Health 2017;4(1):e9
URL: http://mental.jmir.org/2017/1/e9/
doi:10.2196/mental.7387
PMID:28356241

XSL•FO
RenderX

©Vartan C Tashjian, Sasan Mosadeghi, Amber R Howard, Mayra Lopez, Taylor Dupuy, Mark Reid, Bibiana Martinez, Shahzad Ahmed, Francis Dailey, Karen Robbins, Bradley Rosen, Garth Fuller, Itai Danovitch, Waguih IsHak, Brennan Spiegel. Originally published in JMIR Mental Health (http://mental.jmir.org), 29.03.2017. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Mental Health, is properly cited. The complete bibliographic information, a link to the original publication on http://mental.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org

XSL•FO
RenderX