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Addressing Depression Comorbid With Diabetes or Hypertension in Resource-Poor Settings: A Qualitative Study About User Perception of a Nurse-Supported Smartphone App in Peru

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Abstract

Background: Smartphone apps could constitute a cost-effective strategy to overcome health care system access barriers to mental health services for people in low- and middle-income countries.

Objective: The aim of this paper was to explore the patients’ perspectives of CONEMO (Emotional Control, in Spanish: Control Emocional), a technology-driven, psychoeducational, and nurse-supported intervention delivered via a smartphone app aimed at reducing depressive symptoms in people with diabetes, hypertension or both who attend public health care centers, as well as the nurses’ feedback about their role and its feasibility to be scaled up.

Methods: This study combines data from 2 pilot studies performed in Lima, Peru, between 2015 and 2016, to test the feasibility of CONEMO. Interviews were conducted with 29 patients with diabetes, hypertension or both with comorbid depressive symptoms who used CONEMO and 6 staff nurses who accompanied the intervention. Using a content analysis approach, interview notes from patient interviews were transferred to a digital format, coded, and categorized into 6 main domains: the perceived health benefit, usability, adherence, user satisfaction with the app, nurse’s support, and suggestions to improve the intervention. Interviews with nurses were analyzed by the same approach and categorized into 4 domains: general feedback, evaluation of training, evaluation of study activities, and feasibility of implementing this intervention within the existing structures of health system.

Results: Patients perceived improvement in their emotional health because of CONEMO, whereas some also reported better physical health. Many encountered some difficulties with using CONEMO, but resolved them with time and practice. However, the interactive elements of the app, such as short message service, android notifications, and pop-up messages were mostly perceived as challenging. Satisfaction with CONEMO was high, as was the self-reported adherence. Overall, patients evaluated the nurse accompaniment positively, but they suggested improvements in the technological training and an increase in the amount of contact. Nurses reported some difficulties in completing their tasks and explained that the CONEMO intervention activities competed with their everyday work routine.

Conclusions: Using a nurse-supported smartphone app to reduce depressive symptoms among people with chronic diseases is possible and mostly perceived beneficial by the patients, but it requires context-specific adaptations regarding the implementation...
of a task shifting approach within the public health care system. These results provide valuable information about user feedback for those building mobile health interventions for depression.

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**KEYWORDS**

mental health; depression; noncommunicable diseases; mHealth; smartphone; developing countries

**Introduction**

Mental health disorders are one of the main health burdens worldwide. Of the 20 leading causes of years lived with disability in the world, 9 of them are mental, neurological or substance use disorders [1]; neuropsychiatric disorders make a contribution of 13% to 14% to the global burden of disease, measured by the disability-adjusted life years (DALYs), because of the mortality and years of life lost derived from the time lived with compromised health [2-4]. In Peru, neuropsychiatric disorders are even considered as the ones that cause the highest burden of disease in the country, with a contribution of 16% to the DALYs [5]. Furthermore, unipolar depression is the main cause of burden of disease among this group [3] and is even higher among those with comorbid chronic noncommunicable diseases (NCDs), such as diabetes or hypertension [6-12]. Considering this high comorbidity, the great incidence of NCDs in low- and middle-income countries (LMICs) [13,14], as well as the important possible negative consequences of this relationship on health outcomes [6,11,12,14-18] and adherence to treatment [8,16], interventions specifically designed for individuals with depression and comorbid diabetes, hypertension or both are needed.

Access to mental health services is poor across LMICs. For example, in Peru, most health insurance does not cover mental health care [5]. Furthermore, there are far fewer psychologists and psychiatrists per inhabitant than in other upper- and middle-income countries, and of those who are available, 85% are located in Lima, the Peruvian capital [19]. Only 24.3% of the population in Lima with mental health disorders receive any mental health care [20], which is even less than 10.4% in rural Andean regions [21]. One approach to confront system-related barriers for mental health care is task shifting [22-24]. Shifting tasks within health care from a specialized professional to a person not specialized in the same field, for example, from a psychiatrist to a comprehensively trained nurse or other health worker not specialized in mental health, is a cost-effective [25,26] and cost-saving approach [27-31]. Similarly, it has shown promising results for a wide variety of health outcomes, including mental health conditions [32,33] such as depression [29,33], and could therefore be an ideal option for LMIC settings to amplify the access to health care [34] where human resources are scarce.

Other strategies to overcome health system barriers and make mental health care more accessible to the community [35,36] are mobile health (mHealth) [35,37-41] and other digital self-help interventions [42-45], which have been shown to improve mental health-related outcomes. There are several mobile depression apps already on the market, but in addition to stand-alone, unguided self-management apps, linking interventions to existing resources from local health care systems merits exploration. Furthermore, many of the depression apps currently on the market often lack a solid theoretical background or do not follow clinical guidelines that have already proven to be effective [46,47], and besides, most of them are not available in Spanish. Evidence from high-income countries indicates that the effectiveness of and adherence to digital interventions is higher when the health app is easy to use [39,48,49], is individually tailored [46], and includes human interaction [48,50-52]. Hence, it is crucial to evaluate the users’ perspective and feasibility of using mHealth apps in the LMIC context.

Although they are not ubiquitous yet, as pervasiveness of smartphones is continuously increasing in developing countries [53,54], mHealth apps will become more needed in the near future. In Peru, the access to smartphones increased from 14.8% to 30.8% among people aged between 46 and 50 years and from 6.8% to 18.0% in those aged 51 years or older in only 1 year (2014-2015) [55], and it is expected that these percentages will continue to grow.

The Latin America Treatment and Innovation Network in Mental Health (LATIN-MH) [56] integrated these strategies and developed a new smartphone app, CONEMO (*Emotional Control*, in Spanish: *Control Emocional*), a technology-driven, psychoeducational, and nurse-supported intervention aimed at reducing depressive symptoms in people with diabetes, hypertension or both. This study is derived from the qualitative formative research conducted in Lima, Peru, in preparation for a randomized controlled trial testing the effectiveness of CONEMO. The aims of this study were to explore (1) the experience of patients using CONEMO with regard to perceived health benefit, usability, adherence to CONEMO, satisfaction, suggestions for CONEMO, as well as the evaluation of the nurse-support received and (2) the experience of nurses supporting CONEMO users regarding general nurse feedback, evaluation of training received, evaluation of activities related to the study, and their perception of the feasibility of using this type of *self-management-plus-coaching* approach within the Peruvian public health care system. The quantitative outcomes of the pilot studies will be reported elsewhere [57].

**Methods**

**Study Design and Theoretical Framework**

This study analyzes the qualitative information acquired from interviews with patients and nurses about their experiences in 2 pilot studies. Interviews were selected as the most suitable technique, which were applied after their participation in these studies. The data were analyzed using qualitative content analysis, as, for example, described by Bengtsson [58], considering it as “a research method that provides a systematic and objective means to make valid inferences from verbal,
visual, or written data in order to describe and quantify specific phenomena” [59].

**Setting**

The 2 pilot studies were conducted between 2015 and 2016 in Lima; the first pilot study was implemented in 1 general hospital of the Ministry of Health (MINSA) and the second in 2 primary health care centers of EsSalud, Perú’s Social Security System. Those are 2 distinct public health care systems in Peru, which differ in their organization and functioning. The reason for conducting 2 pilot studies was, first, to pilot test the implementation in the 2 different national health care systems, and second, to test the feasibility of working with staff nurses from the health care system within this study instead of hired nurses, which was not possible in the first pilot study in the MINSA hospital.

**Participant Selection**

**Sampling**

The study integrated data from 2 groups of participants: the patient’s experience with CONEMO and the nurses’ experience of conducting the nurse-support of CONEMO within the health care system.

Using a convenience sampling strategy, patients were selected based on the following criteria: having a diagnosis of diabetes, hypertension or both by a physician or receiving treatment for it, being aged at least 21 years, being able to read and write in Spanish (all of the above were self-reported), and experiencing clinically significant depressive symptoms, as measured by the Patient Health Questionnaire-9 (cutoff score ≥10) [60]. Patients who were pregnant or showed cognitive impairment (measured with the Brief Community Screening Instrument for Dementia [61]) or psychotic symptoms (measured with the Psychosis Screening Questionnaire [62]) were excluded.

In the first pilot study, implemented in a hospital of the MINSA, 1 nurse was hired by the project. In the second pilot study, nurses from the Social Security System were selected and assigned to the study by the health care centers’ administration. In 1 health care center, all 5 nurses who were working there at the time were assigned to participate in the study, whereas in the other health care center, 1 nurse who was working in the elderly adult program was selected.

**Method of Approach**

In the MINSA hospital, recruitment took place in the endocrinology and cardiology outpatient clinics, whereas in the 2 primary health care centers, patients were recruited in the waiting areas or in the elderly adult consultation unit that monitors people with NCDs. Some patients were approached before or after their regular consultations, whereas others were referred to the fieldwork team by health care providers. Patients were screened by 1 of 4 fieldworkers who were all psychologists. If the inclusion criteria were fulfilled, they were invited to participate in the 6-week study and to sign a consent form.

Afterward, patients were invited to return to the health care center to complete a baseline questionnaire. Subsequently, they were assigned to a nurse who then scheduled an individual appointment with each patient to train them and provide the study materials. As, at the time of the pilot, smartphones were not yet ubiquitous among low-income Peruvians, all patients were given an Android smartphone with CONEMO installed as well as 2 guidebooks: one about how to use the smartphone and CONEMO and one about the research project. The nurses trained the patients in the use of the technology and informed them that their activities could be followed on a Web-based platform and that they would receive at least 2 monitoring phone calls throughout the intervention period to address difficulties if applicable.

The nurses were approached via the centers’ administration. After the managers of the centers accepted to participate, they selected the nurses and facilitated the contact to the research team. Afterward, all nurses underwent a 3-month theoretical and practical training course with 1 to 2 hours of weekly training sessions to perform their activities before starting to receive patients.

**Sample Size and Nonparticipation**

Over the 2 pilot studies, 45 patients signed the consent form to participate, but 12 of them did not return to the health care center to receive CONEMO. Of the 33 patients who finally received CONEMO, 29 responded to the interviews (15 of pilot study 1, monitored by a hired nurse, and 14 of pilot study 2, monitored by staff nurses from the health care system).

With regard to the nurses, 6 staff nurses, who were working within the Social Security System and who participated in the second pilot study, were interviewed after finalizing the pilot study activities. The nurse hired in the first pilot study was not considered in the interviews, considering that she would not represent the perspectives of someone working within the health care system.

**Intervention: CONEMO (Emotional Control)**

CONEMO is a technology-driven, psychoeducational, and nurse-supported intervention that was delivered via a smartphone app (see Multimedia Appendix 1 for a screenshot of CONEMO). A literature review was conducted to develop both the content, which was based on the theoretical framework of behavioral activation [63-66], as well as the design and structure of the CONEMO app.

Behavioral activation aims at reducing depression by motivating patients to identify and complete activities to obtain a sense of pleasure and accomplishment [66]. In that sense, the content of the intervention included psychoeducation about depression, various lists of potential activities that patients could be interested in, motivational content to stimulate activity completion, as well as strategies to help patients complete these activities. These content elements were delivered in the form of both text and videos. The videos featured a middle-aged woman representing a health practitioner who did not embody any specific social class or background.

Providing a list of suggested activities to the participant was also used in other apps based on behavioral activation to lower depressive symptoms [67,68]. Previous behavioral activation
research suggested a list of 11 activity categories in which patients could start doing activities [66]. Owing to the length of our intervention, those 11 domains were regrouped into 3 categories: pleasant activities (eg, based on hobbies and entertainment among others, such as reading a book or meeting friends), healthy activities (based on sports and health, such as following their indicated diet and exercising), and tasks (based on domestic activities, which included activities such as cleaning the house). In this process, activities were discussed and adapted by the research team to ensure the appropriateness of the listed activities, considering the target population’s health characteristics and culture. Finally, CONEMO included interactive elements, such as Android notifications and dialogue pop-ups to remind patients to complete their sessions and activities and let them give feedback, short message service (SMS) text messaging to remind them of their appointments with the nurse, as well as an option to request help from the nurse.

For the development of the structure of the CONEMO app, other behavioral activation intervention outlines, as well as existing mobile intervention designs, were considered. Although in-person interventions based on behavioral activation usually have a duration of 5 to 12 weekly sessions, with each session lasting approximately 45 min [69,70], interventions using technology need to deliver the core elements of the treatment by adapting them to the interface used and not as a mere copy of the content [71]. Other mobile interventions using behavioral activation were typically designed for a duration of 8 to 10 weekly sessions but were also accompanied with weekly psychotherapy sessions [67,68] or pharmacotherapy [72]. Considering the nurse accompanying the CONEMO intervention would only give technical support and that app developers recommend designing interventions of “high frequency, low intensity, and shorter time commitment” [71], it was decided to include 18 sessions in total, delivered 3 times a week over a period of 6 weeks. The completion time for each session (excluding the suggested outside-app activity) was estimated to take between 5 and 10 min.

The role of the nurses was to train all patients in the use of the app and the smartphone, followed by regular monitoring of the patients’ participation throughout the 6 weeks of intervention via a Web-based platform, the nurse dashboard. The nurse-support protocol was based on the principles of supportive accountability [52], with the aim of maintaining patient engagement. Nurses were instructed to contact the patient periodically to positively reinforce use, inquire if they had any difficulties, and resolve possible problems with using CONEMO. In addition, the nurse dashboard served as an activity and progress record, allowing nurses to log their activities, such as the completed phone calls or other contacts they had with the patients. The roughly estimated time expected to be invested per patient was around 2.5 hours in total over the 6-week period (45 to 60 min for the first appointment used for training, 15 to 30 min for the last appointment, and 15 min per remaining week for follow-up calls). Furthermore, during the intervention, all nurses took part in weekly supervision meetings with a psychologist, in which particular cases, tasks, and difficulties were addressed. These supervision meetings were expected to take around 15 to 45 min weekly.

The technology and intervention used in this study was created in collaboration with representatives from the Universidad Peruana Cayetano Heredia in Lima, Peru, and the University of São Paulo in São Paulo, Brazil. Northwestern University’s Center for Behavioral Intervention Technologies in Chicago, United States, supported the design work and provided all software programming. CONEMO was developed to be adaptable linguistically and culturally, providing versions in Spanish, Portuguese, and English.

**Data Collection**

After the 6 weeks of intervention, the trial manager (LRB) and the clinical coordinator (LH)—both female psychologists—conducted the interviews with the patients and nurses. During both the patient and nurse interviews, the interviewers aimed to transcribe as closely as possible the literal content of the participants’ responses and later transferred these notes to the computer to reduce information loss. During some of the patient interviews and all of the nurse interviews, both interviewers took notes simultaneously, compared them afterward, and found high literal consistency between the notes. Subsequently, the digitized notes were integrated into 1 document.

The patients’ semistructured interviews were applied, consisting of 30 questions addressing the 6 areas of interest, which were considered as most important indicators in view of the randomized controlled trial to be implemented subsequently: perceived health benefit, usability, adherence to CONEMO, satisfaction and suggestions for CONEMO, as well as the evaluation of the nurse-support received (see Multimedia Appendix 2 for the interview guide for patients). Satisfaction refers here to the patients’ evaluation of things they liked and disliked about CONEMO. Each interview took between 45 and 60 min.

With the nurses, semistructured interviews consisting of 22 questions to retrieve data about general nurse feedback, evaluation of training received, evaluation of activities related to the study, as well as their perception of feasibility of incorporating CONEMO within primary care (see Multimedia Appendix 3 for the interview guide for nurses) were conducted. Feasibility refers here to the nurses’ perceptions of the viability to scale up the nurse-supported CONEMO within similar health care centers and to be implemented by staff nurses. Each interview took around 40 min. All interviews were conducted in 1 session, without conducting repeat interviews.

**Data Analysis**

The 4 stages of content analysis—decontextualization, recontextualization, categorization, and compilation—as described by Bengtsson [58], were conducted by 2 researchers—the ones who also conducted the interviews—to increase validity and decrease bias, as suggested by various authors [58,73,74]. First, the digitized interview notes for patients, as well as for nurses, were reviewed, and thereby, codes were generated (decontextualization). Both researchers discussed their comprehension of each code and adapted them accordingly.
before actually coding the data. Then, they compared the codes with the original data to control for completeness of the codes (recontextualization). Codes were created for the complete dataset, so that every statement made by a person would be assigned to at least 1 code. The aim was to have at least 1 code for every statement, which would not overlap in its meaning with other codes. Therefore, initially, no information was considered dross [58,73]. After the codification process, the researchers revised the codification of the other person and discussed and adapted discrepancies to control for different interpretations and increase compatibility.

On the basis of this principle, the qualitative data from patients were first divided into 14 principal codes and 39 subcodes (see Multimedia Appendix 4 for complete patient codebook). After a thorough review, data from 11 principal codes and 27 subcodes were assembled to the 6 domains of interest (categorization). The data from the remaining codes were considered as not relevant to the research aim and therefore as dross (recontextualization). Table 1 provides a description of the principal codes and subcodes used to describe each domain. The qualitative data from the nurses were coded into 9 principal codes and 18 subcodes (see Multimedia Appendix 5 for complete nurse codebook), of which data from 16 subcodes over all of the 9 principal codes were selected for this analysis and subsequently categorized into the 4 domains of interest, which are described in Table 2.

Afterward, the data were analyzed within each of the domains (compilation). A manifest analysis technique [58,59,74] was chosen to describe the experience narrated by the informants. Although our analysis was based on qualitative content analysis, in order to draw conclusions from the information retrieved, elements of quantitative content analysis were also applied to receive information about how common certain perspectives were within this population, as suggested by other authors [58,75,76].

**Ethical Considerations**

The formative research and its materials were approved by the Institutional Ethics Committee of the Universidad Peruana Cayetano Heredia in Lima, Peru, as well as by the Data and Safety Monitoring Board of the National Institute of Mental Health in the United States, in accordance with applicable regulations. Informed consent was obtained from all the participants before participating in the study, after screening for fulfillment of inclusion criteria, and having conducted a thorough explanation of the study and all implications of participation. Patients were not paid, but they were reimbursed for transportation costs related to this study.

**Table 1. Domains and codes used for patients’ interviews’ analysis.**

<table>
<thead>
<tr>
<th>Domains</th>
<th>Principal codes</th>
<th>Subcodes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived health benefit of CONEMO</td>
<td>Perceived health benefit of CONEMO</td>
<td>Perceived benefit on psychological health, perceived benefit on physical health, and other benefits perceived</td>
</tr>
<tr>
<td>Usability</td>
<td>Usability of CONEMO</td>
<td>Difficulties with CONEMO usage, and help from others</td>
</tr>
<tr>
<td></td>
<td>Evaluation of smartphone</td>
<td>Difficulties with smartphone usage</td>
</tr>
<tr>
<td></td>
<td>Guidebooks</td>
<td>Revision of guidebooks, and utility of guidebooks</td>
</tr>
<tr>
<td></td>
<td>Interactive tools (notifications, dialogue pop-ups and SMS)</td>
<td></td>
</tr>
<tr>
<td>Adherence to CONEMO</td>
<td>Adherence to CONEMO</td>
<td>Revision of sessions, performing activities, and difficulties (to perform activities)</td>
</tr>
<tr>
<td>Satisfaction with CONEMO</td>
<td>Satisfaction with CONEMO</td>
<td>General feedback, things most liked about CONEMO, things least liked about CONEMO, things most liked about the sessions, things least liked about the sessions, and using smartphones for intervention delivery</td>
</tr>
<tr>
<td>Suggestions for CONEMO</td>
<td>Design</td>
<td>Design of CONEMO</td>
</tr>
<tr>
<td></td>
<td>Duration and frequency</td>
<td>Duration of intervention, and frequency of sessions</td>
</tr>
<tr>
<td></td>
<td>Suggestions for CONEMO</td>
<td>Suggestions to improve CONEMO, and preference of how to receive information</td>
</tr>
<tr>
<td>Evaluation of nurse component</td>
<td>Evaluation of nurse component</td>
<td>Evaluation of training, quantity of contacts, evaluation of contacts, help requests, and suggestions for the nurse component</td>
</tr>
</tbody>
</table>

*aFor some principal codes, further subdivision did not seem to be beneficial; therefore, no subcodes were created.*
### Table 2. Domains and codes used for nurses’ interviews’ analysis.

<table>
<thead>
<tr>
<th>Domains</th>
<th>Principal codes</th>
<th>Subcodes</th>
</tr>
</thead>
<tbody>
<tr>
<td>General nurse feedback</td>
<td>General experience</td>
<td><em>a</em></td>
</tr>
<tr>
<td></td>
<td>Expectations</td>
<td>Expectations preimplementation, and fulfillment of expectations</td>
</tr>
<tr>
<td></td>
<td>Overall satisfaction</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Evaluation of study activities</td>
<td>Satisfaction with tasks</td>
</tr>
<tr>
<td></td>
<td>Benefits</td>
<td>Perceived personal benefits</td>
</tr>
<tr>
<td>Evaluation of training received</td>
<td>Evaluation of training received</td>
<td>Level of preparedness posttraining, missing subjects, and suggestions for training</td>
</tr>
<tr>
<td>Evaluation of activities related to the study</td>
<td>Evaluation of study activities</td>
<td>Initial appointments, monitoring calls, nonadherence calls, help requests, revision of nurse dashboard, registering tasks in nurse dashboard, supervision meetings, and difficulties</td>
</tr>
<tr>
<td>Feasibility of incorporating CONEMO in primary care</td>
<td>Feasibility of scaling up CONEMO</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Incentives</td>
<td>Types of incentives desired</td>
</tr>
<tr>
<td></td>
<td>Suggestions for the project</td>
<td>—</td>
</tr>
</tbody>
</table>

*aFor some principal codes, further subdivision did not seem to be beneficial, therefore no subcodes were created.

### Results

#### Participants’ Characteristics

**Patients**

Among the 29 patients, who responded to the interviews, the mean age was 60 years (SD 9.6, range: 47-85 years) and 69% (N=29) were women. Almost half of the patients were diagnosed with both diabetes and hypertension (45%, N=29), whereas 31% were diagnosed with solely diabetes and 24% with solely hypertension. Less than half of the patients, 45% (N=29), reported having experience in using a smartphone. For an overview of the demographic variables of the patients, see Multimedia Appendix 6.

**Nurses**

All nurses who participated were women, the mean age was 38 years (SD 6.2, range: 31-46 years) and the mean time working in the health care center where they were currently employed was 6.6 years (SD 5.3, range: 3-16 years). All nurses had higher education and were licensed in nursing, 1 additionally had a PhD degree, and most had previous experience with using smartphones (83%, N=6) or tablets (67%, N=6). In 1 of the 2 health care centers, 1 nurse monitored 7 patients, whereas in the other center, 5 nurses monitored 10 patients, 2 patients each, who participated in the second pilot study.

**Patients’ Experience With CONEMO**

**Perceived Health Benefit of CONEMO**

Almost all patients (93%; if not mentioned otherwise, the denominator for all frequencies in this paper is the total number of patients, N=29) said that CONEMO helped them emotionally. Most patients felt that after having used CONEMO, they were calmer, more cheerful, enthusiastic, motivated, and less worried and stressed out. Although more than half of the patients (59%) mentioned doing new activities or having picked up activities they have not been doing in a while, one-third (34%) attributed their improvement in emotional well-being to being more active. People did not only increase healthy activities, but also pleasant activities, such as reading a book, visiting friends and family, playing soccer with other people, or walking the dog. As 1 patient expressed it:

> [CONEMO] has given me the opportunity to rediscover what we have in life. [Patient 32474, female, 65 years, quote #1; see Multimedia Appendix 7 for original quotes in Spanish and previous smartphone experience.]

One patient explained that being more active distracts oneself from the negative thoughts and therefore improves psychological health.

Another important factor related to the perceived improvement was that CONEMO gave them the feeling of not being alone (34%). CONEMO was viewed as a conscious friend, as a personal psychologist, or just as someone that gave them advice, someone they did not have in their lives before, which made them feel not being forgotten about or abandoned, as they had previously assumed. Interestingly, 2 people (7%) also mentioned to have more self-esteem after having used CONEMO, as the following quote describes:

> CONEMO, yes, it improved my emotional health because I felt that I mattered, that I have to allocate some time to myself and that no one matters more than me. I have been feeling better emotionally, freer. I felt that I did not have to depend on anyone and that I can do things for myself. [Patient 12406, female, 51 years, quote #2, Multimedia Appendix 7.]

Some patients also valued positively the study safety procedures—which were not part of the intervention itself—to motivate patients to look for professional help, transfer them to mental health professionals within the health care system, and in cases of severe depressive symptoms, even helping them to receive treatment faster than usual (14%). Some patients felt
that this also contributed positively to their psychological health. However, 2 people (7%) thought that the time of the intervention was not sufficient to accomplish groundbreaking improvements and other 2 did not feel that CONEMO improved their psychological health.

As many activities suggested by the intervention were healthy activities that people with NCDs could complete, some of the patients (34%) also felt that CONEMO helped them improve their physical health. For example, some mentioned having lost weight because of their healthier diet or others to have gained mobility because of increased exercising.

In addition, the majority of the patients mentioned changing their daily habits toward a healthier routine (62%). Most of them reported exercising more, eating healthier, taking the bike to buy groceries, walking or running more, and taking their medication more regularly. One person also described that CONEMO motivated her to go the doctor, whereas she had previously tried to avoid all doctor consultations if possible.

In terms of other benefits perceived, 6 patients (24% of 25) described CONEMO as helping them to organize their everyday routine better to do different activities. Some (20% of 25) also mentioned that through CONEMO they were more conscious about their chronic condition and paid more attention to their health and their body. CONEMO has also changed some of the patients’ relationships with their families and friends (16% of 25), for example, by implementing CONEMO’s suggestion of exercising in form of weekly family volleyball games.

Usability

Most patients encountered some kind of difficulty in using CONEMO or the smartphone (72%) and would have liked to receive more training. Some patients had problems remembering the explanations received from the nurse (14%). Although about half of the patients admitted that they did not know how to handle the technology in the beginning (48%), most patients with difficulties (71% of 21) explained that those generally occurred in the beginning and that, with time and practice, it got easier to use CONEMO and the smartphone. Furthermore, 14 patients (48%) mentioned having received help from others, such as family members, in using CONEMO. The great majority of the patients reported reviewing the guidebooks provided by the research team (90%) and found them helpful (74% of 23).

The specific difficulties with CONEMO and the smartphone mentioned by the patients are described in Figures 1 and 2, respectively. Regarding CONEMO, most difficulties were experienced when selecting a time and date for scheduling an activity by changing the numbers using up and down arrows. Concerning difficulties using the smartphone itself, patients mostly mentioned the fear of getting it stolen.

Furthermore, many people experienced difficulties with the interactive tools used in this intervention, such as SMS, Android notifications, and dialogue pop-ups. The SMS served as a reminder for the appointments within this study. Android notifications informed patients that a new session had arrived, and dialogue pop-ups were designed to retrieve feedback about the completion of the activities through messages appearing on the screen soliciting a response from the patient. There were some technological and connectivity problems, for example, people did not receive the SMS in time. However, most people did not view or use the Android notifications (51% of 24) and opened CONEMO directly from the home screen (71% of 24) to see if new sessions had arrived, and some people did not know how to open the SMS or could only read them with the help of others (21% of 24). The idea behind the dialogue pop-ups—to give feedback about activity completion—was evaluated positively; however, some did not recall them (25% of 24) when asked about them.

Adherence to CONEMO

This section refers to the self-reported adherence to CONEMO in the interviews. Another publication by the LATIN-MH team addresses the quantitative adherence data of the pilot studies [57]. Adherence to CONEMO is defined here as (1) the amount of CONEMO sessions reviewed and (2) the amount of activities completed that were suggested by CONEMO. Regarding adherence to session review, around half of the patients who talked about it said they not only read all of the sessions of CONEMO (65% of 20) but also re-read numerous sessions (50% of 20). In addition, 2 people even re-read the whole intervention again before returning the smartphone to the research team. Some explained that they re-read sessions to better remember the content or because it served them as a reminder to do certain activities, especially in between sessions or at the end, when there were no new sessions available. On the contrary, some people also disclosed that they did not complete all the sessions (30% of 20). In terms of the adherence of activity performance, 9 people (39% of 23) indicated to have done all activities they selected during this intervention and other 9 (39% of 23) completed most of the activities. Thus, the great majority seemed to have been very adherent to the intervention. The activities with the highest completion rate were pleasant activities, such as going out meeting friends and family, and healthy activities, for example, going for a walk, whereas pending tasks, such as organizing the bills or paying them, seemed less frequent to be done. However, 5 (22% of 23) people did few or none of the activities.

The main barrier reported to performing the activities suggested by CONEMO was the users’ health status (36% of 14), such as limited mobility or memory problems. Time (29% of 14) and economic constraints (21% of 14) were also important barriers to doing activities. Other difficulties mentioned were the low motivation to do activities (9% of 23) as well as sudden changes in their plans because of external factors (14% of 14), for example, receiving a phone call or someone else needing assistance.
Satisfaction With CONEMO

Satisfaction refers to the statements that patients made about what they liked and disliked about the app and the sessions, comments that could infer satisfaction, as well as the patients’ perception about using technology for intervention delivery.

The majority of patients expressed great satisfaction with CONEMO (96% of 24), some did not make any statements regarding their satisfaction (17% of 29), and 1 was unsatisfied (4% of 24) because he felt that his health status was too compromised to follow all of the instructions. When the patients were asked what they liked most about the CONEMO app and its sessions, most appreciated the information and advice received (37% of 27), for example:

[…] its important guidelines [to do things one step at a time] instead of doing everything at once. [Patient 32433, female, 60 years, quote #3, Multimedia Appendix 7]

Furthermore, 26% (of 27) of patients most liked the videos incorporated in CONEMO, 15% (of 27) most appreciated that they were reminded by CONEMO to follow their diet, to work out or follow their medication, and 11% (of 27) valued most the types of activities offered, as described by one of the patients:

In the [list of] activities there were things that caught my attention and that I would be able to do. This opened a whole new field for me of other activities I could do and that I had not done before. [Patient 32444, female, 64 years, quote #4, Multimedia Appendix 7]

Furthermore, 2 patients even transcribed the whole intervention on their computer to be able to re-read it again after giving back the smartphone. Of note, one-third (33% of 27) of the patients especially valued being accompanied by CONEMO and the nurse and receiving monitoring phone calls from the research team, which were implemented as a safety procedure within the research rather than a treatment activity. These contacts transmitted a feeling of being cared for, of someone taking a special interest in them and their health, and of trusting them with a technological device:

I didn’t have anyone to talk to, so I watched the woman in the video, […] [Patient 12266, female, 76 years, quote #5, Multimedia Appendix 7]

I was surprised and thought “what did I do to deserve something like this?”. And in addition, they gave me 10 Soles (Peruvian currency) to cover my transport. […] This is the first time in my life that I have received this kind of attention. […] No one has ever been concerned about me, but now there was someone there, who was worried about my health […] [Patient 22131, male, 70 years, quote #6, Multimedia Appendix 7]

Many people (54% of 28) did not spontaneously express negative aspects about CONEMO, although it was specifically asked for. The statements that were made were very diverse, and there was not much consensus (see Figure 3).
Most of the patients (95% of 21) expressed a positive attitude toward using smartphones to deliver the intervention, and 48% (of 21) of people mentioned explicitly the advantage regarding the mobility, whereby the use of the smartphone replaced having to go to the health care center to make an appointment or to see a specialist. This potentially reduces the time spent on health consultation and could “unclog the health care center’s environment” (Patient 22116, female, 52 years, Multimedia Appendix 7, quote #7), as 1 patient explained. In addition, 4 patients (19% of 21) also highlighted the practicality of being able to take the intervention with them, to re-do the sessions, and especially being able to choose the place and time to follow the intervention:

It is convenient, because we are not as close to the doctor or psychologist... Here, it does not matter, where you are, you can still use it. [Patient 32433, female, 60 years, quote #8, Multimedia Appendix 7]

Suggestions for CONEMO

The suggestions that patients expressed to improve CONEMO were wide ranged and could be grouped into 2 categories: (1) suggestions for the content and design of the app and (2) communication with the research team.

Regarding suggestions for the content and design of the app, most patients suggested increasing the duration of the intervention (68% of 28). The other suggestions are displayed in Figure 4. In terms of preference of information delivery, if given the option, most people would prefer to be able to hear the content read to them via an audio (43% of 28) or to have both audio and text (36% of 28), whereas others prefer to only read the text (21% of 28).

In terms of the communication with the research team, patients also desired more. Some patients suggested adding group activities with all the patients and trainings or lectures of different topics (14% of 28). Others would have liked to receive personal face-to-face appointments with the research team for depression monitoring instead of phone calls or specialized psychological care via telephone or audio messages (11% of 28).

Evaluation of the Nurse Support

Most of the patients were satisfied with the nurses’ explanations of how to use CONEMO (59%); however, some patients mentioned that it was still difficult to understand (14%) or that they were not able to use CONEMO at first, directly after the training (17%). Various people said something similar to the following:

The nurse explained well, it is just that maybe I am stupid or something, because when I got home, I did not know how to use it. [Patient 12073, male, 66 years, quote #9, Multimedia Appendix 7]

However, some of the patients who were accompanied by a nurse from the health system perceived the nurse as being in a hurry during the training (10%) or without interest in explaining the intervention (7%). Comparing both pilot studies, 80% (of 15) of the patients who were accompanied by the hired nurse viewed the training session as useful, with a positive knowledge transfer, whereas only 50% (of 14) of patients monitored by a staff nurse expressed either positive or neutral comments about the quality of the training.

On the basis of the study protocol, all patients should have received at least 2 phone calls by the nurse to see if there are any difficulties with CONEMO and additional calls depending on their adherence and difficulties. Evaluating the quantity of contacts, when working with a hired nurse, most of the patients reported having received between 3 and 4 phone calls from the nurse (53% of 15) during the intervention, whereas most patients accompanied by staff nurses reported to have received 1 to 2 calls (36% of 14; see Figure 5).

Most of the patients in both pilot studies viewed the phone calls as positive (81% of 26) because the nurses helped them to be adherent to the intervention (19% of 26), helped them with their difficulties using CONEMO (19% of 26), paid attention to their health (15% of 26), helped with other problems (8% of 26), and showed the patients that she cared (15% of 26).

Through help requests patients could solicit tech support from the nurse. Most of the patients stated they did not use the help request button within CONEMO (68% of 28), some because they claimed to not have needed it and others because they felt embarrassed, did not remember this function, or thought the nurse would be busy anyway. Some patients also asked for help by error (7% of 28). In addition, 4 people (14% of 28) expressed that they did ask for help and received it, whereas other 3 people stated that they had pressed the button but that no one had called them.

Regarding suggestions for improving the nurse-support, almost half of the patients would have liked to receive more phone calls (44% of 27), and ideally a space to talk about their emotional state, instead of only receiving technical support from the nurse. Others suggested amplifying or improving the quality or depth of the training to feel more confident in using CONEMO (11% of 27).

A summary of the main results retrieved from the patients’ interviews can be found in Table 3.
Main results

Almost all patients perceived improvements in their mental health and some also in their physical health after using CONEMO.

The majority felt more active after using CONEMO, having mostly increased pleasant and healthy activities.

CONEMO was also viewed as a companion, which made them feel less alone.

Initially, most patients encountered difficulties in using CONEMO or the smartphone and with using SMS, Android notifications, and dialogue pop-ups; however, many technological issues also emerged around those elements, which is why the distinction of those two is not completely clear.

Some patients received help from family members or reviewed the guidebooks, and most patients felt that these difficulties subsided with time and practice.

Self-reported adherence was high, most patients completed all sessions and the majority completed most or all activities advised by CONEMO.

The most important barriers to completing the outside-app activities were the patients’ health status, time, and economic constraints.

Satisfaction with CONEMO was high, as it was with using smartphones for intervention delivery.

Features most appreciated were the advice provided, the videos and types of activities suggested, as well as the monitoring calls received by the nurse.

The few critiques were directed at the type of activities suggested by CONEMO and that the sessions were repetitive.

Patients suggested increasing the duration of the intervention, the amount of videos and frequency of sessions and improving the in-build training session.

Many patients also desired a more frequent interaction with the nurses.

Although most praised the explanation from the nurses, some still experienced difficulties afterward, and therefore, they suggested improving the training.

The monitoring calls were viewed as positive and helpful to increase adherence and resolve difficulties.
Nurses’ Experience Supporting CONEMO Users

General Nurse Feedback

Most nurses (5/6) felt that CONEMO was an innovative and useful intervention. They thought, it was a good idea, something different, an opportunity to talk more to the patients and something beneficial to them. Some nurses reported that participating in this project benefited themselves as well because they took part in improving the patients’ health (3/6) and gained experience participating in a research project (1/6). However, most nurses (5/6) mentioned having had difficulties in consolidating their CONEMO activities with their workflow and felt that this increased their workload. The difficulties mentioned were related to the fact that before implementation, the health care centers’ management agreed to provide the nurses with reserved hours to participate in the intervention; however, because of logistical and administrative constraints, once the study started, the nurses had to accommodate these additional activities in their daily routine without adjustments to their existing workload, as 1 nurse describes:

At the beginning, I found it tedious, because we did not have protected hours for this task. I took on more tasks, because I had more free time. [...] When the [chief] doctor saw that we were having trouble, she said that when we were in the clinic, we should ask the auxiliary nurse to cover for us for a moment [to do our tasks related to CONEMO]. [Nurse 306, female, 38 years, quote #10, Multimedia Appendix 7]

All nurses felt strongly that the implementation of CONEMO including nurse-support must imply strictly reserved work hours to be executed as expected.

Evaluation of Training Received

Most nurses (5/6) stated that the training they had received was appropriate. However, 2 of them felt they were not able to remember all the procedures when the study started because of a lack of practice or a lack of concentration during the training sessions.

[I learned] about 80% [of the procedures] because it was difficult to stay focused during the training, due to the number of tasks that we had [to do] in the health care center. [Nurse 304, female, 33 years, quote #11, Multimedia Appendix 7]

Regarding the study technology, 3 of the 6 nurses reported that it was more difficult to use the nurse dashboard in the tablet to monitor their patients than to learn and explain how to use CONEMO, and they recommended increasing the time to practice during the training. Of note, the training of the hired nurse was a lot less time intensive compared with the training practice during the training. Of note, the training of the hired nurse was a lot less time intensive compared with the training practice during the training.

At the same time, maintain their concentration and motivation, and have sufficient time per training session to conduct complete practice runs before the nurses had to leave again.

Evaluation of Activities Related to the Study

To complete their tasks, nurses were supposed to use the nurse dashboard to view and log their tasks as well as monitor their patients. Only 2 nurses revised the dashboard regularly, every other day. The other 4 only revised the dashboard 2 or 3 times during the 2 to 3 months they were monitoring patients because they did not have enough time (3/6), they forgot (1/4), or because the tablet was not always accessible to them (1/4) as it was stored in the director’s office.

One of the most important responsibilities of the nurses was the initial appointments in which they trained patients on how to use CONEMO. Most nurses (4/6) emphasized that their patients had some difficulties in understanding the technology, but that they were able to explain it again afterward or that the patients received help from their family members. Some nurses (2/6) had difficulties during the training because they themselves forgot how certain things worked, and another 1 reported time constraints that forced her to complete it as fast as possible.

Nurses were also supposed to complete monitoring calls; ask their patients if they had difficulties in using CONEMO; motivate them, if needed, to increase adherence; and answer help requests. Half of the nurses made the calls by their own initiative, whereas the other 3 did not complete the calls unless they were reminded to do so by the clinical supervisor. In addition, some of the nurses had great difficulties in reaching some of their patients (2/3).

Supervision meetings led by a psychologist were supposed to be conducted on a weekly basis. In 1 health care center, the nurse was very comfortable with the supervision because she felt the research team addressed her doubts. However, at the other health care center, nurses felt pressured to have those supervision meetings (4/5) mainly because they felt overwhelmed because of their workload:

You, [the research team], were not the problem, but the work burden we have here. We just could not do it, it was pretty uncomfortable because we did not have the time to receive you as we should have. [...] It felt like “another thing” that I have to do. [Nurse 304, female, 33 years, quote #12, Multimedia Appendix 7]

Feasibility of Incorporating CONEMO in Primary Care

Considering the possibility of scaling up CONEMO plus nurse-support, all nurses identified the lack of time to perform the related activities as the main problem for its implementation within the health care system. All nurses considered it necessary that the activities of the nurse-support would be included as part of the monthly schedule and paid work hours, a decision that depends on the administration of the Social Security System:

You would have to separate [CONEMO] as an independent program because here each nurse is responsible for one program. It cannot interfere with other activities. [Nurse 301, female, 38 years, quote #13, Multimedia Appendix 7]
One factor related to this issue, which inhibited the nurses from being adherent to the intervention, was their job insecurity (5/6): Each nurse is required to meet a productivity goal and if it is not achieved, their employment contract may not be renewed again.

When nurses were asked if incentives could improve their performance regarding to CONEMO activities, 3 of 6 nurses stated that they would consider incentives, such as a course or regular meals; however, one of them explained that her main interest in participating was based on the perception that CONEMO benefits her patients. Other 2 nurses said that an incentive might motivate their colleagues but they themselves are uncertain if they would be part of the CONEMO nurse-support again because of their personal time constraints, and 1 stated she would not participate in the intervention again, even if she would get paid.

The results for the nurses are summarized in Table 4.

### Discussion

#### Principal Findings

In this study, we aimed to explore the experience of primary care patients and nurses with CONEMO, a technology-driven, nurse-supported intervention to reduce depressive symptoms in people with diabetes, hypertension or both, to derive lessons informing future adaptations, and to assess the feasibility of using this technology in LMIC settings. Almost all patients felt that CONEMO helped them to improve their mental health by being more active, increasing their self-esteem, and making them feel valuable. Many patients also experienced improvements in their physical health related to healthier diets and more physical activity. The self-reported adherence to this intervention was relatively high. Although most people reported some difficulties with the technology in the beginning and suggested amplifying the training, the majority felt that it got easier with time. Using smartphones for intervention delivery was generally seen as practical and time saving. The main recommendations were to include more sessions and videos, to increase personal contact, and to make it more personalized. Most patients viewed the nurse-support as positive, although the evaluation of the support of the hired nurse was more frequently positive than of the staff nurses. The majority of staff nurses participating in the pilot study felt that the intervention was valuable for patients but that the activities of CONEMO conflicted with their daily work routine.

#### Reflections and Comparison With Previous Work

A growing body of research is aimed at capitalizing on the expansion of technology and its potential to introduce newer vehicles to target mental health, suggesting potential effectiveness of Web-based, text-messaging, and telephone support interventions [77]. However, few studies are being conducted in LMIC settings [78], which makes our studies highly relevant.

Multimorbidities, defined as having 2 or more diseases, including NCDs and mental conditions, constitute a growing health threat, especially in LMICs. However, most available treatments usually only focus on 1 health condition instead of approaching multimorbidities in a more integrative way [79,80]. Therefore, cost-effective treatments that address multiple conditions are highly needed, and future research should be aimed at testing the effectiveness of mHealth interventions targeting multiple conditions. Nevertheless, in technological interventions designed for people with multiple health conditions, such as CONEMO, special consideration needs to be put on the specific target population. For example, one challenge, especially in behavioral activation interventions, could be balancing the activity suggestions, considering the demand of physical mobility to complete them, so that people with more compromised health statuses can still participate, without feeling frustrated. In general, but especially in LMIC settings, economic constraints also have to be considered when creating activity selections. Other studies have also recommended that researchers be aware of additional challenges of people with chronic conditions, such as limited mobile literacy [81], which is in line with our findings. Although our study has shown satisfactory results, usability could be optimized by improving and amplifying training, considering the large proportion of people in this population, who are unfamiliar with the devices.

Although most people found the guidebooks useful and argued that the nurses generally explained well how to handle the technology, the majority reported some kind of difficulty in the beginning and suggested extending or improving the training. Although many difficulties will most likely subside as smartphones become ubiquitous, some changes to the design of CONEMO could also improve usability. Although most
patients did not provide more information about how the training or design could be improved, one hypothesis was that a more realistic demonstration (using an in-build training session close to the actual CONEMO sessions) as well as a training video could be helpful to both nurses and patients. This way, the training would be more structured and more standardized over the nurses and, furthermore, would give the patient the opportunity to practice twice, while still being with the nurse: first, when conducting the training session and second, when completing the first real session. Nevertheless, in this study, as well as in others [82-86], there seems to be a natural learning curve, which for most patients resulted in the ability to use CONEMO. For some people, this learnability curve was intensified by receiving help from other family members. This suggests, on one hand, that reading about how to use the smartphone app seems to be less effective in this population than hearing the explanations from other people and receiving demonstrations of how to do it and, on the other hand, that friends or family members frequently become involved to some extent in the intervention delivery.

Although this intervention was created specifically for people with diabetes, hypertension or both, some of the results could also be relevant for other mental health interventions with different populations. Other studies suggest that key features of acceptable smartphone health apps seem to be self-help suggestions and feedback to the patients’ responses, they should be easy to use (foolproof), and not take too much time (maximum 10 min per single usage) [39,49]. A study by Baker et al [46] established 16 recommendations for developing mental health smartphone apps, of which 12 seem to apply to CONEMO, for example, encouraging non-technology-based activities, recording the patients’ behaviors, having a log of patients’ app use, applying reminders to engage them, and using a simple and intuitive interface. Other studies from high-income countries also indicate that the effectiveness, motivation, or adherence is higher when the health app is easy to use [39,48,49], is individually tailored [46], and includes human interaction [48,50-52]. Although most studies regarding depression apps where completed in high-income countries [39], our results appear to be in line with such previous findings.

Nevertheless, some of our interactive features showed low utility, and some technological problems were encountered. For example, most people did not check the Android notifications to see if a new session was available. It is plausible that those notification symbols were too small for this population, considering their average age. Another hypothesis could be that considering most people were novice users, who had not yet integrated the smartphone into their everyday lives and, hence, only used the smartphone for one app—CONEMO—they would not be interested in other Android notifications of the default apps already installed on the smartphone. Therefore, it might have appeared easier to open the one app of interest directly from the home screen. The utility of the other interactive elements, such as SMS and dialogue pop-ups, was difficult to evaluate given the technological problems experienced. Considering that those difficulties were not encountered during the testing phase and some could be related to signal changes in the field, formative research for large studies including technological platforms appears to be of high importance.

Another important consideration about health apps is related to the setting with special emphasis on crime rate. Given the perception of insecurity and fearing a possible robbery, many patients were reluctant to borrow a smartphone from the research team. This fear could be reduced by explaining that in case of a robbery patients would not be charged for the phone. However, as a consequence, many people did not use it as a mobile device, outside of their homes. This suggests that the socioeconomic conditions related to security can have an effect on the user’s experience with mHealth interventions. Nevertheless, after concluding the pilot studies, only 1 smartphone was stolen and 1 was not returned, constituting a loss of 6%, which was a lot lower than expected. Considering scalability, installing CONEMO on the patients’ own phones if available and, hence, reducing the perceived responsibility for a borrowed phone could be one way to reduce this reluctance besides not holding patients accountable for a possible robbery or loss of the smartphone and covering those costs.

Evidence shows that in technology-only interventions, where people are left alone with mobile self-help interventions, participants are less adherent [37,50-52] and less motivated to engage in the program [87] than people who are accompanied by professionals or coaches or have some other kind of face-to-face interaction as part of the intervention. In this formative research, the nurse embodied this role. The majority of patients reported being highly satisfied with CONEMO, they valued the advice and information provided, but some patients especially appreciated the attention received within the study. This was not anticipated, considering that the nurses’ role was based on giving technological support, but apparently, their accompaniment was perceived as beyond that role. In line with this finding, other studies emphasized that supportive accountability increases the adherence to any intervention and the extent of influence is characterized by “the bond between the user and supporting individual, the sense of accountability, and the user’s perception of the supporting individual as possessing legitimacy and expertise” [50]. It is plausible to assume that the combination of technology with an in-person monitoring in these studies also influenced the slightly higher self-reported adherence rates of 65% to 78% and the low dropout rate of 12%, when compared with other similar studies, which found average adherence rates of 50% to 70% and dropout rates of 1% to 57% [88].

In addition to the nurse-support, CONEMO contained an intermediate feature between technology and a personal component, which is relevant to consider: the videos in the CONEMO sessions were narrated by a real person, who was maintained throughout the intervention. Although patients never met this person, some people felt a connection to her and imagined she was the face behind the technology, who talked directly to them, who monitored them, and who had a leading role steering this intervention. Therefore, some people felt a personal relationship to the woman in the videos.

The importance of the videos was also highlighted by the patients’ suggestion to incorporate more of them. However,
when designing this type of intervention and considering the number of videos, developers need to prioritize and contemplate the size of the videos (especially in a fully functioning offline app), which influences the speed of installation versus, for example, relying on a stable internet connection to watch videos on the Web. Those technological considerations need to be in line with the research priorities.

Feasibility of working with nurses within the health system to monitor the patients was low because of the conflicting use of time with their daily activities. Especially given their job uncertainty, many nurses felt pressured. Other studies in a very similar context also identified workload and time constraints as the most important barriers to implementation, especially taking into account that the studies’ activities were additional to their existing tasks, without considering more paid time [89]. Therefore, when scaling up these types of task shifting interventions within the public health sector, specific resource allocation, such as workflow adaptations or incentives, have to be considered to overcome those barriers. It is also crucial to conduct cost-effectiveness studies and evaluate potential cost-savings to address organizational-level interests in implementing technology-based interventions and make correlated resource allocation more appealing to health care systems.

Adherence to the study activities can also be influenced by other factors specific to the health care center settings. For example, in our study, adherence seemed to be to some extent related to the attitudes of the nurses toward the study (positive attitude—higher adherence, and vice versa). This, in turn, could have been influenced by the management style of the health care center; the 5 nurses from 1 health care center who monitored 2 patients each were all assigned by their superiors to this study, although most were initially reluctant to participate. The one nurse with the highest workload—monitoring 7 patients—who had experience participating in different health programs, was asked by her superior beforehand, and she had the most positive attitude toward the intervention, was highly motivated, and ultimately was less affected by the workload of CONEMO. Therefore, although some health care center managers were initially enthusiastic about the study, important factors, distinct for each health care center, such as staff management, work climate, and conditions, could also influence implementation success. Furthermore, although it is ideal to find motivated nurses enthusiastic with this intervention, this may not be feasible across all of Lima or Peru, presenting a challenge to scalability; thus, structured resources should be put in place.

LATIN-MH benefited from this detailed formative phase conducted across 2 distinct health care provider systems in Lima, a large Latin American capital. Conducting qualitative formative research stages to shape mental health interventions has also been beneficial for other studies [90]. In our case, this approach set the foundation for the modifications and adaptations of the intervention to build an app tailored to the patients’ needs before deploying a complex intervention such as CONEMO in a large randomized controlled trial, as recommended by other studies [45,46,50].

**Limitations**

Although this study has provided important insights in the evaluation of an mHealth intervention for people with NCDs and depressive symptoms, this study also had some limitations. For example, although all patients were provided with the same intervention and number of sessions, the intervention uptake might not have been the same for all of the patients, depending on their adherence to review the sessions. However, the number of patients included in this study was sufficient to signal positive and negative experiences with the CONEMO intervention [58]. Therefore, we feel confident that we have sufficient information to improve the future design of CONEMO for the clinical trial.

Another limitation of this study is related to the fact that for the first pilot study in the MINSA hospital, a nurse was hired, whereas in the second pilot study in the Social Security System, nurses from the health system accompanied the patients. Therefore, although the perspectives of patients from both public health systems were obtained, only the perspectives of the nurses within the Social Security System were analyzed. Furthermore, it is plausible that the patients’ experience differed depending on what type of nurse accompanied them throughout the intervention beyond what has been identified and described here. However, conducting this second pilot study with staff nurses was extremely beneficial for the study purposes to explore feasibility of working with staff nurses and understanding the challenges they encounter, which might be similar in other public health systems. Therefore, after the first experience, it was crucial to conduct a second pilot study with this aim.

Furthermore, the interviews were not recorded and, therefore, there is a possibility that some information from the participants was lost. However, the 2 people who conducted the interviews aimed at writing down the verbal statements literally and took notes simultaneously during some of the interviews, which were contrasted afterward and which showed high literal consistency. This makes us confident that the notes represent the participants’ statements reliably.

**Next Steps**

Although generalizability is limited, all of these findings are relevant and crucial to inform the development of future complex interventions for mental health conditions, multimorbidity, and specifically for further designing and testing the efficacy of CONEMO under more controlled designs; indeed, CONEMO will be tested in 2 parallel randomized controlled trials. Other studies have demonstrated that mobile apps can effectively change behavior; however, considering the limited evidence, uncertainty of long-term effects and the predominance of those studies in high-income countries so far [39], the randomized controlled trial will give important insights regarding this type of interventions in LMIC settings.

Furthermore, this study is especially relevant considering the current mental health reform in Peru, where for the last 12 years, several efforts have been made aimed at improving the availability of free and universal access to mental health care for Peruvian citizens through a community-based approach, including primary health care centers [19,91]. In this effort,
tasks are already being shifted toward personnel not specialized in the same field, integrating mental health care in a variety of different medical settings. This development creates an opportunity for scaling up cost-effective mHealth interventions with task shifting components in the public health care system.

**Conclusions**

Smartphone apps constitute a potentially cost-effective opportunity in LMIC settings to overcome health system barriers and extend mental health care to large populations. On the basis of the experiences and opinions of the patients, it seems feasible to use this nurse-supported mHealth intervention for people with chronic diseases and comorbid depressive symptoms in Peru. CONEMO is perceived as helpful in improving mental health, but it requires context-specific adaptations, especially regarding the implementation of a task shifting approach within the public health care system; working with staff nurses using a task shifting approach within the public health system in Lima will only be feasible if the nurses’ time is protected for the program. Findings from this study will provide important information to develop a larger study focused on testing the effectiveness of this program on patients’ health and mental health outcomes.

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**Authors' Contributions**

PRM, RA, JM, and DM conceptualized the LATIN-MH program of research, for which this was a substudy of the formative phase. FDC and LRB designed this substudy and LRB and LH conducted it (LRB as trial manager and LH as clinical coordinator), under supervision of FDC. LRB and LH created the codebook and codified the interviews. LRB analyzed the data and wrote this paper with guidance from JM and FDC and contributions from LH. After the first draft, PRM, RA, JM, DM, and FDC reviewed the paper and contributed to the final version submitted.

**Conflicts of Interest**

None declared.

**Multimedia Appendix 1**

Screenshot of CONEMO.

[PNG File, 56KB - mental_v6i6e11701_app1.png ]

**Multimedia Appendix 2**

Interview guide—patients.

[DOCX File, 16KB - mental_v6i6e11701_app2.docx ]

**Multimedia Appendix 3**

Interview guide—nurses.

[DOCX File, 15KB - mental_v6i6e11701_app3.docx ]

**Multimedia Appendix 4**

Codebook—patients.

[DOCX File, 16KB - mental_v6i6e11701_app4.docx ]

**Multimedia Appendix 5**

Codebook—nurses.

[DOCX File, 14KB - mental_v6i6e11701_app5.docx ]

**Multimedia Appendix 6**

Demographic variables—patients.

[DOCX File, 16KB - mental_v6i6e11701_app6.docx ]
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Abbreviations

- DALY: disability-adjusted life year
- LATIN-MH: Latin America Treatment and Innovation Network in Mental Health
- LMIC: low- and middle-income country
- mHealth: mobile health
- MINSA: Ministry of Health
- NCD: noncommunicable disease
- SMS: short message service
Teens Using Screens for Help: Impact of Suicidal Ideation, Anxiety, and Depression Levels on Youth Preferences for Telemental Health Resources

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Abstract

Background: High rates of mental illness, stress, and suicidality among teens constitute a major public health concern in the United States. However, treatment rates remain low, partially because of barriers that could be mitigated with tech-based telemental health (TMH) resources, separate from or in addition to traditional care.

Objective: This study aimed to analyze TMH resource usage by high school students to establish current user characteristics and provide a framework for future development.

Methods: A total of 2789 students were surveyed regarding demographics, recent anxiety and depression symptoms, suicidality, and stress; people with whom they could openly and honestly discuss stress or problems, and prior TMH use. Logistic regression models and a general linear model were used to test relationships between variables.

Results: Overall, 30.58% (853/2789) and 22.91% (639/2789) of students reported moderate to severe anxiety and depression symptoms, respectively, in the past 2 weeks; 16.24% (414/2550) had seriously considered suicide in the past year, consistent with national averages. Meanwhile, 16.03% (447/2789) of students had previously used at least 1 of 4 types of TMH resources (ie, self-help, anonymous chat, online counselor, or crisis text line). Teens reporting depression symptoms, higher stress, or suicidality were less likely to talk to a parent about stress or problems and more likely to tell no one. Suicidality was related to the use of all 4 types of TMH resources. Depression symptoms were related to the use of anonymous chat and crisis text line, and those with higher stress were more likely to have used an online counselor. Those reporting anxiety symptoms were less likely to have no one to talk to and more likely to have used a self-help resource.

Conclusions: Youth struggling with mental health symptoms, some of whom lack real-life confidants, are using existing TMH support, with resource preferences related to symptoms. Future research should consider these preferences and assist in the creation of specialized, evidence-based TMH resources.

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KEYWORDS
adolescent; students; telemedicine; mental health; suicidal ideation; depression; anxiety; health resources; online social networking; mental health services; help-seeking behavior
**Introduction**

**Background**

With rates rising over the last decade [1], suicide is the second leading cause of death among adolescents and young adults aged 15 to 24 years [2]. In 2016, 17.2% of high school students reported serious suicidal thoughts, 13.6% made a plan, and 7.4% attempted suicide. The rate of suicidal ideation among adolescents with depression is much higher, with some estimates as high as 40 to 50% [3,4]. Depression itself is a public health concern for youth, as well: in 2016, 12.8% of adolescents aged 12 to 17 years reported experiencing a major depressive episode in the last year [5]. Another survey from the same year suggested an even higher prevalence of subclinical depression symptoms, with 31.5% of high school students feeling sad and hopeless nearly every day in the past 2 weeks [6]. Anxiety disorders are also present among teens aged 13 to 18 years at high rates (31% lifetime prevalence) [7], and, like suicidality and depression, affect females more than males [5-7].

As with all health care, there are barriers to mental health service access. Less than 30% of teens experiencing suicidality and 40% of teens experiencing major depression seek professional treatment [5,8], and only about a third of teenagers with any mental health issues are treated by a specialist [9]. Treatment rates are even lower among minorities [3,8] and those with geographical constraints [4,8]. In addition to physician shortage [10-12] and patient financial struggles [8,10], stigma is a major factor discouraging teens from seeking mental health treatment, which includes reticence with sharing symptoms with a parent to initiate the process [13-17]. This may disproportionately affect male teens, who are less likely to seek help for suicidal ideation than females [8,15]. Teens also may lack awareness of their symptoms or treatment options [13,16-18], perceive high stress as normal [8,13], have confidentiality concerns [8,13-16], or feel that adults will not understand their problems [13,15].

Youth may instead seek out informal sources of help, such as friends or the internet [13-15,19,20], or attempt to handle their problems alone [8,13-15,20,21]. Those endorsing self-reliance are more likely to be depressed and suicidal and less likely to seek traditional care; however, they are more likely to seek support from anonymous Web-based sources such as forums, chat rooms, or support groups [20]. Some adolescents and young adults report that social interaction on the internet enhances their real-life friendships and contributes to a feeling of social connectedness [22-24]; however, social media can also be a source of stress or negative feelings, and problematic use (ie, that which mirrors behavioral addiction) is associated with depression and anxiety [21,25,26]. Those with higher levels of depression and anxiety are also likely to share their stresses on social media [21,27], as this venue may provide greater control over social interaction with nonjudgmental peers [28]. With regard to social media as a conduit to formal mental health care, 1 study showed that almost 63% of youth were open to a provider proactively contacting them via social media, and 70% expressed a favorable view of receiving professional advice on the internet [27]. However, some view social media as personal space where they do not want provider involvement, citing stigma and confidentiality as concerns [29].

Researchers have suggested that digital health interventions could be particularly successful among younger individuals because of their frequent technology usage [30]. Indeed, 95% of American teens own smartphones and nearly half use the internet “almost constantly,” [22] with those aged 13 to 18 years spending an average of over 6.5 hours per day with screen media, including over 2.5 hours of social media, video-chatting, browsing the Web, or engaging in other computer or mobile activities besides gaming or watching video [31]. Although the health care industry has been slower to utilize the full potential of the internet compared with other sectors [32], many digital health innovations (ie, electronic health, mobile health, and telehealth) have been developed over the last decade to supplement or deliver care [30]. Such innovations have been used successfully with youth to improve chronic disease management [33-36], assist with symptom and behavior monitoring [37,38], supplement face-to-face treatment [39,40], and provide health education [41,42]. In recent years, Web-based services specifically designed to support mental health (ie, telemental health, or TMH) have been developed as well [43]; however, thus far, these resources have not been integrated within the health system, which represents a significant opportunity for improved care [44]. TMH refers to a range of services provided or accessible via communications technologies, such as videoconferencing administered by professionals [11], platforms to mutually discuss problems and seek peer support (eg, chat rooms), and self-help mobile apps [43]. These resources are numerous—recent estimates show over 10,000 commercially available mental health apps, for example—but are not always evidence-based or formally evaluated [45].

At present, data regarding effectiveness and perceptions of TMH resources are both mixed and somewhat limited [17,30,39,46-51]. Upon reviewing trials of TMH resources, researchers note methodological difficulties that inhibit definitive conclusions about efficacy, cost-effectiveness, and clinical applicability [30,52]. However, extant literature suggests that TMH resources based in cognitive behavioral therapy principles may improve symptoms in teens with mild to moderate depression and anxiety [30,48] and that self-monitoring mobile apps, particularly in addition to traditional treatment, may benefit individuals struggling with stress, anxiety, and depression [39,52-55]. In one qualitative study, users discussed the contrasting benefits of both face-to-face and Web-based support (ie, the website 7 Cups of Tea): face-to-face support is administered by a trained professional with whom a patient has a relationship, whereas the website allows anonymous real-time support from people who sympathize with the users’ problems [49]. Researches also note ongoing concerns about the true potential of these resources to expand access to mental health care, noting that some studies have found a lack of user interest, even among younger age groups, and that not all providers endorse this type of nontraditional care [30]. However, many individuals lack knowledge of these resources, and opinions may become more positive with increased information and awareness [46,47,56].
**Objective**

Due to the novelty and ever-evolving nature of communication technology, ongoing research of TMH resources is necessary to direct continual development [30, 43, 48, 57-60]. In this study, we investigated the relationships between depression, suicidal ideation, stress, anxiety, communication preferences, and TMH use, with the intent to establish use patterns, especially among at-risk youth, and provide a framework for development and implementation of future technologies.

**Methods**

**Sample and Data Collection**

Participants were from 4 northwestern Indiana high schools (2 suburban, 2 rural). These schools were representative of the general area of study, which contains 1 midsize city with much suburban sprawl, surrounded by several large rural counties. Surveys were conducted during educational assemblies at each school in February and March 2017. Schools provided detailed study information to parents at least 2 weeks before each event. Parents either passively consented or opted out on their child’s behalf; students also completed an age-appropriate consent or assent process directly before the survey.

Students assembled into their school’s auditorium or gymnasium and connected their tablet, laptop, or mobile phone to the secure local Wi-Fi network provided by the study team. Survey questions were presented via prerecorded video, integrated within an hour-long media-rich educational presentation. In addition to the large screen displayed to the group, questions were shown on students’ devices, on which they responded confidentially. Anonymous aggregate responses were displayed to the group after all answers for each question had been recorded, contributing to a larger message of stigma reduction within the presentation. See Figure 1 for screen images.

A more detailed description of these events is available in our methodology paper regarding the use of immediate response technologies to gather health data from youth [61]. The events were engineered by a contracted company specializing in audiovisual presentations, which was vetted by the research institution’s legal department. All procedures were approved by the research institution’s institutional review board (PRC15-1001).

The original sample included 3412 high school students. We removed responses from 168 students who only completed the practice questions, 434 students who stopped the survey before the 30th question, and 27 students who responded “prefer not to answer” or did not respond for 80% or more of the questions, leaving a final sample of 2789. To maintain representativeness in the sample, participants who provided partial data were retained where possible (n=1667), and analysis was performed with pairwise deletions, resulting in varying sample sizes across the results.

**Measures**

The 35-question survey began with demographic questions, including age, race, and gender and included the measures below. Due to the sensitive nature of some measures, participants could select “prefer not to answer” or skip any question, with the exception of an initial question regarding age (ie, minor status) to determine consent versus assent.

**Depression and anxiety** were measured with the Patient Health Questionnaire-4 (PHQ-4) [62], a validated 4-item measure of depression and anxiety [63, 64] in young adults [65], which includes the 2 items in the PHQ-2 plus 2 items from the Generalized Anxiety Disorder 7-item (GAD-7) scale, both of which have been validated as appropriately sensitive and specific measures of detecting depression and anxiety in adolescents aged 13 to 17 years [66, 67]. Students used a 4-point Likert scale (0=not at all, 3=nearly every day) to indicate how often they had experienced anxiety (items 1 and 2) and depression (items 3 and 4) symptoms in the last 2 weeks. These items were summed to create a total PHQ score, as well as depression and anxiety subscale scores, in which a score of 0 to 2 indicates no or mild symptoms, and a score of 3 to 6 indicates moderate or severe symptoms.

**Suicidality** was assessed with 1 item from the Youth Risk Behavior Surveillance System survey [68], a validated measure of recent suicidal thoughts and behaviors in adolescents [69]. Participants were asked, “In the last 12 months, did you ever seriously consider attempting suicide?” and responded yes (1) or no (0).

**Stress level** was measured with 1 item, adapted from the American Psychological Association’s Stress in America survey [70], that asked students to rate their stress level over the past month on a scale of 0 to 10, where 0= no stress and 10= a great deal of stress.

**Communication preferences** were established by asking students with whom they could openly and honestly discuss stress or problems with multiple response options (of which they could select any or all), including parent or guardian; friend; teacher; guidance counselor; or school staff; health professional; other adult; someone else; or no one.

**Prior use of TMH resources** was measured with 4 questions regarding use of anonymous online chat, self-help resources, online therapist or counselor, and crisis text line. To inform students of available resources and improve the sensitivity of these questions, the presentation included audiovisual educational information about each type, including specific websites, apps, and services. Students indicated prior use with “yes, and it was helpful,” “yes, but it was not helpful,” “maybe, I’m not sure,” or “no.” Both “yes” answers were combined for analyses predicting prior use.
**Statistical Analysis**

Summary statistics were calculated for demographics, suicidality, PHQ-4 anxiety and depression scores, stress, and previous TMH use. To explore bivariate relationships between predictors and outcomes, zero-order correlations were computed (tetrachoric and polychoric for categorical variables, and Pearson coefficients for continuous variables). A total of 3 series of statistical models were tested. First, to understand how covariates were related to mental health outcomes, demographic characteristics (age, gender, race) were entered into separate logistic regression models predicting suicidality, moderate or severe anxiety, and moderate or severe depression; for stress, the same set of covariates were tested using a general linear model. Second, demographics and mental health outcomes were related to individuals with whom students felt they could openly and honestly discuss problems—parents, friends, or no one—using separate logistic regression models. Third, separate
ordinal logistic models were used to relate demographics, suicidal ideation, anxiety, depression, and stress to students' previous use of the aforementioned 4 types of TMH resources (3 = yes, 2 = maybe, 1 = no). Analyses were conducted using SAS software 9.4. (SAS Institute Inc). SAS and all other SAS Institute Inc product or service names are registered trademarks or trademarks of SAS Institute Inc, Cary, NC, United States.

Results

Demographics and Mental Health

As shown in Table 1, the sample was 51.70% (1442/2789) female and 62.60% (1746/2789) white with an average age of 16.09 years (SD 1.20; range=13-19). In addition, 16.24% (414/2550) reported seriously considering a suicide attempt in the previous 12 months, and 30.58% (853/2789) and 22.91% (639/2789) of the sample reported moderate to severe anxiety (mean 1.64, SD 1.49; range=0-4) and depression symptoms (mean 1.37, SD 1.38; range=0-4), respectively, in the last 2 weeks. On average, students reported 6.06 on the stress scale (SD 2.83; range=0-10). Figure 2 includes a histogram for suicidality responses, scores for the PHQ anxiety and depression scales, stress levels, and previous TMH use.

In preliminary analyses examining zero-order correlations for demographics with mental health outcomes, all correlations were low ($r<.30$). Across these mental health outcomes, gender had highest correlations with suicidality ($r=-.10$), anxiety ($r=-.30$), depression ($r=-.15$), and stress ($r=-.30$). Consistently, as shown in Table 2, females compared with males ($P<.001$) and other gender compared with females ($P<.001$) were significantly more likely to report symptoms of anxiety and depression and considering suicide. Similarly, females reported more stress than males ($P<.001$). White students were more likely to report experiencing anxiety ($P<.001$) and stress ($P<.01$) than minorities. Age was also positively related to anxiety ($P=.03$) and stress ($P=.04$).

Table 1. High school sample characteristics.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>13-14</td>
<td>235 (8.43)</td>
</tr>
<tr>
<td>15-16</td>
<td>1514 (54.30)</td>
</tr>
<tr>
<td>17-19</td>
<td>1039 (37.27)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>1746 (62.60)</td>
</tr>
<tr>
<td>Black</td>
<td>342 (12.26)</td>
</tr>
<tr>
<td>Hispanic American or Latino</td>
<td>211 (7.57)</td>
</tr>
<tr>
<td>Other</td>
<td>339 (12.15)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>151 (5.41)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1266 (45.39)</td>
</tr>
<tr>
<td>Female</td>
<td>1442 (51.70)</td>
</tr>
<tr>
<td>Other</td>
<td>81 (2.90)</td>
</tr>
<tr>
<td>Seriously considered suicide in the last 12 months</td>
<td></td>
</tr>
<tr>
<td>414 (16.24)</td>
<td></td>
</tr>
<tr>
<td>Moderate or severe anxiety symptoms last 2 weeks</td>
<td></td>
</tr>
<tr>
<td>853 (30.58)</td>
<td></td>
</tr>
<tr>
<td>Moderate or severe depression symptoms last 2 weeks</td>
<td></td>
</tr>
<tr>
<td>639 (22.91)</td>
<td></td>
</tr>
<tr>
<td>Stress (0-10)</td>
<td></td>
</tr>
<tr>
<td>0-3</td>
<td>516 (20.32)</td>
</tr>
<tr>
<td>4-7</td>
<td>1131 (44.55)</td>
</tr>
<tr>
<td>8-10</td>
<td>892 (35.13)</td>
</tr>
</tbody>
</table>
Figure 2. Histogram of number of responses or scores for suicidality, Patient Health Questionnaire (PHQ) anxiety, PHQ depression, stress, and website, anonymous online chat, online counselor, and crisis text line use for telemental health.
Table 2. Binary logistic regression analyses for combined demographics predicting suicidality, anxiety, and depression and generalized linear model analysis for combined demographics predicting stress.

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Seriously considered suicide in the last 12 months (n=2427)</th>
<th>Moderate or severe anxiety in the last 2 weeks (n=2637)</th>
<th>Moderate or severe depression in the last 2 weeks (n=2637)</th>
<th>Average stress during past month (n=2403)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B (SE) OR (95% CI)</td>
<td>B (SE) OR (95% CI)</td>
<td>B (SE) OR (95% CI)</td>
<td>B (SE) Wald 95% confidence limit</td>
</tr>
<tr>
<td>Intercept</td>
<td>–0.80 (0.76) –0.80 (0.76)</td>
<td>–1.94 (0.60) –1.87 (0.63)</td>
<td>–1.87 (0.63) –1.77 (0.67)</td>
<td>5.50 (0.73) 4.06, 6.94</td>
</tr>
<tr>
<td>Age</td>
<td>–0.045 (0.05) 0.96 (0.88-1.06)</td>
<td>0.11 (0.04) 1.12 (1.04-1.20)</td>
<td>0.06 (0.04) 1.06 (0.98-1.14)</td>
<td>0.09 (0.05) 0.005, 0.18</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not white</td>
<td>–0.06 (0.12) 0.94 (0.74-1.19)</td>
<td>–0.48 (0.10) 0.62 (0.51-0.75)</td>
<td>0.14 (0.10) 1.15 (0.94-1.39)</td>
<td>–0.29 (0.11) –0.52, –0.07</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male versus female</td>
<td>–0.77 (0.12) 0.46 (0.37-0.59)</td>
<td>–1.34 (0.10) 0.26 (0.22-0.32)</td>
<td>–0.84 (0.10) 0.43 (0.36-0.53)</td>
<td>–1.88 (0.11) –2.10, –1.67</td>
</tr>
<tr>
<td>Other versus female</td>
<td>1.54 (0.29) 4.68 (2.65-8.28)</td>
<td>1.08 (0.29) 2.94 (1.68-5.14)</td>
<td>1.03 (0.27) 2.81 (1.65-4.78)</td>
<td>0.91 (0.39) 0.14, 1.68</td>
</tr>
</tbody>
</table>

aUnstandardized parameter estimate.
bSE: standard error.
cOR: odds ratio.
dCI: Confidence Interval.
eNot available.
fRepresents significant findings, P<.05.

Communication Preferences

More students indicated that they could openly and honestly discuss stress or problems with friends (1874/2682, 69.87%) than with parents or guardians (1204/2682, 44.89%); teachers, guidance counselors, or school staff (360/2682, 13.42%); other adults (270/2682, 10.07%); health professionals (204/2682, 7.60%); or someone else not listed (281/2682, 10.48%). Unfortunately, 19.35% (519/2682) of students reported that they could talk with no one about their stress or problems. The largest zero-order correlation coefficients were observed between talking with a parent and previous suicidality (r=-.38), anxiety (r=-.26), depression (r=-.33), and stress (r=-.27). Consistently, as shown in Table 3, students who were not white (P=.03), male (P=.001) with previous suicidality (P<.001) and more depression symptoms (P<.001) and stress (P=.01) were less likely to report that they could talk open and honestly with parents. All other correlations were less than .25. Students who were not white (P<.001), male (P<.001) with depression symptoms (P=.04) were less likely to talk with friends in an open and honest fashion. Finally, students who were not white (P=.02), male (P<.001), other gender (P<.001) with depression symptoms (P<.001) and higher stress levels (P<.05) were more likely to report that they could talk to no one; interestingly, students with more anxiety were significantly less likely to report talking to no one (P=.047).
Table 3. Binary logistic regression analyses for combined demographics, suicidality, depression, anxiety, and stress predicting talking with friends, parents, or no one (n=2168).

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Talk to friend B² (SE)</th>
<th>OR (95% CI)</th>
<th>Talk to parent or guardian B (SE)</th>
<th>OR (95% CI)</th>
<th>Talk to no one B (SE)</th>
<th>OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>0.96 (0.67)</td>
<td>——</td>
<td>0.90 (0.62)</td>
<td>——</td>
<td>——</td>
<td>——</td>
</tr>
<tr>
<td>Age</td>
<td>0.02 (0.04)</td>
<td>1.02 (0.94-1.11)</td>
<td>—0.001 (0.04)</td>
<td>1.0 (0.93-1.08)</td>
<td>—0.03 (0.05)</td>
<td>0.98 (0.89-1.07)</td>
</tr>
<tr>
<td>Race: not white</td>
<td>-0.64f (0.10)</td>
<td>0.53 (0.43-0.64)</td>
<td>-0.22f (0.10)</td>
<td>0.81 (0.67-0.98)</td>
<td>0.28f (0.12)</td>
<td>1.32 (1.05-1.68)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male versus female</td>
<td>-0.37f (0.11)</td>
<td>0.69 (0.56-0.85)</td>
<td>-0.32f (0.10)</td>
<td>0.73 (0.60-0.88)</td>
<td>0.49f (0.13)</td>
<td>1.63 (1.28-2.09)</td>
</tr>
<tr>
<td>Other versus female</td>
<td>-0.55 (0.34)</td>
<td>0.58 (0.30-1.12)</td>
<td>-0.83f (0.42)</td>
<td>0.44 (0.19-1.00)</td>
<td>1.31f (0.34)</td>
<td>3.70 (1.89-7.22)</td>
</tr>
<tr>
<td>Suicide: Yes</td>
<td>-0.13 (0.15)</td>
<td>1.14 (0.85-1.53)</td>
<td>-0.50f (0.15)</td>
<td>1.80 (1.34-2.41)</td>
<td>0.31f (0.16)</td>
<td>1.37 (1.00-1.87)</td>
</tr>
<tr>
<td>Depression</td>
<td>-0.10f (0.05)</td>
<td>0.90 (0.82-0.99)</td>
<td>-0.24f (0.05)</td>
<td>0.79 (0.72-0.86)</td>
<td>0.28f (0.06)</td>
<td>1.32 (1.18-1.48)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.005 (0.05)</td>
<td>1.01 (0.91-1.11)</td>
<td>-0.06f (0.04)</td>
<td>0.95 (0.87-1.03)</td>
<td>-0.13f (0.06)</td>
<td>0.88 (0.79-0.99)</td>
</tr>
<tr>
<td>Stress</td>
<td>0.04f (0.02)</td>
<td>1.05 (1.00-1.09)</td>
<td>-0.05f (0.02)</td>
<td>0.95 (0.91-0.99)</td>
<td>0.05f (0.03)</td>
<td>1.06 (1.00-1.12)</td>
</tr>
</tbody>
</table>

аUnstandardized parameter estimate.
bSE: standard error.
cOR: odds ratio.
dCI: Confidence Interval.
eNot available.
fRepresents significant findings, \( P<.05 \).
gRepresents marginally significant findings, \( P<.10 \).

Prior Telemental Health Resource Use

Overall, 447 students reported using 1 or more of the 4 TMH tools, with most (318/447, 71.1%) of this group using only 1 type. Anonymous online chat (189/2523, 7.49%) and self-help apps or websites (191/2616, 7.30%) were the most common, followed by the crisis text line (158/2615, 6.04%) and online counselor (92/2652, 3.46%). In review of zero-order correlations involving TMH use, suicidality had the largest correlations with all 4 types (TMH website: \( r=.28 \), chat: \( r=.28 \), counselor: \( r=.27 \), text line: \( r=.34 \)). Other equivalent correlations were between anxiety and self-help app or website use (\( r=.28 \)), and between depression and online anonymous chat (\( r=.29 \); all other correlations were lower. As displayed in Table 4, students who had seriously considered suicide (TMH website: \( P=.003 \), chat: \( P=.03 \), counselor: \( P=.002 \), text line: \( P<.001 \)) or identified their gender as “other” (TMH website: \( P=.051 \), chat: \( P<.001 \), counselor: \( P<.001 \), text line: \( P=.002 \)) were more likely to report previous use of each of the 4 types. Depression predicted previous use of anonymous online chat (\( P<.001 \)) and crisis text line (\( P=.01 \)). Anxiety predicted previous self-help app or website use (\( P<.001 \)); stress predicted previous use of an online counselor or therapist (\( P=.02 \)). Female students were more likely to have used a self-help app or website than males (\( P=.02 \)); males were more likely to use the crisis text line (\( P=.04 \)) than females.
Table 4. Ordinal logistic regression analyses for combined variables predicting previous telemental health tool use (app or website, anonymous online chat, online counselor, crisis text line).

<table>
<thead>
<tr>
<th>Model and predictors</th>
<th>B coefficient (SE(^b))</th>
<th>Odds ratio (95% CI(^c))</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>App or website (n=2404)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept 1</td>
<td>-2.42(^d) (0.14)</td>
<td>—</td>
</tr>
<tr>
<td>Intercept 2</td>
<td>-3.02(^d) (0.15)</td>
<td>—</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male versus female</td>
<td>-0.32(^c) (0.14)</td>
<td>0.73 (0.55-0.96)</td>
</tr>
<tr>
<td>Other versus female</td>
<td>0.59(^c) (0.30)</td>
<td>1.80 (1.00-3.26)</td>
</tr>
<tr>
<td>Suicide: Yes</td>
<td>0.46(^c) (0.16)</td>
<td>1.59 (1.17-2.16)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.25(^c) (0.05)</td>
<td>1.28 (1.17-1.41)</td>
</tr>
<tr>
<td><strong>Anonymous online chat (n=2319)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept 1</td>
<td>-2.46(^c) (0.13)</td>
<td>—</td>
</tr>
<tr>
<td>Intercept 2</td>
<td>-3.12(^c) (0.14)</td>
<td>—</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male versus female</td>
<td>-0.15 (0.14)</td>
<td>0.86 (0.66-1.13)</td>
</tr>
<tr>
<td>Other versus female</td>
<td>1.06(^c) (0.29)</td>
<td>2.89 (1.64-5.07)</td>
</tr>
<tr>
<td>Suicide: Yes</td>
<td>0.36(^c) (0.17)</td>
<td>1.43 (1.03-1.99)</td>
</tr>
<tr>
<td>Depression</td>
<td>0.28(^c) (0.05)</td>
<td>1.33 (1.20-1.47)</td>
</tr>
<tr>
<td><strong>Online counselor (n=2119)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept 1</td>
<td>-3.83(^c) (0.31)</td>
<td>—</td>
</tr>
<tr>
<td>Intercept 2</td>
<td>-4.38(^c) (0.32)</td>
<td>—</td>
</tr>
<tr>
<td>Race: Not white</td>
<td>0.53(^c) (0.19)</td>
<td>1.70 (1.18-2.47)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male versus female</td>
<td>0.19 (0.20)</td>
<td>1.21 (0.81-1.80)</td>
</tr>
<tr>
<td>Other versus female</td>
<td>1.49(^c) (0.39)</td>
<td>4.42 (2.04-9.57)</td>
</tr>
<tr>
<td>Suicide: Yes</td>
<td>0.69(^c) (0.23)</td>
<td>2.00 (1.29-3.12)</td>
</tr>
<tr>
<td>Stress</td>
<td>0.09(^c) (0.04)</td>
<td>1.09 (1.01-1.18)</td>
</tr>
<tr>
<td><strong>Crisis Text Line (n=2294)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept 1</td>
<td>-2.70(^d) (0.14)</td>
<td>—</td>
</tr>
<tr>
<td>Intercept 2</td>
<td>-3.58(^d) (0.15)</td>
<td>—</td>
</tr>
<tr>
<td>Race: Not white</td>
<td>0.66(^c) (0.13)</td>
<td>1.94 (1.51-2.50)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male versus female</td>
<td>0.27(^c) (0.13)</td>
<td>1.31 (1.01-1.70)</td>
</tr>
<tr>
<td>Other versus female</td>
<td>0.98(^c) (0.32)</td>
<td>2.67 (1.43-5.00)</td>
</tr>
<tr>
<td>Suicide: Yes</td>
<td>0.88(^c) (0.16)</td>
<td>2.41 (1.74-3.32)</td>
</tr>
<tr>
<td>Depression</td>
<td>0.14(^c) (0.05)</td>
<td>1.15 (1.04-1.27)</td>
</tr>
</tbody>
</table>

\(^{a}\)SE: standard error.

\(^{b}\)CI: Confidence Interval.

\(^{c}\)Represents significant findings, \(P<.05\).

http://mental.jmir.org/2019/6/e13230/
Discussion

Results and Prior Work

Youth in this high school sample reported high rates of anxiety and depression symptoms and suicidal ideation that were consistent with national averages among teenagers (31% [7], 12.8-31.5% [5,6], and 17.2% [6], respectively). In addition, more than 35% reported high stress (ie, ≥8 out of 10) in the last month. With regard to their usage of TMH, approximately 16% of youth had utilized 1 or more types of TMH resources. This number may seem low, but it is important to consider within context, as not all students have a need for these resources. Approximately half of the sample (1378/2789, 49.4%) indicated high stress, moderate or high depression or anxiety, and/or suicidal thoughts. However, as we asked about symptoms within constrained time periods but TMH usage at any time, and some students may have accessed traditional mental health care and not TMH, we did not expect these measures to be congruent. However, our prevalence statistics for stress, anxiety, and depression provide some evidence on the percentage of youth who would be likely to need such resources.

Prior research has found similarly low TMH usage rates: in 1 recent study of patients who were older than our sample (average age=57.5 years), but all had a documented need for mental health care, only 10% had previously used TMH apps, but over 70% were interested in doing so once informed of them [71]. This pattern of increased interest in TMH after receiving education has been noted in other research, as well [46,47]. Our sample had not necessarily received formal education on these resources before the assembly, and TMH does not encompass prototypical treatment options (ie, visiting a therapist in person or taking medication) of which they would likely be aware. We did not ask about students’ prior awareness of these resources, only their use, but in a recent longitudinal study of college students, only 10% had initially used a self-help website and even less could identify one by name; however, both use and awareness increased throughout the study period [56].

Depression and anxiety symptoms occurred at higher rates among female students, consistent with national trends [1-4,6]. However, female students were not more likely to have used anonymous chat or an online therapist than males, though they were more likely to access self-help resources, whereas males were more likely to have used the crisis text line. In addition, although the number of gender nonconforming students was small, they were more likely than those who identified as male or female to experience stress and symptoms of anxiety and depression, as well as use every form of TMH. White students reported experiencing more anxiety symptoms than minorities, and they were more likely to talk about their stress or problems with parents or friends and were less likely to talk to no one. However, minority students were more likely than white students to have used an online counselor or the crisis text line. Combined, these findings underscore the importance of measuring gender, race, and ethnicity in an inclusive way so that these relationships are more thoroughly explored and at-risk students might be better identified, educated, and treated.

In general, teens who reported issues with their mental health were more likely to have utilized TMH resources than those who did not, indicating that those who are struggling are attempting to find help and TMH has potential to serve these groups. Teens experiencing suicidality were more likely to have used all 4 categories of TMH resources, those with depressive symptoms were more likely to have used anonymous chat and the crisis text line, and those with higher stress were more likely have used an online therapist. A related theme that emerged, reflecting previous findings [8,13-15,20,21], was self-reliance and its correlation with depression and suicidality. Teens who reported depressive symptoms, higher stress, and/or suicidal ideation were less likely to report they could speak openly and honestly with their parents about problems, and more likely to have no one to talk to. Nearly 20% of students in total reported talking to no one when struggling, including 22% of prior TMH users, in line with previous findings that teens who endorse self-reliance are more likely to utilize anonymous Web-based support for problems [20]. These teens may feel more comfortable using a phone or computer to discuss mental health than, for example, asking their parent to see a therapist [15,20,43] and may benefit from the anonymity and relative independence afforded by TMH [72].

In contrast, teens reporting anxiety, as well as those who did not report any mental health symptoms, were more likely to talk to parents or friends about their problems and less likely to talk to no one. Overall, they had not used the full scope of TMH resources compared with those struggling with depression and suicidality, although they were more likely to have tried self-help apps. Together, this collection of preferences related to symptom type and available confidants represents an important consideration for researchers and developers of TMH services. Future research could further evaluate these unique preferences among symptom groups, and, assuming preferences remain, engage these target end users in participatory design and usability testing related to the specific types of apps they have shown preferences for. For example, those designing services with the goal of helping with depression and stress management could focus on evidence-based services that allow anonymous disclosure (ie, online therapy and anonymous chat) and allow these potential users to give feedback on their experiences using prototypes of the service before it is released. Services designed to reach those with anxiety could use a self-help model, and all services could potentially include information about resources (both tech-based and in local communities) to help those considering suicide.

Future Directions

Nearly a third of the students in our study who reported recent anxiety or depression symptoms, high stress, or suicidal ideation also reported prior use of a TMH resource. However, we did not investigate in detail whether they found TMH helpful, although this is an important area of consideration for future study. In asking about prior use, we allowed students to select...
“yes, and it was helpful” or “yes, but it was not helpful,” which were collapsed into 1 answer of “yes” for most analyses. These responses were split nearly evenly overall (49/51%, respectively), with little variation across resource categories. However, these data alone do not provide much insight without further information regarding exact services participants were using, how they hoped to benefit from them, and why they were unsatisfied with their experience. Other research has suggested that insufficient personalization of resources is likely a factor affecting use but emphasized the difficulty of drawing these conclusions merely from survey data [71]. This reinforces the need for evidence-based and tailored resources [30], along with education about them, as discussed in the Objectives of this study.

Even when effective TMH resources are created, there should be continued work to integrate them into the health care system, likely in conjunction with face-to-face care, as this has not yet been sustainedly executed on a large scale [44,57]. When attempting to integrate TMH technologies into formal health care, it is important to engage the target audience in user-centered design processes to further ensure efficacy and sustainability [45]. As stigma is a major barrier to traditional mental health treatment [8,13-17], the relative flexibility, immediacy, and anonymity of TMH may mitigate this concern [13]. Prior research also suggests that successful Web-based self-disclosure, in general, may lead to self-disclosure in person [73]; thus, future research could additionally explore TMH as a bridge between self-reliance and professional help. In addition, many prior studies have revealed insufficient knowledge about both traditional mental health care and TMH [13,17,18]. To effectively locate and utilize TMH resources, youth must be able to identify their symptoms and find reputable avenues of support. Although the events connected to this study educated participants about available sources of tech-based help, barriers to TMH use (including lack of awareness, stigma, and feelings of trust) should be a focus of future research.

TMH also has the potential to play an important role in suicide prevention—youth in this study who had considered suicide were more likely to have used all categories of resources. Given the disparity between urban and rural suicide rates [74], and the fact that individuals in rural locations may particularly benefit from TMH resources [4,17,43] because of geographic isolation from traditional treatment, TMH may be a useful addition to suicide treatment and prevention efforts, which, in light of current trends, need revision or supplementation [8,17]. Our sample included only suburban and rural schools, and we did not evaluate the urban or rural status of individual students; thus, we are unable to elucidate the usefulness of TMH among these different groups. However, we believe it is an important direction for future research.

Finally, participants in prior research have cited data protection, information security, and anonymity as important concerns related to health care delivered via apps or websites [30]; therefore, TMH resources must be able to guarantee that personal health information will be safe [43,45]. With regard to public buy-in, concerns related to teen social media and internet use persist, as anonymous online behavior may increase susceptibility to cyberbullying and leave individuals more vulnerable in a suicide attempt, without a real-life support network to intervene [20]. However, extant literature suggests that benefits of TMH outweigh concerns [38], many of which could be mitigated by appropriate design, moderation, or professional involvement [43,45,50]. Future research should continue to consider these safety-related factors when developing new interventions.

Limitations

Our sample included only students enrolled in and present at school, whose parents had not opted out. Several variables (ie, male or other gender, minority race, higher depression level) related positively to nonresponse, potentially limiting data for topics particularly sensitive to these individuals. The setting of the survey (ie, an auditorium or gymnasium in which students were seated near each other and could not be truly prevented from speaking) could have contributed to nonresponse or skewed responses toward lower reporting of stigmatized topics. Conversely, the group setting may have kept other students engaged. In addition, the themed presentation may have influenced students to respond either positively or negatively to the TMH-related questions, if they assumed we were seeking positive response and chose to fulfill or deny this expectation. However, we do not believe these limitations would necessarily create strong trends in any specific direction, nor would they be entirely mitigated in a different setting (ie, classroom or computer lab).

In addition, the number of students reporting their gender as “other” was small, but gender-nonconformity was associated with higher rates of depression and anxiety symptoms, suicidal ideation, stress, inability to discuss stress or problems openly and honestly with a parent (or anyone), and prior use of all 4 TMH categories. We did not record sexual orientation, but given the consistency of gender nonconformity as a predictor, future research should explore both gender and sexual minority status in relation to mental health help-seeking. These 2 groups, which sometimes overlap, face similar sets of social and familial challenges and may uniquely benefit from the lack of required parental involvement involved in TMH help-seeking.

This high school survey was part of a larger study about TMH usage that also included college students; thus, the PHQ-4 was used for consistency among both groups, although it has not been specifically validated with adolescents. However, over 37% of our sample for this study was aged 17 to 19 years (for whom the PHQ-4 has been validated [65]), and the 2 measures from which the PHQ-4 was created (the PHQ-2 and GAD-7) have been validated among adolescents aged 13 to 17 years [66,67]. Given these factors, along with the expected rates of depression and anxiety reported by our sample, we believe the PHQ-4 was an acceptable choice for the 13 to 19 years age group despite lacking validation in its exact 4-item format for the younger students.

Conclusions

Overall, our results indicate that teenagers experiencing mental distress are utilizing existing TMH resources at a moderate rate consistent with extant literature. Type of resource usage correlated with mental health and demographic variables,
providing a framework for future research and targeted resource development. Suicidality and gender nonconformity predicted use of all 4 categories of resources; depression, anxiety, and stress all predicted use of at least 1 unique type. In addition, suicidality, depression, and stress were correlated with lacking confidants with whom to discuss stress or problems, whereas those with anxiety were less likely to report this. As the mental health field progresses toward electronically-based care, it is important to consider findings such as these to provide appropriate interventions that target specific populations for effective and tailored care or supplementation of care [60]. Particularly, access to evidence-based resources that use varying methods of engagement based on symptoms or preference [13,29] and/or allow students to discuss their issues informally, on their own time, mutually, and anonymously [17,21,28,43,46,49,50] may be promising routes for providing support for specific symptoms, stressors, or demographics among youth who are in need of mental health interventions.

Acknowledgments

Support for this research was provided by the Robert Wood Johnson Foundation (grant #73055). The views expressed here do not necessarily reflect the views of the foundation. The authors would like to acknowledge and thank the high school administrators and students that participated in this research.

Conflicts of Interest

None declared.

References


Abbreviations

PHQ: Patient Health Questionnaire
TMH: telemental health

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Preferences of Information Dissemination on Treatment for Bipolar Disorder: Patient-Centered Focus Group Study

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Abstract

Background: Patient education has taken center stage in successfully shared decision making between patients and health care providers. However, little is known about how patients with bipolar disorder typically obtain information on their illness and the treatment options available to them.

Objective: This study aimed to obtain the perspectives of patients with bipolar disorder and their family members on the preferred and most effectively used information channels on bipolar disorder and the available treatment options.

Methods: We conducted nine focus groups in Montana, New Mexico, and California, in which we surveyed 84 individuals including patients with bipolar disorder and family members of patients with bipolar disorder. The participants were recruited using National Alliance on Mental Illness mailing lists and websites. Written verbatim responses to semistructured questionnaires were analyzed using summative content analysis based on grounded theory. Two annotators coded and analyzed the data on the sentence or phrase level to create themes. Relationships between demographics and information channel were also examined using the Chi-square and Fisher exact tests.

Results: The focus group participants mentioned a broad range of information channels that were successfully used in the past and could be recommended for future information dissemination. The majority of participants used providers (74%) and internet-based resources (75%) as their main information sources. There was no association between internet use and basic
demographics such as age or geographical region of the focus groups. Patients considered time constraints and the fast pace in which an overwhelming amount of information is often presented by the provider as major barriers to successful provider-patient interactions. If Web-based channels were used, the participants perceived information obtained through Web-based channels as more helpful than information received in the provider’s office ($P<.05$).

**Conclusions:** Web-based resources are increasingly used by patients with bipolar disorder and their family members to educate themselves about the disease and its treatment. Although provider-patient interactions are frequently perceived to be burdened with time constraints, Web-based information sources are considered reliable and helpful. Future research should explore how high-quality websites could be used to empower patients and improve provider-patient interactions with the goal of enhancing shared decision making between patients and providers.

**Methods**

**Study Participants and Research Team**

To achieve the study goals, we conducted nine focus groups with 4-12 participants each. Study participants were recruited through the National Alliance on Mental Illness (NAMI) mailing lists in three regions of the United States: Great Falls and Helena, Montana; Albuquerque, New Mexico; and Los Angeles, California. Purposive sampling was used to select participants who had the potential to provide rich, relevant, and diverse perspectives. During the first year of this study, three focus groups of 11-12 participants each were conducted, with participants of all ages. Participants were either individuals with bipolar disorder or family members of individuals with bipolar disorder. During the second year, three focus groups were conducted with a special focus on participants aged 18-24 years, and three focus groups were held with elderly participants, most aged 65 years and older; these focus groups were smaller in size, between 4 and 11 participants each, and restricted to individuals with bipolar disorder. The participants were reimbursed for their participation with a gift certificate for a major retailer, and 100% study retention was achieved. For consistency, the focus groups were led by the principal investigator of the study. In addition, each focus group included 2-3 study members who took notes and at least one clinician whose primary role was to provide clinical support, if needed.

**Introduction**

The importance of informing patients about their disease and involving them in decisions about their treatment has been increasingly recognized in studies on recovery from severe mental illness [1-3]. The claim for shared decision making has been justified on ethical grounds, framed as a basic right to self-determination [4], but an association with positive clinical outcomes has also been reported in some studies [5-9]. Patients with depression described better self-management and reduction of symptoms [5], and patients with schizophrenia experienced faster social recovery, more satisfaction with treatment, and fewer rehospitalizations with such an approach [6,7]. Patients with substance use disorder testified to a higher quality of life, increased decision making ability with regard to drug use, and a reduction in psychiatric symptoms after discharge [8,9]. To our knowledge, unfortunately, there are no such studies on patients with bipolar disorder. Systematic reviews of the literature found some overall evidence for more favorable adherence to therapeutic decisions made by shared decision making [10], but the lack of standardization and insufficiencies in both quantity and quality of the studies have hindered establishment of final conclusions [11]. In the process of shared decision making, patient education is crucial to achieve successful treatment outcomes [12,13].

For patients with bipolar disorder and their family members, the process of seeking information about the disorder and treatment is often challenging. First, multiple, and sometimes contradicting, guidelines are available in the scientific literature and on the internet [14-20]. In addition, complex technical language and frequent updates to the treatment guidelines make it challenging to keep up with the field. Furthermore, the evidence of the best available treatment for each patient may be limited. Some medications could also have undesirable side effects, which, from the patient’s perspective, may outweigh the benefits. Uncertainty about treatment options and benefits could influence the communication processes between doctors and patients and challenge treatment adherence.

The literature is sparse on publications that address information seeking by patients with bipolar disorder [21]. Therefore, we aimed to fill this knowledge gap. We conducted focus groups with patients diagnosed with bipolar disorder and some family members of the patients to gain insight into the process of information seeking and shared decision making. We inquired about how evidence on the comparative effectiveness of treatments could best be communicated to patients and their families to empower them as partners in care and to improve outcomes. The key objectives of this exploratory focus group study were three-fold: (1) to better understand how patients and their family members would prefer to be informed about their disease and the available evidence-based treatment options, (2) to identify facilitators and barriers in the education and information-seeking process, and (3) to test if the perception of usefulness of information obtained was independent of the information channels used.
Setting and Informed Consent

The focus groups took place at four different locations—Great Falls, Montana; Helena, Montana; Albuquerque, New Mexico; and Los Angeles, California—between September 23, 2017, and December 15, 2018. The focus groups lasted for 2-3 hours and were held at local NAMI centers or hotel conference rooms at a convenient time for the participants.

All procedures involving human subjects/patients were approved by the Institutional Review Board of the University of New Mexico (#16-243). All participants provided written informed consent to participate in the focus groups and to use the data for research after the nature and possible consequences of the study were explained. After a brief introduction to the study goals and the research team, the focus group participants had the opportunity to discuss the topic and ask questions. The participants were then asked to share their perspectives through anonymized semistructured questionnaires and to respond to the following open-ended questions: (1) “How can we best communicate information about disease management and therapies to newly diagnosed patients with bipolar disorder?” (2) “Where did you get your information about bipolar disorder management?” (3) “What has worked to provide you the education and information you need?” (4) “What has not worked to provide you the education and information you need?” Each participant was asked to describe several sources of information to elicit the maximum number of resources used.

Quantitative Data Analysis

Demographics of the focus groups were collected without personal identifiers. The demographics were summarized as total numbers and percentages of the total number of participants. The Chi-square test and Fisher exact test for small numbers were used for statistical testing with an alpha level of .05 (two-tailed).

Data Coding and Qualitative Data Analysis

We used an inductive approach (open coding) to generate themes for the analysis of the written responses using grounded theory and summative content analysis [22,23]. The Consolidated Criteria for Reporting Qualitative Research Checklist was used to report the methodology and findings [24]. Two data coders analyzed the data independently on the sentence or phrase level, if no sentences were used. They then discussed the codes among themselves to generate themes for the analysis through consensus. Codes that were conceptually related were combined, if appropriate, and linked to the more general, overarching themes. The coding process and generation of the themes were then reviewed by the entire research team. Finally, consensus was reached by discussion and included the following themes and information sources: medical doctors and psychiatrists, peer support, patient advocacy organizations, pamphlets, online or in-person educational classes, websites, social media, videos and film, scientific literature and books, mobile phone apps, family members, and social workers and counselors. In some geographical regions, nurse practitioners or therapists served in the function of doctors and psychiatrists. In these cases, the responses were merged with the category “medical doctors and psychiatrists.” The overarching themes and the verbatim phrases that were related to the themes can be found in Table 1.

After the final draft of the paper was completed, feedback on the research findings was obtained from our patient partner advisory group to add validity to our interpretation and ensure that the participants’ own meanings and perspectives were represented and not distorted by the researchers’ agenda and knowledge. The data were then summarized and reported as the total number of times a theme was mentioned and as a percentage of all possible times a theme could have been mentioned. If a participant mentioned several similar or conceptually related information channels, they were counted as one. To better understand facilitators and barriers to the information-seeking process, we further examined the verbatim answers of the focus group participants that referred to this issue. We attempted to group the responses according to a widely accepted model of successful communication between doctors and patients [25,26].

Complete information was obtained on demographic data for age, gender, ethnicity, and race. For the rest of the variables or themes, the theme was annotated as present if mentioned or as absent if not mentioned. Therefore, no missing values were encountered.
Table 1. Themes and concepts.

<table>
<thead>
<tr>
<th>Themes and concepts</th>
<th>Verbatim phrases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical doctors and psychiatrists</td>
<td>Therapist, hospitals, Kaiser, Department of Mental Health, outpatient treatment facilities, mental health treatment facilities, clinics, treatment team, provider, mental health treatment community, pharmacist, primary care doctors, hospital staff, emergency room, public services, naturopathic doctors, medical professionals, neurologist, Shodair children’s hospital, medication manager, psychotherapist, nurse, VA\textsuperscript{a} Psychology, behavioral health, inpatient, outpatient, residential program, Veterans administration, nurse practitioner, rehabilitation in mental health facilities</td>
</tr>
<tr>
<td>Peer support</td>
<td>Kaiser groups, BP\textsuperscript{b} groups, groups, other people who have mental health issues, peer ed\textsuperscript{c} programs, peer movement, the recovery community, The Sisterhood support group, one-on-one peer advantage, mentor, peer to peer networking, Peer-Bridging (MHC\textsuperscript{d}), sharing with others and learning their experiences, talking to others with lived experience, the experience of living with someone with BP, conversations with diagnosed individuals, hearing lived experiences of others, sharing my story, lived experience, 12-step groups, support network, friends who have also struggled, friends with bipolar disorder, recovery international, vet\textsuperscript{e} to vet, talking to others with the same diagnosis</td>
</tr>
<tr>
<td>Patient advocacy organizations</td>
<td>NAMI, advocate, Psychosocial Rehabilitation Association of New Mexico (PSRANM), NAMI\textsuperscript{f} conferences, Depression and Bipolar Support Alliance (DBSA), interNational Association of Peer Supporters (iNAPS), Mental Health America, Bipolar/depression alliance</td>
</tr>
<tr>
<td>Pamphlets</td>
<td>Hand-outs, booklets, release packets, reading material, forms, print-outs, info that comes with prescriptions, brochure, drug warning pamphlet</td>
</tr>
<tr>
<td>Classes in person/online</td>
<td>MFCT\textsuperscript{g} master’s program, seminars, conferences, family to family classes, peer to peer class, provider class, hand-on activities, trainings, power point, educators, college, high schools, patient orientation to educate on meds and diagnosis, charts, workshops, presentations, CEU’s\textsuperscript{h} for license, group education settings, universities, AWARE\textsuperscript{i}</td>
</tr>
<tr>
<td>Videos and film</td>
<td>Film with information about pros and cons of med, film with interviews with successfully treated patients, YouTube videos, movies, TV shows, documentaries of live experience</td>
</tr>
<tr>
<td>Social media</td>
<td>Twitter, facebook, message boards, Yahoo groups, instagram, celebrities who have it, Demi Lovato</td>
</tr>
<tr>
<td>Scientific literature and books</td>
<td>Books, scientific papers, articles, B(behavioral)H(ealth) magazine, journals, medical journals, medical conferences, physician conferences, Psychology today, B(i)polar magazine, publication of synopses in widely distributed magazines, library books, medical journal articles, biographies, memoirs, “An unquiet mind,” “The bipolar survival guide,” public library</td>
</tr>
<tr>
<td>Websites</td>
<td>Dr Google, online, online resources, databases, webMD, bipolaradvantage.com, internet, websites dedicated to providing information on medication and medical history, self-paced web course, Mental Health resources online, NIMH\textsuperscript{j} websites, NCBI\textsuperscript{k}, Google Scholar, Google, The Wellness Recovery Action Plan (WRAP), do your own research online, blogs, articles on internet, University of New Mexico (UNM) psychiatry website, NAMI websites, internet research, research online, drugs.com, beyond meds website, mad in America website</td>
</tr>
<tr>
<td>Mobile phone apps</td>
<td>B(ipolar)D(disorder) app</td>
</tr>
<tr>
<td>Family members</td>
<td>cousin, son, dad, father</td>
</tr>
<tr>
<td>Social workers and counselors</td>
<td>counseling, caseworkers, case management</td>
</tr>
</tbody>
</table>

\textsuperscript{a}VA: veterans affairs. 
\textsuperscript{b}BP: bipolar disorder. 
\textsuperscript{c}Ed: education. 
\textsuperscript{d}MHC: Mental Health Court. 
\textsuperscript{e}Vet: veteran. 
\textsuperscript{f}NAMI: National Alliance on Mental Illness. 
\textsuperscript{g}MFCT: Marriage, Family, Child Therapist. 
\textsuperscript{h}CEU: Continuing Education Unit. 
\textsuperscript{i}AWARE: Arming Women Against Rape and Endangerment. 
\textsuperscript{j}NIMH: National Institute of Mental Health. 
\textsuperscript{k}NCBI: National Center for Biotechnology Information.
Results

Demographics
A total of 84 people participated in the nine focus groups. The median age of the participants was 48.5 years, with a range of 18-79 years. Because we oversampled the younger and older age groups during the second year, one-third of the sample belonged to the age group of 18-29 years (n=28, 33%), and almost one-third of the sample was aged 70 years and above (n=23, 27%; Table 2). About two-thirds of the participants were female (n=54, 64%) and almost two-thirds were non-Hispanic white individuals (n=53, 63%). The majority of the participants (n=78, 93%) were diagnosed with bipolar disorder, and only a small number of participants (n=6, 7%) were family members of patients with bipolar disorder but had not been diagnosed with the disease themselves.

Table 2. Demographics of the participants in the focus groups (N=84).

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Values, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>28 (33)</td>
</tr>
<tr>
<td>30-39</td>
<td>4 (5)</td>
</tr>
<tr>
<td>40-49</td>
<td>8 (10)</td>
</tr>
<tr>
<td>50-59</td>
<td>5 (6)</td>
</tr>
<tr>
<td>60-69</td>
<td>16 (19)</td>
</tr>
<tr>
<td>≥70</td>
<td>23 (27)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>54 (64)</td>
</tr>
<tr>
<td>Male</td>
<td>29 (35)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1)</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White (non-Hispanic)</td>
<td>53 (63)</td>
</tr>
<tr>
<td>White (Hispanic)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Black</td>
<td>14 (17)</td>
</tr>
<tr>
<td>Multiracial</td>
<td>10 (12)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (7)</td>
</tr>
</tbody>
</table>

Channels of Information Dissemination
Overall, the participants mentioned a broad range of preferred channels through which patients newly diagnosed with bipolar disorder could be informed about the disease characteristics and available treatment options (Table 3). Medical doctors and psychiatrists were the most common sources of information (n=38, 45%), followed by peers and patient advocacy groups (n=29, 35% each). Short written material such as pamphlets and in-person or online educational classes were also popular (n=13 each, 15% each). About 15% of participants mentioned that they would prefer to use websites (n=13, 15%) or social media (n=12, 14%) as a source of information. Videos/films were mentioned by 12% of the participants (n=10) and scientific literature/books, by 10% of participants (n=8). Other information channels including mobile phone apps, family members, or social workers/counselors were rarely mentioned (n=2 in each category, 2%).

To better understand preferences for distribution of information, we also asked the focus group participants about information channels that they had used in the past. Again, the answers covered a wide range of information sources. Leading the list were websites (n=62, 74%) and medical doctors and psychiatrists (n=61, 73%), followed by patient advocacy organizations (n=30, 36%) and peer support (n=28, 33%). The scientific literature (n=19, 23%) and family members (n=10, 12%) were also mentioned by some participants. Educational classes and social workers/counselors (n=8, 10% each) were less frequently used. Film/videos (n=3, 4%) and social media (n=2, 2%) were rarely mentioned. Disease-specific mobile phone apps were not used at all (n=0, 0%).
Table 3. Frequency of variables in the data set.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Preferred information sources</strong></td>
<td></td>
</tr>
<tr>
<td>Medical doctors and psychiatrists</td>
<td>38 (45)</td>
</tr>
<tr>
<td>Peer support</td>
<td>29 (35)</td>
</tr>
<tr>
<td>Patient advocacy organizations</td>
<td>29 (35)</td>
</tr>
<tr>
<td>Pamphlets</td>
<td>13 (15)</td>
</tr>
<tr>
<td>Classes in person/online</td>
<td>13 (15)</td>
</tr>
<tr>
<td>Websites</td>
<td>13 (15)</td>
</tr>
<tr>
<td>Social media</td>
<td>12 (14)</td>
</tr>
<tr>
<td>Videos/film</td>
<td>10 (12)</td>
</tr>
<tr>
<td>Scientific literature/books</td>
<td>8 (10)</td>
</tr>
<tr>
<td>Mobile phone apps</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Family members</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Social workers and counselors</td>
<td>2 (2)</td>
</tr>
<tr>
<td><strong>Information sources used in the past</strong></td>
<td></td>
</tr>
<tr>
<td>Medical doctors and psychiatrists</td>
<td>61 (73)</td>
</tr>
<tr>
<td>Peer support</td>
<td>28 (33)</td>
</tr>
<tr>
<td>Patient advocacy organizations</td>
<td>30 (36)</td>
</tr>
<tr>
<td>Pamphlets</td>
<td>5 (6)</td>
</tr>
<tr>
<td>Classes in person/online</td>
<td>8 (10)</td>
</tr>
<tr>
<td>Videos</td>
<td>3 (4)</td>
</tr>
<tr>
<td>Social media</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Scientific literature</td>
<td>19 (23)</td>
</tr>
<tr>
<td>Websites</td>
<td>62 (74)</td>
</tr>
<tr>
<td>Mobile phone apps</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Family members</td>
<td>10 (12)</td>
</tr>
<tr>
<td>Social workers and counselors</td>
<td>8 (10)</td>
</tr>
<tr>
<td><strong>Information sources perceived as helpful</strong></td>
<td></td>
</tr>
<tr>
<td>Medical doctors and psychiatrists</td>
<td>25 (30)</td>
</tr>
<tr>
<td>Peer support</td>
<td>23 (27)</td>
</tr>
<tr>
<td>Patient advocacy organizations</td>
<td>25 (30)</td>
</tr>
<tr>
<td>Pamphlets</td>
<td>5 (6)</td>
</tr>
<tr>
<td>Classes in person/online</td>
<td>12 (14)</td>
</tr>
<tr>
<td>Websites</td>
<td>27 (32)</td>
</tr>
<tr>
<td>Social media</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Videos/film</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Scientific literature/books</td>
<td>12 (14)</td>
</tr>
<tr>
<td>Mobile phone apps</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Family members</td>
<td>3 (4)</td>
</tr>
<tr>
<td>Social workers and counselors</td>
<td>3 (4)</td>
</tr>
<tr>
<td><strong>Information sources perceived as not helpful</strong></td>
<td></td>
</tr>
<tr>
<td>Medical doctors and psychiatrists</td>
<td>34 (40)</td>
</tr>
<tr>
<td>Peer support</td>
<td>1 (1)</td>
</tr>
</tbody>
</table>
In a post hoc analysis, we did not detect any statistically significant association between website use and regional location of the focus group ($\chi^2=2.7$, $P=.26$). Based on data collected during the second year of the study, in which focus groups were held separately for two different age groups (Group 1: 18-24 years vs Group 2: 65 years and above), we did not detect any statistically significant associations between age groups and Web-based resource use ($\chi^2=0.03$, $P=.87$).

**Barriers and Facilitators of the Information-Seeking Process**

To learn about potential barriers and facilitators in the process of obtaining information on bipolar disorder, we asked the focus group participants about what has particularly worked or not worked for them to obtain the information they needed to manage the disease. Participants who had used Web-based resources as well as some who had not, perceived the information that they had received on websites to be helpful (n=27, 32%). In contrast, only one-third of all participants considered the information that they had received from their doctors and psychiatrist helpful (n=25, 30%; Textbox 1). For other information sources, the discrepancy was less marked. Patients who had used patient advocacy organizations and peer support found these resources generally helpful (n=25, 30%; Textbox 1). For other information sources, the discrepancy was less marked. Patients who had used patient advocacy organizations and peer support found these resources generally helpful (n=25, 30%, and n=23, 27%, respectively). Even though used less frequently, classes in-person or online and books or scientific literature (n=12, 14% each) were generally perceived to be helpful. However, information obtained from family members and social workers or counselors were less frequently considered helpful (n=3, 4% each). Only a small number of people found information obtained through short written materials (n=5, 6%), videos/film, and social media (n=2, 2% each) helpful. Since disease-specific mobile phone apps were not used, they were also not perceived to be helpful.

When asked about barriers in the process of obtaining information on bipolar disorder, patients mentioned four main issues (Textbox 1). About 40% of focus group participants (n=34, 40%) perceived the information that they had received from their doctors as not always helpful. Unhelpful interactions with family members (n=3, 4%) and peers (n=1; 1%) were also mentioned by some participants. A few participants found that the way in which information was presented in pamphlets (n=4, 4%), on websites (n=3, 4%), or in the scientific literature (n=2, 2%) was not helpful to them or that they had encountered barriers to understanding the information when they used these channels. Other information channels, including patient advocacy organizations and educational classes, were generally seen in a positive light.

When asked about what had worked and had not worked to provide them with education and information needed, the focus group participants most often described aspects of successful or unsuccessful communication between doctors and patients. The responses could be grouped in three categories: introducing choice; describing options, often by integrating the use of patient decision support; and helping patients explore preferences and make decisions (Textbox 1) [25,26]. Some patients testified to a successful patient-doctor relationship that had met their needs and expectations and to effective ways of receiving information in the doctor-patient relationship. However, many other responses pointed to shortcomings in patient-doctor communication, especially with regard to presenting the information known; discussing benefits, risks, and costs; and clarifying the patient’s understanding. Patients also testified that, in their experience, their values and preferences had not been considered; they experienced a more clinician-led doctor-patient relationship as they struggled to be seen as competent and equal partners in decision-making situations. Potentially related to barriers in the communication processes between doctors and patients was the perception by some focus group participants that information provided by the doctor was not trustworthy or helpful. Generally, the focus group participants expressed a sense of responsibility to find the information that was needed to make decisions on their own.

In contrast, information obtained on the internet was described as reliable and useful. When we compared the perceived helpfulness of information obtained from a doctor and that obtained from the internet, the perception of helpfulness was not independent of the source (Fisher exact test, $P<.05$). Only three focus group participants voiced some concern about the potentially overwhelming task to sort through Web-based information. There was no significant relationship between age group and perceived helpfulness of Web-based resources ($\chi^2=0.2$, $P=.65$).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient advocacy organizations</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Pamphlets</td>
<td>4 (5)</td>
</tr>
<tr>
<td>Classes in person/online</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Websites</td>
<td>3 (4)</td>
</tr>
<tr>
<td>Social media</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Videos/film</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Scientific literature/books</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Mobile phone apps</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Family members</td>
<td>3 (4)</td>
</tr>
<tr>
<td>Social workers and counselors</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

*Note: Frequency numbers not for citation purposes.*
Textbox 1. Barriers and facilitators of information seeking in the doctor-patient relationship. Representative quotes are provided from focus group participants at the three locations.

Introducing choice
Positive experiences:
- I can’t say that there is anything that specifically hasn’t worked. I have benefited from everything. [Participant from Los Angeles, California]
- I think treatment has really worked. [Participant from Los Angeles, California]
- My providers have worked to provide me with education. [Participant from Great Falls, Montana]
- Doctor interactions have worked- keeping me informed. [Participant from Great Falls, Montana]

Negative experiences:
- Having choices forced upon me by psychiatrists. [Participant from Great Falls, Montana]
- Not being my own advocate has not worked. I have to seek the information I want. [Participant from Albuquerque, New Mexico]
- Being put on medication I know nothing about has not worked. [Participant from Great Falls, Montana]
- Doctors are the worst for educating. They don’t have enough time. Doctors should encourage individuals on UNM website & the website should educate about UNM Psych programs, disorders, management of disorders & laws governing mental health. [Participant from Albuquerque, New Mexico]
- The mental health system is so overrun- very hard to get appointments with psychiatrists, then used very medical language that was hard to understand. [Participant from Los Angeles, California]
- Psychiatrist often don’t brief fully on what the drug might be doing or side effects. [Participant from Los Angeles, California]
- Rehabilitation in mental facilities made it hard for me to get the information I needed. [Participant from Los Angeles, California]
- I found talking to others with the same diagnosis was initially the best way and then I connected with NAMI. My doctors were not helpful the majority of the time. [Participant from Los Angeles, California]

Describing options, often by integrating the use of patient decision support
Positive experiences:
- Asking my psychiatrist about medicines and my disorder has help educate me. [Participant from Los Angeles, California]

Negative experiences:
- There is such a generalized abundance of information. It is not something that’s much discussed. [Participant from Los Angeles, California]
- Not getting the correct information at the places where I expected it. [Participant from Los Angeles, California]
- While my psychiatrist has provided some info, I don’t really expect him to teach me about bipolar disorder as he seems more focused on prescribing drugs. He just encourages me to go to groups and see my therapist. [Participant from Los Angeles, California]
- I found miscellaneous doctors and psychiatrist to be either ill-informed or poor communicators, poor diagnostic skills, too busy, etc. Some that I collaborated with tried very hard to keep patients out of the hospital with meds. [Participant from Los Angeles, California]
- …just needing some of the purple pamphlets that are provided at the doctor’s office. [Participant from Los Angeles, California]
- The doctors I’ve seen have never explained anything nor directed me to groups or places to know more. [Participant from Los Angeles, California]

Helping patients explore preferences and make decisions
Positive experiences:
- Working with my mental health professional team is most effective since the information can be tailored to me and allows me to ask questions. [Participant from Great Falls, Montana]
- What has worked is person to person discussion between me and my doctor. [Participant from Great Falls, Montana]

Negative experiences:
- Having doctors who have huge patient caseloads that are only going by what they know and have learned opposed to patients personal accounts. [Participant from Albuquerque, New Mexico]
- …feeling like a statistic by the doctors not listening, misguided information. [Participant from Albuquerque, New Mexico]
- The differences in thinking. [Participant from Albuquerque, New Mexico]
- Provider not listening to me. Telling me what I should be feeling. [Participant from Albuquerque, New Mexico]
- Doctors who are dismissive. [Participant from Albuquerque, New Mexico]
Discussion

Principal Results

Many patients with bipolar disorder and family members of patients with bipolar disorder would prefer to be educated by mental health professionals about their disease and the treatment options available to them. In addition, internet-based resources and websites are increasingly used by patients with bipolar disorder to meet their information needs. In this regard, patients with mood disorder do not differ greatly from patients with other complex medical conditions in the primary care setting [27]. Searching the internet for information on medical conditions is a well-accepted approach [28]. For some population subgroups, searching health information on the Web as an initial source of information has become even more common than talking to a doctor [29]. Our study contributes to the small but growing literature on internet use by psychiatric patients to inform themselves about treatment options and medication side effects [30-35]. Educating oneself about the disease and treatment options has been recognized as an important element in the recovery process [36]. In contrast to other studies, we did not find a difference in internet use between younger and elderly patients [37]. However, our study agrees that very few patients seemed to be aware of quality codes for medical websites on the internet. Nevertheless, compared to other studies, fewer patients reported negative experiences with the internet [38]. This might be related to the fact that most participants in our study were involved in peer support groups and patient advocacy organizations, which might have directed their attention to more reliable websites. Overall, disease-specific websites and online courses dedicated to education about psychiatric diseases have become popular, and not only in rural areas, since access to health care professionals has become challenging [39,40].

Although the testimonies of the focus group participants spoke to the frequent use and the perceived usefulness of online resources, they also acknowledged the challenges associated with using the internet. Some focus group participants voiced concerns about the abundant and sometimes conflicting information on bipolar disorder and drug treatment available online. Patients felt that sorting through helpful and unhelpful online information was challenging and sometimes overwhelming. This finding is in accordance with existing research that highlighted concerns about the reliability of health care information on the internet [41]. Information distribution and data use on the internet are challenged by limited oversight or regulation [42]. Ethical issues with internet use have not only concerned patients but also health care providers and other stakeholders [43]. Therefore, creating and monitoring reliable health information websites should be a priority [44].

Despite the widespread use of the internet as an information source, patients and their family members expected to gain most of their knowledge about bipolar disorder and its pharmacological treatment from their health care providers. However, they also admitted that doctors had often not been able to fulfill their expectations. Across all geographical regions, barriers to information gathering were encountered in the doctor-patient relationship. Failed doctor-patient communication was universally perceived as an obstacle to successful treatment outcomes. Our findings are not surprising in light of recent publications and one meta-analysis, which concluded that shared decision making and patient-centeredness of mental health care delivery has not been widely implemented despite strong recommendations [45,46].

To assist in the difficult task of making evidence-based treatment decisions, resources and tools have been developed to aid patients and doctors. Computer-based decision aids have been tested in the research arena [47-49], but the dissemination and implementation of these tools seem to have been limited, as evidenced by the fact that none of our focus group participants reported their use. On the other hand, the focus group participants mentioned that attending conferences, classes, and workshops was beneficial. They also emphasized the importance of peer support, a factor that has been recognized to be central in the recovery process [50,51]. This result supports previous findings that peers could be an important source of information for patients with bipolar disorder [52-55]. Based on this finding, further studies should explore how patients and patient advocates could be involved in the design of digital health interventions and the development of Web-based information sources [56].

Limitations

Limitations of our study include the relatively small sample size and the heterogeneity of the sample, which was recruited in three states that are culturally very different from each other. Although we saw the opportunity of sampling in underserved and rural areas of the United States as well as in one metropolitan area to elicit a wide range of responses and opinions, we acknowledge that in order to determine statistically significant differences, a larger sample size would be required. In addition, the diagnoses of the patients were not formally verified. Additional information on disease, such as course, duration, and severity was not collected.

Another limitation of our study is related to the sampling among members of patient advocacy organizations, which limits the generalizability of the results. Although this sampling approach was convenient and allowed us to easily reach motivated participants for our focus groups, this approach might have biased the results. Future studies should apply a more broadly defined and unbiased sampling scheme.
Due to the local membership demographics of the patient advocacy organizations in Great Falls, Montana; Helena, Montana; Albuquerque, New Mexico; and Los Angeles, California, certain ethnicities, including but not limited to Hispanic and Asian people, have been underrepresented or completely missing in our sample. Further research should address these shortcomings in a more representative sample.

Our data collection instrument used open-ended questions, and we did not explicitly ask about the use or importance of specific information channels. Consequently, some information sources used in the past might have been missed or forgotten. Our data also do not reflect the influences of Web-based information on the doctor-patient relationship.

Future Research

Our study highlights a variety of information channels that could be used to inform patients with bipolar disorder about treatment options and choices. Some of these opportunities are currently underused but could potentially be helpful. Given the limited resources in mental health care delivery, directing patients to high-quality websites or utilizing peer support could be beneficial for patients and doctors alike. A recent study suggested that information found on the internet could have both positive and challenging effects on the communication processes between patients and doctors [57]. Therefore, further studies should assess whether Web-based resources could assist doctors and empower patients in shared decision making about health care choices or potentially also cause harm. We would recommend funding agencies to dedicate funding resources to this topic, so that researchers could study the potential of reliable Web-based resources to enhance health care delivery, increase patient satisfaction, and improve outcomes.

Conclusions

Web-based resources are increasingly used by patients with bipolar disorder and their family members to educate themselves about the disease and its treatment. Although doctor-patient interactions are frequently perceived to be burdened with time constraints, Web-based information sources are considered a reliable and helpful information source. Future research should explore how high-quality websites could be used to empower patients and improve doctor-patient interactions, with the goal to enhance shared decision making between patients and doctors.

Acknowledgments

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Conflicts of Interest

RK is a former employee and holds stock in GlaxoSmithKline, AstraZeneca, Abbott Labs, and Lorex Pharmaceuticals; he is a consultant to Takeda Pharmaceuticals and is Chairman of the Board of Pierian Biosciences. MT was a full-time employee at Lilly (1997-2008). He has received honoraria from or consulted for Abbott, Actavis, AstraZeneca, Bristol Myers Squibb, GlaxoSmithKline, Lilly, Johnson & Johnson, Otsuka, Merck, Sunovion, Forest, Gedeon Richter, Roche, Elian, Alkermes, Allergan, Lundbeck, Teva, Pamlab, Wyeth, and Wiley Publishing. His spouse was a full-time employee at Lilly (1998-2013). The rest of the authors have no conflicts of interest to disclose.

References


Abbreviations

AWARE: Arming Women Against Rape and Endangerment
BP: bipolar disorder
CEU: Continuing Education Unit
Ed: education
MHC: Mental Health Court
MFCT: Marriage, Family, Child Therapist
NAMI: National Alliance on Mental Illness
NCBI: National Center for Biotechnology Information
NIMH: National Institute of Mental Health
VA: Veterans Affairs
Vet: veteran

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Exposure Therapy With Personalized Real-Time Arousal Detection and Feedback to Alleviate Social Anxiety Symptoms in an Analogue Adult Sample: Pilot Proof-of-Concept Randomized Controlled Trial

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Abstract

Background: Exposure therapy is highly effective for social anxiety disorder. However, there is room for improvement.

Objective: This is a first attempt to examine the feasibility of an arousal feedback–based exposure therapy to alleviate social anxiety symptoms in an analogue adult sample.

Methods: A randomized, pilot, proof-of-concept trial was conducted to evaluate the acceptability, safety, and preliminary efficacy of our treatment program. Sessions were administered once a week for 4 weeks (1 hour each) to an analogue sample of 50 young adults who reported at least minimal social anxiety symptoms. Participants in both intervention and waitlist control groups completed assessments for social anxiety symptoms at the baseline, week 5, and week 10.

Results: Most participants found the intervention acceptable (82.0%, 95% CI 69.0%-91.0%). Seven (14.9%, 95% CI 7.0%-28.0%) participants reported at least one mild adverse event over the course of study. No moderate or serious adverse events were reported. Participants in the intervention group demonstrated greater improvements on all outcome measures of public speaking anxiety from baseline to week 5 as compared to the waitlist control group (Cohen d=0.61-1.39). Effect size of the difference in mean change on the overall Liebowitz Social Anxiety Scale was small (Cohen d=0.13).

Conclusions: Our results indicated that it is worthwhile to proceed to a larger trial for our treatment program. This new medium of administration for exposure therapy may be feasible for treating a subset of social anxiety symptoms. Additional studies are warranted to explore its therapeutic mechanisms.

Trial Registration: ClinicalTrials.gov NCT02493010; https://clinicaltrials.gov/ct2/show/NCT02493010
**Introduction**

**Background**

Social anxiety disorder (SAD) is one of the most prevalent anxiety disorders [1], with the highest prevalence in high-income countries and an early age of onset globally [2]. It is chronic and associated with diminished quality of life [3-4]. SAD remains one of the most undiagnosed and undertreated mental disorders [5]. European data estimated that SAD cost €7277 million in direct health care costs in 2010, while indirect costs, factoring in absenteeism from work and early pension, amounted to €4806 million [6]. People affected by SAD reported impaired occupational productivity due to emotional problems and increased absences [7-8], and studies have found that they achieve lower educational attainment and earn wages 10% lower than a nonclinical population [9-10]. The core feature of SAD is a marked fear or anxiety about social interactions and performance situations in which one is exposed to possible evaluation by others, as described in the Diagnostic and Statistical Manual of Mental Disorders - 5th edition [11].

Generalized and nongeneralized subtypes of SAD can be differentiated as follows: The generalized subtype is characterized by anxiety in most social situations, whereas the nongeneralized subtype is indicated by anxiety under specific circumstances such as public speaking [12-13]. Public speaking anxiety is found to be the most common characteristic of SAD, regardless of differences between the subtypes [14]. Accordingly, there is a need to target SAD with particular emphasis on public speaking anxiety.

Exposure therapy is the mainstay of SAD treatment. Individuals afflicted by SAD often do not seek treatment unless it is persistent, pervasive, or accompanied by other more acute psychiatric conditions [15-17]. Many avoid or are averse to seek help; therefore, self-administered technology offers a promising mode of delivery to raise treatment acceptance and accessibility. A meta-analysis of technology-assisted interventions for SAD suggested that internet-delivered cognitive behavioral therapy (iCBT) and virtual reality exposure therapy (VRET) are effective in relieving SAD symptoms [18]. Randomized controlled trials found VRET to be as efficacious as exposure group therapy [19-20] or traditional cognitive behavioral therapy (CBT) involving *in vivo* exposure [21-24]. Nonetheless, these interventions served only as alternative therapist-mediated treatment modalities in clinics. There are only a few rigorous studies on technology-assisted exposure therapy for SAD; as such, the reported positive outcomes remain preliminary at best. Mobile technology-based exposure therapy, which enables interventions to be taken home by those who need treatment support or find treatment in clinics difficult to tolerate, needs to be developed and tested.

Prevailing technology-based exposure therapies for SAD including VRETs are therapist-mediated and thus require manual adjustment of exposure parameters to suit individual needs. Anderson et al reported that therapists modified virtual audience reactions and environments physically depending on patients’ hierarchy of fears [20]. Kampmann et al reported that therapists using VRET manipulated the duration and difficulty level of interactions between patients and virtual humans, such as the degree of friendliness, gestures, or gender of avatars [22]. Since VRET served as adjunctive treatment under the therapist’s control in these studies, it is unclear whether an unmediated technology-only program is efficacious in reducing SAD symptoms. To our best knowledge, only two studies explored such an intervention. Kim et al conducted a 2-week, unmediated, mobile-based virtual reality program for patients with SAD and found the outcomes to be marginally significantly more positive among patients than those among normal age-matched controls [25]. Lindner et al evaluated a self-led one-session virtual reality program and found benefits for individuals with public speaking anxiety [26]. Instead of having therapists select exposure exercises for the individual, Lindner et al provided individuals with instructions within the program to self-direct and sort their own exposure exercises. Using a randomized controlled procedure, this study sought to clarify whether exposure therapy delivered by technology in the absence of therapist intervention could improve social anxiety symptoms.

Recent advances in the conceptualization of exposure therapy posit inhibitory learning as a more parsimonious theory to explain treatment effects and failure and advocate inhibitory learning techniques to optimize treatment effects among patients [27-28]. In cases of successful inhibitory learning-based exposure, fearful associations continue to exist but compete poorly with newly acquired associations. Thus, in theory, exposure therapies must aim to strengthen newly learned inhibitory associations for these associations to compete effectively with one’s previously held fearful associations. One means of strengthening newly learned inhibitory associations is to subject patients to prolonged and intense distress during exposure. Accordingly, we aimed to incorporate inhibitory learning into our intervention by means of sustaining distress to enhance exposure treatment outcomes.

Anxiety disorders have also been treated using biofeedback-based interventions. By convention, exposure therapies and biofeedback-based interventions progress along distinct lines of research: The former facilitates desensitization to a prespecified hierarchy of anxiety-provoking situations (eg, public speaking or eating in public) by *in vivo* or *in virtuo* exposure, and the latter targets anxiety in a predominantly broad manner by entraining anxiety regulation using physiological processes. Among psychiatric disorders treated by biofeedback-based interventions, anxiety disorders constituted the most commonly treated conditions, and electroencephalographic (EEG) biofeedback was the modality that received most attention [29]. Heart rate variability biofeedback-based programs were found to be associated with anxiety and stress reduction in a recent meta-analysis [30].
general, biofeedback-based treatments involve a noninvasive procedure to train the patient to gain control over normally involuntary body functions. A patient’s physiological outputs (e.g., brainwaves and heart rate) are detected, monitored, and processed electronically and then returned as feedback in different forms (e.g., visual and auditory) to the same individual. Positive outcomes in the patient’s targeted physiology (e.g., reduced physiological arousal) are yielded through constant positive feedback [31]. In other words, one’s anxiety is gradually reduced by receiving rewarding feedback every time he/she successfully lowers his/her anxiety during the course of the intervention.

Our study aimed to integrate biofeedback with portable hardware to enhance current technology-assisted exposure interventions for SAD. We argue that biofeedback technologies automate real-time modifications in exposure therapy as well as provide a means to sustain participant distress during exposure in accordance with inhibitory learning theory. Mechanistically different from typical biofeedback programs for anxiety, we designed and utilized a first-of-a-kind arousal feedback–based system that runs on inputs from individuals’ EEG and heart rate detection. An underlying arousal feedback–based machine learning algorithm combined EEG band powers, heart rate, and heart rate variability to influence difficulty parameters of the virtual exposure environment in real time. These dynamic changes facilitated retention of discrepancy between participants’ actual and anticipated consequences, thereby sustaining inhibitory learning throughout the exposure session. Our combination of technologies forms an expedient means to deliver exposure therapy. Participants can be repeatedly exposed to newly learned safety associations and subjected to prolonged distress in a controlled virtual environment. Biofeedback technology helped calibrate and address individual differences in baseline anxiety and distress as well as automatize the exposure function through arousal feedback.

This was the first study to examine the viability of using biofeedback and portable technologies in delivering, personalizing, and optimizing exposure therapy in a laboratory setting. In particular, the purpose of our pilot trial was to investigate the feasibility of an arousal feedback–based exposure therapy to alleviate social anxiety symptoms, with particular emphasis on public speaking anxiety. We employed a randomized, waitlist-controlled design to evaluate the acceptability, safety, and preliminary efficacy of this treatment program. The study was conducted over a 4-week period with a 5-week follow-up of an analogue sample of 30 young adults who had public speaking anxiety complaints and reported at least minimal social anxiety symptoms.

Specific Hypotheses

In this paper, we examined the feasibility of our exposure therapy with real-time arousal detection and feedback in reducing social anxiety symptoms. Specifically, for our primary objectives, we hypothesized that the acceptability rate of our program would be high, that adverse event rate would be low, and that participants in the intervention group would show greater improvement in social anxiety symptoms between baseline and week 5 assessments than the waitlist-control group.

For our secondary objectives, we hypothesized that compared to the waitlist-control group participants, the intervention group participants would demonstrate greater improvements in public speaking anxiety, fear of negative evaluation, and self-statements made during public speaking from baseline to week 5.

Methods

Study Design

This was a randomized, waitlist-controlled, single-center open-label study. Participants completed assessments at baseline, week 5, and week 10. The intervention group attended intervention sessions from weeks 1 to 4, and the waitlist control group attended sessions between weeks 6 and 9. This study was approved by the Institutional Review Board of the National University of Singapore (reference code: B-14-098).

Participants and Setting

The study was conducted from May 2016 to May 2017 at Duke-NUS Medical School, Singapore. Participants were recruited on a voluntary basis through various modes of advertising including clinician referrals, posters, newspapers, social media, institutional email notices (ie, Duke-NUS Medical School, National University of Singapore), and word of mouth. Interested participants were scheduled for a written informed consent and brief screening session. Each participant was told to complete an intervention schedule once a week over a 4-week period. Participants were also instructed to complete assessments at the baseline, week 5, and week 10. Reimbursement for time and transport was provided on a prorated basis upon completion or termination of the study. All participants were told that they may or may not benefit from participating in the intervention.

Eligibility was determined after consent was obtained. The inclusion criteria were age between 21 and 35 years, literacy in English and computer skills, absence of current or previous history of neuropsychiatric disorders, and willingness to be video recorded. Eligible participants had scores of ≥31 on the Liebowitz Social Anxiety Scale (LSAS) [32-33], ≥60 on the Public Speaking Anxiety Scale (PSAS) [34], and ≤8 on the Alcohol Use Disorders Identification Test [35]. Those who had suicidal ideation (indicated by item 9 of the Beck Depression Inventory - 2nd edition) [36], irregular heart rhythm, gross visual or hearing impairments, psychoactive medication, or concurrent psychotherapy were excluded from the study. Participants were also excluded if they were involved in any other longitudinal research study.

Arousal Feedback–Based Exposure Therapy

The intervention was implemented using a locally developed, noninvasive portable headband (Figure 1) that connected wirelessly to a 14-inch commercial laptop via Bluetooth technology. The headband contained two EEG electrodes at the FP1 and FP2 locations, a heart pulse rate monitor, and an ear-clip with a grounding electrode. During training, the participant’s EEG waves and pulse rates were detected from the headband and transmitted to our system.
All participants completed the calibration process followed by the intervention process. During the calibration process, our system constructed a personalized arousal profile for each individual, based on unique physiological signatures (ie, EEG and photoplethysmogram patterns detected by our hardware) occurring during alternating induced periods of high and low arousal. The personalized arousal profile consisted of an adapted threshold, which was required to manipulate each individual’s exposure environment.

Our intervention consisted of 4 weekly sessions, each lasting about 60 minutes. Each session was conducted between 8.30 am and 8.30 pm on weekdays. During the intervention session, participants underwent three types of tasks: an interactive psychoeducation on screen, brief arousal control games, and arousal feedback–based speech tasks to a virtual audience. All materials were presented on the monitor of the same 14-inch laptop used to process physiological signals by the biofeedback system. Participants completed each session independently in a quiet room and were instructed to follow all instructions on the screen. The psychoeducation component delivered information about social anxiety and coping strategies and highlighted typical maladaptive thoughts and behaviors associated with particular anxiety-provoking social situations. To support the in-session learning material, participants were tested on key takeaways and tasked to identify their specific social anxiety-related concerns through pen-and-paper homework. Homework was to be completed every week before the next session. No formal assessment of homework performance was conducted.

A brief arousal control game (Figure 2) was interspersed eight times between psychoeducation and six arousal feedback–based speech tasks. In this game, participants wore the headband and were instructed to increase and sustain the height of bird flight on the game interface by lowering their arousal levels. The bird avatar would fly lower when the arousal levels increased. This height of the bird flight served as nonthreatening, real-time feedback for participants to gain awareness of and actively manage their high arousal levels.

In the arousal feedback–based speech task, participants were tasked to deliver six 2-minute speeches to a virtual audience (Figure 3). The virtual audience was put together using prerecordings of real-life individuals who would display different types of facial expressions and body language, which simulated positive (smiling), neutral (straight face), or negative emotional expressions (disinterested, bored, sleeping, and looking at the mobile phone). While participants delivered their speech, they received concurrent feedback on their arousal levels indicated by an “arousal score” on screen. The arousal score was computed by our system’s algorithm in real time based on participants’ EEG and photoplethysmogram inputs, which modified the behavior of the virtual audience. An increasing proportion of the virtual audience exhibited negative expressions or body language, when participants’ arousal levels exceeded stipulated thresholds. Conversely, the virtual audience showed positive, affirming expressions when the arousal levels fell below the thresholds. As a result, the degree of anxiety provocation of virtual speech tasks was adapted to suit individual needs. Speech tasks were also made more difficult over the course of the intervention by increasing the size of the virtual audience, displaying less encouraging initial facial expressions of the virtual audience, presenting increasingly formal attire of the virtual audience, and assigning more demanding speech topics in a controlled step-wise manner. Difficulty of speech topics was predetermined by the degree of spontaneity and deliberation required: Personal topics were deemed easiest, followed by informative, persuasive, and impromptu topics. Participants were given 3 minutes to prepare prior to giving personal, informal, and persuasive speeches. No additional time was provided before participants gave impromptu speeches. Participants did not have control over these other parameters, which maintained difficulty in the speech tasks to support sustaining of inhibitory learning throughout the course of exposure sessions.

Figure 1. Locally developed, noninvasive headband.
Assessments at Baseline, Week 5, and Week 10

The LSAS is a validated and widely used 24-item questionnaire that assesses fear or anxiety and avoidance on a variety of social interaction and performance situations [32-33]. On a 4-point scale, participants rated their fear or anxiety (0=none, 3=severe) and avoidance (0=never, 3=usually) of each social situation. The scale yields an overall score by summing the item scores; higher scores indicate greater anxiety. An LSAS score of ≤30 indicates that SAD is unlikely. Internal consistency of the current sample was high (α=0.95).

The PSAS is a recently published 17-item self-rated questionnaire that measures cognitive, behavioral, and physiological manifestations of public speaking anxiety [34]. Participants rated positive and negative statements about giving speeches on a 5-point Likert-type scale (1=not at all, 5=extremely). The scale yields an overall score (items 6, 7, 8, 16, 17 are reverse coded); higher scores indicate greater anxiety. Internal consistency of the current sample was high (α=0.86).

The Fear of Negative Evaluation - Brief questionnaire (FNE-B) is a validated 12-item scale that assesses one’s fear of being judged negatively by others [37]. Participants rated positive and negative statements on a 5-point Likert-type scale (1=not at all characteristic of me, 5=extremely characteristic of me). The scale yields an overall score (items 2, 4, 7, and 10 are reverse coded); higher scores reflect greater fear. Internal consistency of the current sample was high (α=0.88).

The Self-Statements made during Public Speaking (SSPS) scale measures positive and negative thoughts about oneself during public speaking situations [38]. Participants rated 10 statements on a 6-point scale (0=do not agree, 5=agree extremely). The scale yields an overall score (items 1, 3, 5, 6, and 9 are reverse coded); higher scores reflect greater negativity. Internal consistency of the current sample was high (α=0.78).
Acceptability was defined as a rating of 5, 6, or 7 on “How would you rate the quality of the training system?” This was measured as part of a study-specific satisfaction and immersion questionnaire (SIQ; internal consistency: α=0.85) that examined participants’ attitudes toward the arousal feedback–based intervention on a 7-point Likert-type scale (1=poor, 7=excellent) postintervention. The form included a final open-ended question to capture comments or suggestions. All participants completed the SIQ postintervention.

Sample Size
A total sample size of 41 participants was required to yield a precision (width of 95% CI) of approximately 12% in the proportion of participants who provide positive feedback on acceptability, assuming the true proportion is approximately 80%. Assuming an attrition rate of approximately 20%, a total sample size of 50 subjects was required. We simultaneously evaluated the preliminary efficacy of the training system to determine whether a larger-scale trial is warranted, by using Simon’s randomized selection design [39,40]. A total sample size of 50 would guarantee an 80% probability of correctly selecting the intervention arm as superior to the waitlist if it was truly superior by an effect size of 0.3 SD. If a positive difference was observed for preliminary efficacy in LSAS regardless of statistical significance, the intervention would be concluded to be promising and worthy of further investigation in a larger trial as per the randomized selection design.

Randomization and Blinding
Randomization was performed in a 1:1 allocation ratio, using blocks of 10 with permuted subblocks of sizes 4 and 6, via a password-protected Web-based program. Block size was determined by the study statistician and not made known to clinical investigators or site personnel until after study closure.

Statistical Analyses
Acceptability analysis was based on all enrolled subjects. Safety analyses were conducted for treated participants who received at least one intervention session. Efficacy analyses were intention-to-treat (ITT) and involved all randomized participants, with per protocol (PP) analysis conducted as sensitivity analysis. Acceptability analyses were rated by pooling responses on the SIQ question “How would you rate the quality of the training system?” from both intervention and waitlist control groups after receiving treatment. Missing acceptability assessment was imputed as “not acceptable.” Further complete-case sensitivity analyses of primary and secondary efficacy endpoints analyzed all participants with baseline assessments, accounting for missing data using a mixed-effects model with random subject intercepts, adjusted for group, time, and group-time interaction and with restricted maximum likelihood estimation.

Data for participants that found the training system acceptable and for whom the training system was safe were presented as Wilson score CIs. Preliminary efficacy evaluation was conducted using Cohen’s d for difference in change of LSAS total score from baseline to week 5 between the intervention and waitlist control groups.

Supplementary analyses compared median change and adjusted mean change (Multimedia Appendix 1). Sustainability of effect was described for the within-participant differences between preintervention and postintervention scores and loosely classified as nonreversion to preintervention levels or nonworsening of postintervention scores compared to preintervention scores. Pooled pre-post outcome scores from both the intervention and waitlist control groups were reported. Statistical analyses were performed using SAS software (v9.4; SAS Institute Inc, Cary, NC). All statistical procedures, including randomization and data analyses, were managed by an independent third party (Singapore Clinical Research Institute Private Limited, Singapore).

Results

Demographic and Baseline Characteristics
A total of 72 participants were screened, of whom 22 were excluded. Fifty were recruited and randomized into the intervention group (n=25) or waitlist control group (n=25). The majority of participants were female (n=37, 74%) and Chinese (n=42, 84%), with a mean age of 25.6 years. Baseline characteristics were similar between the intervention and waitlist control groups of the ITT population (Table 1) and between the ITT and PP populations (results not shown).

A majority (n=44, 88%) of the participants received all four intervention sessions; in addition, 45 (90%) completed week 5 assessments and 44 (88%) completed week 10 assessments. There were five (10%) withdrawals initiated by participants due to their inability to commit to the study and one (2%) by the investigator due to an ear condition that interfered with hardware administration. Three withdrawals occurred before intervention, and three occurred at weeks 1, 2, and 3. The Consolidated Standards of Reporting Trials (CONSORT) flow diagram is shown in Figure 4. Six cases of incomplete assessments were considered protocol violations and excluded from PP analyses. The number of participants in ITT or PP analyses, at each time point, was reported in Multimedia Appendix 1.
Table 1. Demographic and baseline characteristics.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Intervention (n=25)</th>
<th>Waitlist control (n=25)</th>
<th>Total (N=50)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years), mean (SD)</strong></td>
<td>24.2 (3.23)</td>
<td>27.0 (4.19)</td>
<td>25.6 (3.96)</td>
</tr>
<tr>
<td><strong>Female, n (%)</strong></td>
<td>17 (68.0)</td>
<td>20 (80.0)</td>
<td>37 (74.0)</td>
</tr>
<tr>
<td><strong>Ethnicity, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>20 (80)</td>
<td>22 (88)</td>
<td>42 (84)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (20)</td>
<td>3 (12)</td>
<td>8 (16)</td>
</tr>
<tr>
<td><strong>Current education, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary education</td>
<td>0 (0)</td>
<td>1 (4.0)</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td>Preuniversity</td>
<td>0 (0)</td>
<td>2 (8.0)</td>
<td>2 (4.0)</td>
</tr>
<tr>
<td>Currently in/graduated from university</td>
<td>25 (100)</td>
<td>22 (88.0)</td>
<td>47 (94.0)</td>
</tr>
<tr>
<td><strong>BDI-II (^a) total score, mean (SD)</strong></td>
<td>12.0 (7.52)</td>
<td>10.0 (9.10)</td>
<td>11.0 (8.32)</td>
</tr>
<tr>
<td><strong>AUDIT (^b) total score, mean (SD)</strong></td>
<td>1.1 (1.59)</td>
<td>1.9 (2.22)</td>
<td>1.5 (1.95)</td>
</tr>
<tr>
<td><strong>LSAS (^c) total score, mean (SD)</strong></td>
<td>68.8 (20.63)</td>
<td>69.7 (21.61)</td>
<td>69.3 (20.91)</td>
</tr>
<tr>
<td><strong>PSAS (^d) total score, mean (SD)</strong></td>
<td>67.0 (4.53)</td>
<td>68.4 (5.92)</td>
<td>67.7 (5.27)</td>
</tr>
<tr>
<td><strong>FNE-B (^e) total score, mean (SD)</strong></td>
<td>45.6 (7.08)</td>
<td>43.6 (6.65)</td>
<td>44.6 (6.88)</td>
</tr>
<tr>
<td><strong>SSPS (^f) total score, mean (SD)</strong></td>
<td>26.5 (5.67)</td>
<td>24.1 (7.35)</td>
<td>25.4 (6.57)</td>
</tr>
</tbody>
</table>

\(^a\)BDI-II: Beck Depression Inventory (2nd edition).
\(^b\)AUDIT: Alcohol Use Disorders Identification Test.
\(^c\)LSAS: Liebowitz Social Anxiety Scale.
\(^d\)PSAS: Public Speaking Anxiety Scale.
\(^e\)FNE-B: Fear of Negative Evaluation - Brief questionnaire.
\(^f\)SSPS: Self-Statements made during Public Speaking scale.
Acceptability
Most participants (82.0%, 95% CI 69.0%-91.0%) found the training system acceptable. The remaining, including 6 missing assessments, were classified as “not acceptable.”

Safety
Seven (14.9%, 95% CI 7.0%-28.0%) participants reported at least one adverse event over the course of the study. There were a total of eight mild adverse events including eye strain (n=1), itch on forehead and scalp (n=1), headache (n=3), and dizziness (n=3). No moderate or serious adverse events were reported.

Change in Efficacy Scores
Table 2 showed the mean total LSAS, PSAS, FNE-B, and SSPS scores at weeks 0 and 5 for the intervention and waitlist control groups. Mean total LSAS scores between weeks 0 and 5 decreased by 1.5 points in the intervention group and increased by 0.8 points in the waitlist control group. The Cohen $d$ effect size for differences in mean change in total LSAS scores between groups was 0.13 points. Mean change scores of PSAS, FNE-B, and SSPS between weeks 0 and 5 ranged from 3.0 to 10.2 points in the intervention group and −0.9 to 1.3 points in the waitlist control group. The Cohen $d$ estimates of differences in mean change scores of PSAS, FNE-B, and SSPS between groups were 1.39, 0.61, and 0.79, respectively. Similar results were found in the PP population (results not shown).
Table 2. Mean total efficacy scores (SD), mean change scores (SD), and effect sizes of differences in mean changes between weeks 0 and 5. Change in total score = week 0 total score – week 5 total score. A positive change in total score indicates improvement (a reduction in symptoms/scores).

<table>
<thead>
<tr>
<th>Measures</th>
<th>Group</th>
<th>Change</th>
<th>Cohen d effect size, mean (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention</td>
<td>Waitlist</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Week 0</td>
<td>Week 5</td>
<td>Week 0</td>
</tr>
<tr>
<td>LSASa</td>
<td>68.8 (20.63)</td>
<td>67.7 (20.87)</td>
<td>1.5 (20.54)</td>
</tr>
<tr>
<td>PSASb</td>
<td>67.0 (4.53)</td>
<td>56.9 (9.83)</td>
<td>10.2 (8.56)</td>
</tr>
<tr>
<td>FNE-Bc</td>
<td>45.6 (7.08)</td>
<td>43.0 (9.20)</td>
<td>3.0 (8.10)</td>
</tr>
<tr>
<td>SSPSd</td>
<td>26.5 (5.67)</td>
<td>21.2 (8.24)</td>
<td>6.2 (8.42)</td>
</tr>
</tbody>
</table>

aLSAS: Liebowitz Social Anxiety Scale.
bPSAS: Public Speaking Anxiety Scale.
cFNE-B: Fear of Negative Evaluation - Brief questionnaire.
dSSPS: Self-Statements made during Public Speaking scale.

Supplementary and Sensitivity Analyses

Unadjusted and adjusted results for efficacy measures were qualitatively the same as results for Cohen $d$; results from sensitivity analyses were similar to the unadjusted results (Multimedia Appendix 1).

Sustainability Analysis

The waitlist control group received the intervention from weeks 6 to 9, with mean changes in efficacy measures between weeks 5 and 10 ranging from 2.2 to 6.5. Corresponding mean changes in efficacy measures between weeks 5 and 10 of the intervention group ranged from 0.9 to 10.0. Pooled pre- and postintervention changes of both arms showed improvement (changes in mean point estimates of 2.6-8.2) on all efficacy outcomes (Table 3). Exploratory analyses found secondary efficacy outcomes of PSAS, FNE-B, and SSPS to be significant ($P<.05$).

Table 3. Pooled pre- and postintervention efficacy scores. The pooled pre- and post- intervention change score is calculated as the sum of change scores of both arms, where the intervention arm change score is scores of week 0 – week 5, and waitlist control arm change score is score of week 5 – week 10; a positive change indicates improvement (a reduction in symptoms).

<table>
<thead>
<tr>
<th>Measures</th>
<th>Mean change (SD)</th>
<th>P valuea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LSASb</td>
<td>4.0 (21.66)</td>
<td>.23</td>
</tr>
<tr>
<td>Secondary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSASc</td>
<td>8.2 (7.50)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>FNE-Bd</td>
<td>2.6 (6.59)</td>
<td>.01</td>
</tr>
<tr>
<td>SSPSc</td>
<td>5.5 (7.80)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

a$P$ value from one-sample $t$ test.
bLSAS: Liebowitz Social Anxiety Scale.
cPSAS: Public Speaking Anxiety Scale.
dFNE-B: Fear of Negative Evaluation - Brief questionnaire.
eSSPS: Self-Statements made during Public Speaking scale.

Discussion

The study results indicated that the arousal feedback–based exposure therapy was acceptable and safe. Improvements in the PSAS, FNE-B, and SSPS scores, which were sustained over a follow-up 5-week period, suggested that our intervention might be efficacious in alleviating adult public speaking anxiety. Our findings did not provide strong support for the efficacy of our intervention in reducing overall social anxiety symptoms on the LSAS. Caution is also needed when interpreting the difference in change scores, as the randomized selection design was only meant to identify intervention that is worthy of further research instead of providing confirmation of efficacy. Overall, our preliminary findings indicated that it is worthwhile to proceed with a larger trial.

The intervention was safe and acceptable. Majority of the few complaints concerned prolonged use of hardware rather than treatment material and software. Young adults today are mobile- and technologically savvy but not yet accustomed to biofeedback technologies. Thus, discomfort with system usage was not unforeseeable. Regarding the treatment material, study participants indicated that “simulations did not feel real” and...
“having real life audience would be helpful” in the feedback comments. Although the levels of immersive exposure experience may not reach those elicited by in vivo speech tasks [41], there were no significant differences found on self-reported anxiety, heart rate, heart rate variability, and saliva cortisol levels when comparing in vivo and in virtuo exposures [42]. Performance-based social anxiety including public speaking anxiety is also significantly associated with physiological hyperarousal [43]. Thus, our findings demonstrated the relevance of targeting the physiological level in exposure therapies for SAD. The arousal feedback–based exposure therapy that targeted physiological processes during public speaking in a laboratory setting could alleviate public speaking anxiety despite subjective negative perceptions of immersion. In addition, our computer display was sufficient to elicit ameliorating effects on public speaking anxiety symptoms; it is possible that by using hardware of higher resolution and comfort, specifically a virtual reality headset, the degree of immersive experience and thus benefits of exposure could be increased.

Our study recruited an analogue adult sample and did not include formal clinical diagnoses. Nonetheless, participants enrolled in this study were not unlikely to have SAD, as indicated by baseline scores of ≥31 on the LSAS [32]. Majority of participants (64%) who completed all parts of the study had moderate to very severe SAD symptoms, reporting scores between 60 and 118 points on the LSAS at baseline. Although improvements in social anxiety were observed at postintervention, the effect size of change on the LSAS was small (ie, Cohen $d=0.13$), and the corresponding absolute outcome scores remained at subclinical levels. It was possible that this negative result was due to the relatively small sample size and thus poor statistical power.

Another more probable explanation for the negative result found on the LSAS was that our intervention helped specifically in addressing public speaking anxiety, which constitutes a subset of SAD symptoms. Effect sizes of improvements on secondary outcome measures, i.e., the PSAS, FNE-B, and SSPS scale, ranged from moderate to large (ie, Cohen $d$ ranged from 0.61 to 1.39). The differential findings between overall social anxiety and secondary measures of public speaking anxiety provided preliminary support for the efficacy of our arousal feedback–based exposure therapy in reducing specific public speaking anxiety symptoms. However, our intervention had multiple components (eg, inclusion of psychoeducation, which have known effects); therefore, dismantling studies are necessary to explore the potential mechanisms for treatment efficacy.

Our findings further concurred with extant literature indicating that SAD should be differentiated and treated according to a more severe generalized subtype or a less severe nongeneralized subtype encompassing public speaking anxiety [10,44]. Our intervention demonstrated greater potential efficacy in ameliorating specific symptoms of public speaking anxiety than in the overall syndrome of social anxiety. Interestingly, some researchers had suggested that public speaking anxiety could be a distinct SAD subtype of its own [12]. Others proposed defining SAD as a continuum of clinical severity based on the number of feared social situations [45]. Although the characterization of public speaking anxiety in SAD remains contentious, public speaking continues to be a major source of anxiety in SAD and warrants intervention.

Our exposure therapy integrated a key feature of inhibitory learning (ie, distress tolerance) to enhance treatment effects. However, we did not maximize violations of participants’ fear-based expectancies for harm or provide multiple contexts to facilitate the decontextualization of newly learned inhibitory associations [46]. In theory, participants should be constantly reminded of the discrepancy between actual and anticipated consequences. They should be continually exposed to new and actual safety associations (eg, no repercussions from stumbling in speech) as opposed to anticipated feared associations (eg, “people make fun of me when I stumble in speech”). Diverse contexts are also necessary to increase one’s mental accessibility beyond the treatment session to new associations learned. By expanding the range of contextual cues that are associated with new learning, freshly acquired inhibitory associations can be strengthened in-session. The exclusion from intervention of other anxiety-provoking social situations could also partially explain why benefits were found in public speaking anxiety-specific measures but not on the overall social anxiety measure. To better align our arousal feedback–based exposure therapy with inhibitory learning, violations of participants’ fear-based expectancies for harm need to be incorporated and maximized. Our intervention can be extended to treat other domains of SAD by developing and targeting other anxiety-provoking social situations.

Set against traditional habituation-based exposure therapies, exposure treatments based on the inhibitory learning model do not necessitate fear reduction during exposure to produce posttreatment fear extinction. Although habitation models suggest that fearful associations (eg, “people hate to hear me speak”) must be eliminated altogether for treatment efficacy, inhibitory learning models postulate that successful exposure occurs even when fearful associations are not eliminated. Although described initially as different theories of exposure therapy [27], the distinction between habitation and inhibitory learning models remains arbitrary. Benito and Walther clarified that habitation does not necessarily entail replacement of feared associations with newly learned safety associations, contrary to what was conceived in its parent Emotional Processing Theory [47,48]. The authors argued that habitation is a “therapeutic process...somewhat agnostic to the precise underlying mechanism.” Fear activation and minimization of maladaptive anxiety-reducing behaviors are imperative to optimize exposure therapy. These habituation-based elements are analogous to sustaining distress and inducing tolerance during inhibitory learning-based exposure. One postulated difference between the two models appears to lie in the disparity between within-session and between-session anxiety reduction. Specifically, inhibitory learning happens when between-session anxiety reduction occurs in the absence of within-session anxiety reduction, whereas both within- and between-session anxiety reductions ought to take place to elicit habituation-based treatment effects. Unfortunately, within- and between-session anxiety reductions have been traditionally difficult to study. For instance, it is challenging to operationalize within-session anxiety reduction as well as to examine between-session anxiety.
reduction, given confounding factors such as increasing exposure task difficulty over the course of intervention [47]. Bearing this difficulty in mind, laboratory-based experimental studies need to be carefully designed to investigate therapeutic mechanisms of inhibitory learning techniques in the context of our exposure therapy as well as to differentiate between habituation-based and inhibitory learning-based exposure therapeutic mechanisms, in general.

Some limitations restricted the generalizability of our study findings to patients with SAD, including the recruitment of an analogue subclinical adult sample and a lack of objective outcome measures (eg, measuring performance and arousal during speech to a real audience). This study employed self-rated measurement tools that could be confounded by participant bias or motivation to alleviate social anxiety. However, this was unlikely, given the differential outcomes of the overall social anxiety vis-à-vis specific public speaking anxiety measures. Nonetheless, a replication study investigating the effects of arousal feedback–based exposure therapy using a clinically representative sample and objective assessment tools should be conducted. Future research should also consider conducting active-control studies to tease out the differential effects between arousal feedback–based exposure therapy and therapist-mediated exposure therapy.

In conclusion, it is worthwhile to proceed to a larger trial. This pilot proof-of-concept study is a first attempt to establish the acceptability, safety, and potential efficacy of an arousal feedback–based exposure therapy for an analogue adult sample in order to reduce a subset of social anxiety symptoms. Our findings contribute to a growing body of literature on incorporating technology into mental health care services to improve treatment accessibility. Technology-assisted exposure therapies were previously found to be more cost-effective and amenable to therapists or clients than CBT for SAD [21,24]. Importantly, although we do not purport the displacement of pharmacotherapy and CBT as first-line treatments, our unmediated arousal feedback–based exposure therapy circumvents limitations in personalization of existing VRETs. Thus, it serves as an enhanced complement to current treatment modalities for SAD.

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Conflicts of Interest

XL, TSL, YC, LL, HZ, ZC, CW, RK, and CG received grants from the National Medical Research Council Singapore during the study. HZ, ZC, CW, and CG have a patent Closed Loop Virtual Reality Exposure Therapy for Social Anxiety Disorder Based on Arousal Detection pending. RK reports intellectual property in related areas that have been signed to Neeuro Private Limited. RK holds ownership rights in Cennerv Pharma and is the Chief Executive Officer of Rush Health System and Chairman of National Medical Research Council, Ministry of Health Singapore. RK is also on the CHS Board of Directors and Singhealth Board of Directors.

Multimedia Appendix 1

Statistical analysis.

[DOCX File, 17KB - mental_v6i6e13869_app1.docx]

Multimedia Appendix 2

CONSORT - EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 2MB - mental_v6i6e13869_app2.pdf]

References


Abbreviations

AUDIT: Alcohol Use Disorders Identification Test
BDI-II: Beck Depression Inventory (2nd ed)
CFT: cognitive behavioral therapy
EEG: electroencephalogram
FNE-B: Fear of Negative Evaluation - Brief questionnaire
iCFT: internet-delivered cognitive behavioral therapy
ITT: intention to treat
LSAS: Liebowitz Social Anxiety Scale
PP: per protocol
PSAS: Public Speaking Anxiety Scale
SAD: social anxiety disorder
SIQ: satisfaction and immersion questionnaire
SSPS: Self-Statements made during Public Speaking
VRET: virtual reality exposure therapy

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Gamification in Apps and Technologies for Improving Mental Health and Well-Being: Systematic Review

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Abstract

Background: There is little research on the application of gamification to mental health and well-being. Furthermore, usage of gamification-related terminology is inconsistent. Current applications of gamification for health and well-being have also been critiqued for adopting a behaviorist approach that relies on positive reinforcement and extrinsic motivators.

Objective: This study aimed to analyze current applications of gamification for mental health and well-being by answering 3 research questions (RQs). RQ1: which gamification elements are most commonly applied to apps and technologies for improving mental health and well-being? RQ2: which mental health and well-being domains are most commonly targeted by these gamified apps and technologies? RQ3: what reasons do researchers give for applying gamification to these apps and technologies? A systematic review of the literature was conducted to answer these questions.

Methods: We searched ACM Digital Library, CINAHL, Cochrane Library, EMBASE, IEEE Explore, JMIR, MEDLINE, PsycINFO, PubMed, ScienceDirect, Scopus, and Web of Science for qualifying papers published between the years 2013 and 2018. To answer RQ1 and RQ2, papers were coded for gamification elements and mental health and well-being domains according to existing taxonomies in the game studies and medical literature. During the coding process, it was necessary to adapt our coding frame and revise these taxonomies. Thematic analysis was conducted to answer RQ3.

Results: The search and screening process identified 70 qualifying papers that collectively reported on 50 apps and technologies. The most commonly observed gamification elements were levels or progress feedback, points or scoring, rewards or prizes, narrative or theme, personalization, and customization; the least commonly observed elements were artificial assistance, unlockable content, social cooperation, exploratory or open-world approach, artificial challenge, and randomness. The most commonly observed mental health and well-being domains were anxiety disorders and well-being, whereas the least commonly observed domains were conduct disorder and bipolar disorders. Researchers’ justification for applying gamification to improving mental health and well-being was coded in 59% (41/70) of the papers and was broadly divided into 2 themes: (1) promoting engagement and (2) enhancing an intervention’s intended effects.

Conclusions: Our findings suggest that the current application of gamification to apps and technologies for improving mental health and well-being does not align with the trend of positive reinforcement critiqued in the greater health and well-being literature. We also observed overlap between the most commonly used gamification techniques and existing behavior change frameworks. Results also suggest that the application of gamification is not driven by health behavior change theory, and that many researchers may treat gamification as a black box without consideration for its underlying mechanisms. We call for the inclusion of more comprehensive and explicit descriptions of how gamification is applied and the standardization of applied games terminology within and across fields.
Introduction

Conceptualizing Gamification

Gamification is the application of gameful elements for nongame purposes. Although the term has, on occasion, been used interchangeably [1] with the closely related concept of serious games (video games developed for a primary purpose other than player enjoyment [2]), both concepts are examples of applied games, which involve the implementation of “design concepts and qualities from the game world” [3]. Despite being a relatively new example of applied games, gamification has received considerable interest from the health research community for its potential to increase engagement with health interventions and motivate behavior change [4-8]. However, it should not be assumed that any intervention automatically incorporating gamification will have increased engagement [4]. Even the commonly cited ability of gamification to provide fun and engaging experiences cannot be taken for granted, as fun does not necessarily translate to increased motivation to engage [9]. Nonetheless, proponents of gamification point to its potential cost-effectiveness, accessibility, and flexibility, as well as the increasing worldwide popularity of video games and the potential of gamification to increase intrinsic motivation [6,10,11], as reasons to apply it to health and well-being.

Multiple definitions have been proposed for the term gamification, including the “use of game design elements in non-game contexts” by Deterding et al [12], and “a process of enhancing a service with affordances for gameful experiences in order to support user’s overall value creation” by Huotari and Hamari [13]. They each provide a guiding framework through which to conceptualize it, with different definitions fitting different usage and research contexts. For example, Huotari and Hamari’s definition of gamification emphasizes how it can be used to enhance existing services, such as mental health and well-being interventions, and the mechanisms through which they work. It is a useful way to conceptualize gamification when implementing it for mental health and well-being purposes and is arguably more compatible with the general goals of health research.

On the other hand, the definition by Deterding et al is more useful for operationalizing gamification. By emphasizing the contrast between playfulness (paidia) and gamefulness (ludus), Deterding et al categorize gamification as games-based in part form, comparable but distinct to serious games (games-based in whole form) and playful design (play-based in part form), and the conceptual opposite to toys (play-based in whole form). This definition also prioritizes game design elements, implying a taxonomical approach useful for piecing out the individual elements of gamification and operationalizing the various ways it can be applied. This makes this definition useful for studying gamification.

Gamification for Health and Well-Being

Recent reviews find that gamification is most commonly applied to physical fitness interventions and to motivate health behaviors for managing chronic illnesses, and although gamified mental health and well-being interventions exist, they are less common [6,7]. This may be due to the inappropriateness of applying common gameful elements (points, rewards, achievements, social comparison, and competition) to mental health, especially in circumstances where users could potentially be in distress [14,15]. According to self-determination theory, humans are intrinsically motivated to satisfy their basic psychological needs of autonomy, competence, and relatedness [16]. As subjective enjoyment of video games has been empirically linked to the satisfaction of these constructs [17], gamification should, in theory, also be compatible with increasing intrinsic motivation. However, many instances of gamification for general health and well-being rely on positive reinforcement and extrinsic motivators [6], an approach that has been criticized [18,19]. There may be an understandable reluctance in the community to extend what is perceived to be a behaviorist implementation of gamification [20] to mental health and well-being domains.

Admittedly, by definition, it is more straightforward to influence intervention users’ extrinsic motivation than their intrinsic motivation. However, organismic integration theory (OIT) posits that there are low-autonomy and high-autonomy variants of extrinsic motivators [16], with low-autonomy variants having the most harmful effect on intrinsic motivation [9]. The ideal implementation of gamification would, therefore, harness intrinsic motivation and the types of extrinsic motivation that are most likely to be internalized, such as identified or integrated regulation [16]. Previous research in the health field has expanded on properties of video games that may be more compatible with intrinsic motivation, such as narrative, fantasy, and interactivity [21-23]. These properties may also be associated with improved emotional intelligence and regulation [24].

Recent reviews also report a lack of explicit linkage between the theory and application of gamification [1,25]. Although gamification elements have been theoretically matched to behavior change techniques [4,26], this has not translated to theory-driven gamification [22]. Furthermore, even when behavior change theory is referenced, its implementation may not be as comprehensive as it could be [22]. Although most calls for gamification and its application for health and well-being (including mental health and well-being) invoke motivational reasons [4-7,27,28], motivation is only 1 driver of behavior change. According to the behavior change wheel by Michie et al [29], the other 2 are capability and opportunity, and it is these drivers that gamification may be missing its potential to support [22].
**Operationalizing Gamification**

It is difficult to review past gamification research when the word *gamification* means slightly different things across papers. For example, in the review of health and fitness mobile phone apps by Lister et al. [22], *gamification* is used to cover the concepts of leaderboards, levels, digital rewards, tangible prizes, competitions, and social pressure but not avatars or “narrative context” (as Lister et al. consider them “game elements”). However, Johnson et al. use *gamification* to describe all these elements in their review [6]. Similarly, although Brown et al. incorporate both narrative and avatars in their gamification element *story/theme* [30], both Johnson et al. and Lister et al. separate these features into 2 elements. In another example, Sardi et al. combine *feedback/rewards* into 1 game mechanic [7], whereas others consider these features separately [6,22,25,30]. In addition, few reviews define their gamification elements. This makes comparison of findings across reviews difficult without in-depth examination of individual review methodology.

The term *game* is notoriously difficult to define [31], which may contribute to why definitions of *gamification* vary considerably. Although games have always been present in culture in varying forms [32], the current bidirectional trend of games influencing culture and vice versa (the *ludification of culture* and the *cultivation of ludus* [33]; gamification being a clear example of the latter) may explain the increasing interest shown by researchers in technologies and components that are not inherently game-like but are culturally associated with video games, such as virtual reality, augmented reality, and avatars [1]. Although the fuzzy boundaries of the term *gamification* point to the enthusiasm people from varying fields have for adopting it and may encourage creativity in games (and gamification) research [31], they also represent a clear challenge for the study of gamification.

In their recent review, Seaborn and Fels recommend that the intentional use of gamification be a key indicator of whether an app or technology can be defined as containing gamification or not [1]. This accounts for the fact that certain elements of gamification, such as social comparison and progress feedback, are also present in other behavior change frameworks such as persuasive systems design [34] and prevents false positives from being identified. It also corresponds with Huotari and Hamari’s definition of gamification as enhancing a basic service provided by the app or technology [13] (in this case, improving mental health and well-being).

**Study Aims**

Previous systematic reviews on gamification in health and well-being (including mental health and well-being) have narrowed foci (eg, on evaluation [6] and adherence [30]), resulting in a somewhat incomplete picture of the implementation of gamification for mental health and well-being across the fields of medicine, psychology, computer science, and other related fields. In addition, it has been 4 years since the most recent comprehensive database search [7] was conducted. This study, therefore, aims to conduct an updated systematic review of the application of gamification in apps and technologies for improving mental health and well-being, with a focus on breadth, and using a more in-depth taxonomy of gamification elements. To ensure maximum relevance given rapidly changing technology, only studies from the past 5 years were considered. This review aimed to answer the following research questions (RQs):

- **RQ1**: Which gamification elements are most commonly applied to apps and technologies for improving mental health and well-being?
- **RQ2**: Which mental health and well-being domains are most commonly targeted by these gamified apps and technologies?
- **RQ3**: What reasons do researchers give for applying gamification to apps and technologies for improving mental health and well-being?

**Methods**

**Search Strategy and Screening Process**

A pilot search was conducted in March 2018 to assess the feasibility of this study. This search was replicated on November 21, 2018, by 1 author (VWSC), who searched the databases ACM Digital Library, CINAHL, Cochrane Library, EMBASE, IEEE Explore, JMIR, MEDLINE, PsycINFO, PubMed, ScienceDirect, Scopus, and Web of Science with the following search string: (gamif* OR gameful*) AND (“mental health” OR “wellbeing” OR “well-being” OR “mental illness” OR “mental disorder”). This string was adjusted to match each database’s requirements. All citations were screened according to the following 5 steps:

1. **Initial search**: All citations were downloaded to a citation manager (Endnote X8) library file.
2. **Probable inclusion**: A preliminary screen was performed according to the inclusion criteria.
3. **Prune duplicates**: All remaining references were collated into 1 group, and duplicates were removed.
4. **Define inclusion**: All remaining references were stringently assessed against inclusion criteria.
5. **Additional literature**: Additional literature was extracted from reference lists of review papers identified in the initial search (step 1), the reference lists of citations from step 4 (eg, for other papers reporting on the same app or technology), and the pilot search. Those that satisfied the inclusion criteria were added to the final dataset.

**Inclusion Criteria**

Identified citations had to satisfy the following main inclusion criteria to qualify for inclusion:

1. Be published between the years 2013 and 2018.
2. Describe an app or technology related to the improvement of mental health and well-being outcomes (including secondary outcomes).
3. Define their app or technology as being *gamification*, *gamefulness*, or *game-based*.
5. Not be labeled a serious game.

The search string was kept general to create a wide search net; however, there are limitations to this approach, which are
discussed later in this paper. Apps or technologies that were labeled as serious games were not included, as serious games are complete games and, therefore, fall outside the scope of this review. Some citations identified in the initial search appeared to use the terms gamification and serious game interchangeably, pointing to the inconsistent use of terminology observed by previous reviews of gamification [1]. These citations were individually discussed by 2 authors (VWSC and KV), with reference to Huotari and Hamari’s definition of gamification (“a process of enhancing a service with affordances for gameful experiences in order to support user’s overall value creation”) [13], until agreement was reached on whether to include or exclude them from the final dataset. Specifically, we considered apps or technologies that appeared to be complete games specifically developed for their purpose as serious games and excluded them from the dataset as a result.

The search also identified many primarily physical health interventions. They were included if assessing an aspect of mental health and well-being as a research outcome (whether primary or secondary).

Coding Process
Due to its breadth, we used the taxonomy of gameful elements by Tondello et al [35] as a foundation for answering RQ1. Similarly, we used the mental and substance use disorders categories from the Global Burden of Disease study [36] as a starting point for answering RQ2. For RQ3, we coded reasons whenever they appeared in the body of the papers in our dataset. The dataset was coded with QSR International’s NVivo 11, a computer-assisted qualitative data analysis software.

Using the above-identified frameworks as a starting base, 2 authors (VWSC and KV) read and re-read the first 10% of papers to assess the preliminary coding frame and identify any further emergent codes. Both authors also independently coded the first 10% of papers based on the preliminary coding frame. Discrepancies between coders were discussed and resolved, and the coding frame was updated with more precise definitions for each gamification element. This process was repeated on the next 10% of papers until sufficient interrater agreement ($\kappa = 0.758$) was reached.

The coding process was not straightforward because of an overlap in terminology. This was particularly the case for RQ1. For example, although the term levels is commonly used to refer to advancing progress, as in leveling up, it is also used to refer to new, more difficult environments [1]. Similarly, we observed points being used as both progress markers (experience points) and currency. This necessitated significant revisions between the preliminary and final coding frames. Furthermore, although certain categories of gameful elements identified by Tondello et al [35] were well represented in our dataset (eg, customization), others were almost nonexistent (eg, altruism). To maintain a balance between simplicity and detail, we collapsed less used gameful element categories into 1 code (eg, collapsing all of Tondello et al’s assistance elements into our gamification element artificial assistance) while keeping other, more used gameful elements separate (eg, maintaining the distinction between social competition, social networking, social cooperation, and social comparison). Similar gameful elements that were commonly observed together (such as levels and progression and progress feedback; or narrative or story and theme) were also grouped together and precisely defined in our coding frame. Our final coding frame containing 18 gamification elements and 17 mental health and well-being domains is presented in Multimedia Appendix 1.

One author (VWSC) then applied this coding frame to the entire dataset, including returning to earlier coded papers and recoding when necessary. Data extracts from each new paper were compared with the previously coded data extracts for all relevant codes, and against the coding frame, to ensure consistency.

Thematic Analysis of Research Question 3 Codes
One author (VWSC) collated and thematically analyzed [37] all data extracts pertaining to RQ3. As mentioned previously, coded data extracts were compared against each other multiple times during coding rounds, and across multiple rounds, to refine the coding frame, ensure consistency, and further delineate the concepts covered by each code.

As RQ3 investigates researchers’ motivations, coding was done using an interpretivist approach, with the aim of staying relatively close to the dataset, that is, the article text was prioritized over the coder’s higher-level interpretations. This was done to prevent the coder from imposing additional meaning that the authors of the original papers may not have intended [38]. For example, although the codes Increase engagement with intervention and Increase motivation to use may appear to cover similar concepts (although not identical [9]), they were coded separately, as we observed multiple instances of those particular wordings. All RQ3 codes and example quotes are also presented in the final coding frame in Multimedia Appendix 1.

Results

Search Strategy and Screening Process
Figure 1 shows a summary of the search and screening process.

At the end of the screening process, 70 qualifying papers were identified, collectively reporting on 50 apps and technologies. Multimedia Appendix 2 presents a summary of each app or technology, including description, mental health and well-being domain(s), and gamification elements.
Figure 1. Flowchart of articles identified by the search and screening process.

Research Question 1: Gamification Elements

Figure 2 shows the number of apps and technologies in the dataset that contain the specified gamification elements.

Of the 18 gamification elements, the most commonly coded were levels or progress feedback (40/50, 80%), points or scoring (28/50, 56%), rewards or prizes (25/50, 50%), narrative or theme (24/50, 48%), personalization (21/50, 44%), and customization (21/50, 44%). The least commonly coded elements were artificial assistance (2/50, 4%), unlockable content (3/50, 6%), social cooperation (5/50, 10%), exploratory or open-world approach (5/50, 10%), artificial challenge (5/50, 10%), and randomness (9/50, 18%).

Figure 3 shows the distribution of the number of gamification elements coded in 1 app or technology, with the mode and median value being 5.
Research Question 2: Mental Health and Well-Being Domains Targeted by Gamification

Figure 4 shows the count of mental health and well-being domains that were represented in the dataset. (The count does not sum to 50, as some apps or technologies targeted multiple mental health and well-being domains.)

Of the 17 mental health and well-being domains, the most commonly coded were anxiety disorders (16/50; 32%), well-being (10/50, 20%), alcohol use disorders (6/50, 12%), depressive disorders (6/50, 12%), and physical health with mental health and well-being outcomes (5/50, 12%). The least commonly coded were conduct disorder (0/50, 0%), bipolar disorders (0/50, 0%), self-injury or suicide (1/50, 2%), schizophrenia (1/50, 2%), mindfulness (1/50, 2%), general motivational impairment, (1/50, 2%), and attention-deficit/hyperactivity disorder (1/50, 2%).
Research Question 3: Reasons for Applying Gamification to Improving Mental Health and Well-Being

We found justification for applying gamification to improving mental health and well-being in 41 of the 70 papers (59%) in the dataset. Figure 5 shows the organization of themes, subthemes, and codes, with themes in ovals, subthemes in rounded rectangles, and codes in rectangles. Example quotes for each code are presented in the coding frame in Multimedia Appendix 1.

The codes were sorted into 5 main subthemes, which were further sorted into 2 main themes: (1) promoting engagement with an intervention and (2) enhancing an intervention’s intended effects.

Of the 5 subthemes, 2 fell under the first theme (promoting engagement): (1) encouraging usage of their app or technology and (2) decreasing barriers to engagement. The former was the most commonly cited reason for using gamification and was coded in 31 of the 41 papers (76%), whereas the latter was much less prevalent (6/41 papers, 15%).

The remaining 3 subthemes fell under the second theme (enhance an intervention’s intended effects): (1) behavior change, (2) intervention efficiency, and (3) intervention efficacy. Of these subthemes, behavior change was the most commonly coded (14/41 papers, 32%), followed by intervention efficiency (12/41 papers, 29%) and intervention efficacy (2/41 papers, 5%).
Figure 5. Thematic diagram showing themes, subthemes, and codes.

Discussion

Summary

The search and screening process identified 70 qualifying papers that collectively reported on 50 apps and technologies. Of the 18 gamification elements in our coding frame, the most commonly coded gamification elements were levels or progress, feedback, points or scoring, rewards or prizes, narrative or theme, personalization, and customization, whereas the least commonly coded were artificial assistance, unlockable content, social cooperation, exploratory or open-world approach, artificial challenge, and randomness. The mode count of gamification elements coded in the included apps and technologies was 5.

Of the 17 mental health and well-being domains in our coding frame, the most commonly coded were anxiety disorders and well-being, whereas the least commonly coded were conduct disorder, bipolar disorders, self-injury or suicide, schizophrenia, mindfulness, general motivational impairment, and attention-deficit/hyperactivity disorder.

Finally, researchers’ justification for applying gamification to apps and technologies for improving mental health and well-being was coded in 59% (41/70) papers. In these 41 papers, we identified 2 main themes: (1) promoting engagement with an intervention and (2) enhancing an intervention’s intended effects.

Research Question 1: Gamification Elements

We observed levels or progress feedback in a vast majority (40/50, 80%) of the apps and technologies that aim to support the improvement of mental health and well-being in our dataset, making it the most commonly applied gamification element. This is consistent with previous reviews of both the academic literature [7] and stress management apps in the Google Play Store [25] and is unsurprising, as in addition to being easy to implement, progress feedback is a key behavior change technique [4,26]. The near-ubiquity of this element may also point at the influence personal informatics has had on health technology [6].

Many critics of gamification point to the inadequacy of the points, badges, and leaderboards approach [39] in targeting intrinsic motivation and creating satisfying user experiences [6,18]. But although these elements were present in the apps and technologies in our dataset, only points or scoring was in the top 5. This contradicts earlier findings that points are used rarely for mental health and well-being [30] and may be due to the difference in inclusion criteria between both reviews. Alternatively, it could be due to developments in the field of health gamification, with recent mental health and well-being apps and technologies drawing on learnings from early adopter health fields such as physical activity and chronic illness. Meanwhile, badges or achievements were observed in 12/50 (24%) apps and technologies. We did not code leaderboards as a specific gamification element, instead including it into our broader gamification element social competition, which we observed in 12/50 (24%) apps and technologies. These results suggest that in mental health and well-being domains, points, badges, and leaderboards are far from dominant and that alternative models of gamification are being applied.

Previous research has outlined the potential of progress feedback, points, and rewards to promote behavior change [40,41]; however, their effectiveness is unclear [42] and may depend on how these elements are designed to fit the basic intrinsic and extrinsic motivational processes underlying the app or technology [6,9]. On the other hand, evidence for the potential of personalization and customization (conceptually similar to the term tailoring commonly used in health behavior change literature) is more promising [8,43]. Tailoring offers users increased levels of autonomy, which, according to OIT, would contribute to increased likelihood of internalized...
motivation and well-being [16]. Ultimately, however, more research is required to establish whether these improvements persist in the long term or merely result from novelty effects [4].

Of the 50 apps and technologies in our dataset, the mode count of gamification elements was 5 (10 apps and technologies, 20%), with the distribution shaped similar to a bell curve with mild positive skew (Figure 3). Our observed mode is much greater than the mode of 1 element identified in previous reviews of Web-based mental health interventions whose evaluation also assessed adherence [30] and stress management apps in the Google Play Store [25]. This finding aligns with recent research showing that a greater diversity of types of rewards in a game led to greater presence, enjoyment, and effort [44]. The fact that our study’s coding frame contains more gamification elements than the study by Brown et al [30] may contribute to this difference; however, as Hoffmann et al’s study [25] coded for 17 gamification techniques, this may not be the only reason. Furthermore, the increased range (1-11) of gamification elements observed in our sample of apps and technologies for improving mental health and well-being suggests that researchers may be growing more comfortable with applying a range of gamification elements for mental health and well-being [30]. Previous calls for the inclusion of more gamification elements in health and well-being interventions [22] may have also contributed to this increase.

Most of the more frequently observed gamification elements in our dataset, namely progress feedback, points, rewards, personalization, badges, quests, and varying social features, overlap with those in other behavior change frameworks [4,26]. Notably, in persuasive systems design, these features are named self-monitoring, praise, rewards, tailoring, recognition, goal setting, normative influence, cooperation, competition, and social comparison [34]. These overlapping elements make up the bulk of our observations in our dataset, with the exception of social cooperation, which we observed infrequently in our dataset (5/50, 10%), includes mini-game (13/50, 26%), and narrative or theme, which is not found in other behavior change frameworks but was one of the most commonly observed gamification elements in our dataset (24/50, 48%). In its current state, the application of gamification to improving mental health and well-being seems difficult to distinguish from approaches stemming from other behavior change frameworks such as persuasive systems design.

So what distinguishes gamification from these approaches? What added value does gamification offer compared with other behavior change frameworks and techniques? The answer may lie in the gamification elements we observed less frequently in our dataset: randomness, artificial challenge, exploratory or open-world approach, social cooperation, unlockable content, and artificial assistance. Although elements such as artificial challenge and artificial assistance are likely underutilized because of their usefulness only in certain contexts (eg, dynamic difficulty adjustment to create a state of flow during attentional bias modification training (ABMT) [45] or providing facial identification cues in an attention training intervention for children on the autism spectrum [46]), other elements such as randomness, exploratory or open-world approach, and social cooperation may be more complementary to mental health and well-being in general.

Randomness, which is one of the key types of play and games according to Caillois [32], can be implemented via a random reinforcement schedule, for example, to facilitate learning [47]. However, more integral to this gamification element is the anticipation of not knowing exactly what to expect, for example, by offering intervention participants missions that have been randomly drawn from a larger pool of missions [48] and the sense of excitement that comes with it. Similarly, designing mental health and well-being interventions to accommodate an exploratory or open-world approach complements the flexibility of contemporary internet experiences and may even be expected by intervention participants [27]. However, it may be challenging to apply this to therapeutic approaches whose structures may be more rigid, such as cognitive behavioral therapy. A possible solution in cases similar to these could be to make all modules immediately accessible but indicate a recommended module order [14]. In this way, the user’s autonomy is not thwarted [16], and they are empowered with the knowledge of how to navigate the intervention in a way that can benefit them most.

Despite the clearly demonstrated benefits of social connectedness on well-being [49], social cooperation is underutilized in mental health and well-being interventions, particularly in comparison with other social elements such as comparison and competition. Social cooperation represents a positive way of interacting with others that does not explicitly place value on all involved parties (as it would through competition or comparison) and is a way to satisfy our innate need for relatedness and promote well-being [16]. Despite this, the only instances of social cooperation we observed in our dataset were in physical activity and well-being interventions, with the majority in the form of cooperation nested within competition (cooperating with team members to compete against other teams). As this approach is still competitive at its core, it may be incompatible with many mental health and well-being domains [14,15]. Most instances of social support we observed in our dataset were instead in the form of social networking, where users of an app or technology could interact with and affirm each other through posts, private messages, and gifts. It may be useful to draw inspiration from cooperative mechanics from commercial video games to identify how best to apply social cooperation to improving mental health and well-being in more task- and domain-compatible ways. For example, in Massively Multiplayer Online games or video games such as Snipperclips [50], players can work together to achieve a system-defined goal (effectively players vs system). Applied to an ABMT intervention, a system-defined social cooperation goal could be having all members of a team complete a stage a certain number of times or collectively achieve a certain score. Designers of mental health and well-being interventions can also consider integrating real-time location data into their functionality (eg, an app aimed at decreasing levels of social anxiety challenges its users to call a gym and provides the phone number of a nearby gym [51]). A recent example of a successful app with this functionality is Pokémon GO [52], which
encourages its users to make meaningful connections with physical locations and people [53].

**Research Question 2: Mental Health and Well-Being Domains Targeted by Gamification**

Anxiety disorders was the most commonly targeted mental health and well-being domain in our dataset (16 apps and technologies, 32%), followed by well-being (10 apps and technologies, 20%). Of note is the fact that no gamified apps and technologies targeting bipolar disorders and conduct disorder were identified in this review. (We did, however, exclude 1 intervention aimed at preventing substance abuse and relationship violence for being a serious game [54].) As these domains, particularly bipolar disorders, have significant associated global burden of disease [36], this may be a research gap worth targeting.

Overall, there is a greater level of diversity in mental health and well-being domains compared with that in previous reviews of the literature [6,7,30]. However, more work remains to be done not only in designing engaging and efficacious gamified mental health and well-being interventions but also in evaluating their effectiveness. The slow pace of clinical research is directly at odds with the fast pace of technological change, frequently rendering interventions obsolete in the time taken to establish their efficacy. For this reason, nontraditional development and evaluation methods such as agile development and rapid prototyping may be more suitable for gamified mental health and well-being interventions [27]. However, care must be taken to ensure that no harm, particularly from the application of gamification [1,55], is caused to intervention testers during these stages of development and testing.

**Research Question 3: Reasons for Applying Gamification to Improving Mental Health and Well-Being**

**Theme 1: Promoting Engagement With an Intervention**

Encouraging usage of the app or technology was the dominant reason for applying gamification, appearing in 31 of the 41 (76%) papers that provided a reason for using gamification. Gamification was purported to improve multiple aspects of engagement, including fun and enjoyableness, and create a sense of mastery. This would encourage both first contact and repeated contact with the app or technology, concepts that are analogous to engagement and retention. However, further research is needed to learn how gamification enhances engagement [4] and whether it may be more effective at establishing initial engagement or ongoing use.

Gamification was also said to be a tool to decrease barriers to engaging with an intervention, both in terms of mitigating participants’ defensiveness and reducing participants’ distress. This was much less used, appearing in 6 (15%) papers. The mental health and well-being domains represented were also limited, with mitigating participants’ defensiveness mentioned only by authors of interventions targeting alcohol use and anxiety disorders [56-59] and reducing participants’ distress exclusively mentioned by authors of interventions targeting phobia [60,61]. Interestingly, despite significant societal levels of stigma against mental health problems, these reasons were not cited for any other mental health and well-being domain.

**Theme 2: Enhancing an Intervention’s Intended Effects**

Most of the data extracts under this theme related to behavior change (14 papers, 32%). Specifically, researchers aimed to use gamification to encourage intended behaviors and sustain behavior change over time. This was unsurprising, given the focus of these apps and technologies on improving mental health and well-being through behavior change, possibly in response to academic calls for action [4,5]. The ability of gamification to support behavior change is also somewhat supported by existing research [41,62,63], although further research is required on whether, and how for long, these effects persist [4].

Other aims related to intervention efficacy were also mentioned, including encouraging attitude change, enhancing learning, improving well-being, and using gamification elements to complement the delivery of intervention ingredients (e.g., by presenting an ABMT task as a game of snap [64]). As mentioned previously, more research is needed to establish the extent of the effects gamification may have on supporting these goals.

Finally, although this was only mentioned in 2 (5%) papers, gamification was touted as a way to potentially increase the cost-effectiveness of interventions either by attracting users to participate without using material incentives or by making the feedback and reward loop interesting enough so that the intervention attracted new users and incentivized the existing users to continually generate new content, creating a closed loop [58]. This specific intervention design was for a personalized normative feedback intervention targeting problemmatic levels of alcohol consumption and may, therefore, be impractical for many mental health and well-being domains requiring trained moderators and therapists. However, designers of more self-directed initiatives such as preventive or well-being interventions (particularly those that rely on social comparison) may find this a useful model.

**Overall**

Of 41 papers, 13 (32%) explicitly linked gamification to motivation to use the app or technology. This points to the origins of gamification as being defined as a motivational affordance and the way it was initially introduced to electronic health and mobile health as a tool to increase engagement and motivate behavior change [4-6]. However, in the context of behavior change theory, motivation is only 1 driver of behavior change, with the other 2 being capability and opportunity [29]. The focus on motivation, seemingly at the expense of capability and opportunity [22], represents lost potential.

Some gamification elements are particularly compatible with capability and opportunity. For example, according to Lister et al, capability can be promoted via self-monitoring, and opportunity by providing cues to action and peer pressure [22]. The gamification equivalent to these techniques would be levels or progress feedback, personalization, and social mechanics (whether competition, cooperation, networking, or comparison) respectively. As an example, a mental health and well-being app or technology might identify certain times of day when...
users are engaged in particular activities or have free time and time notifications accordingly (personalization).

Finally, although the above sections provide insights into what the writers of some papers in our dataset intended to achieve with gamification, it is important to note that reasoning behind the decision to implement gamification was only provided in 41 of 70 (59%) of papers. This may be indicative of a lack of consideration of the mechanisms through which gamification may influence behavior change in a large portion of mental health and well-being–related research. Furthermore, this may indicate that the lack of linkage between the theory and application of gamification observed in the greater literature [1,25] is also present, to a degree, in mental health and well-being. In other words, some applications of gamification to apps and technologies for improving mental health and well-being may be treating gamification as a black box, which is clearly problematic. With reference to Huotari and Hamari’s definition of gamification [13], designers of mental health and well-being interventions may find it helpful to identify the key attitude and behavior change mechanisms and processes through which they intend the intervention to work and how these interact with established evidence-based techniques in their field. Once these core services (or intervention principles [65]) are identified, gamification can then be applied in various ways to enhance these services. This would result in a more targeted, theory-driven, evidence-based application of gamification to improving mental health and well-being.

Study Limitations

This study aimed to systematically review literature published from 2013 to 2018 to identify any and all instances of the application of gamification to apps and technologies for improving mental health and well-being. Furthermore, this review had a broad focus, including sources that are traditionally excluded in systematic reviews such as conference papers and conceptual papers. This was done to ensure as much accuracy as possible in describing the current state of the gamification of health and well-being. However, there are some limitations to this study’s methodology that must be acknowledged to fully contextualize our results.

First, there is a possibility that some qualifying papers were not identified by the search. Although a wide variety of keywords were used to capture as many results as possible, this may particularly be the case for more specialist papers that may only discuss their specific mental illness and not include the phrases mental health, wellbeing, well-being, mental illness, or mental disorder. Furthermore, interventions were frequently described as gamification when they were actually (as judged by the authors) serious games. Although those studies were excluded, the initial search would not have captured any interventions that were the other way around—gamified interventions that were labeled serious games. The search process would also have failed to identify apps or technologies that the academic literature does not report and explicitly link to gamification, including many commercially developed apps or technologies. The results of this review are, therefore, not fully generalizable to commercially developed apps and technologies for improving mental health and well-being.

It is also likely that not all gamification elements in an intervention were able to be coded, as researchers may not have fully described their apps and technologies in the papers. It is also possible that the gamification elements described in papers may have been removed from the app or technology in subsequent software updates. Furthermore, in some studies, as in best practice, gameful design was so embedded within the intervention that the gamification elements could not be separated from the active ingredients of the intervention. Alternatively, and on the other extreme, in some cases, the only mention of gamification was a blanket statement that it had been applied, making it difficult to judge which elements these statements referred to. For these reasons, all features of an intervention were evaluated against the coding frame and coded. In doing so, coding detail was also kept consistent between studies that only evaluated 1 version of an intervention and studies that evaluated a control version against a gamified version (of which there were not many). As the health gamification field matures, there is a need for the inclusion of more detail when describing the implementation of gamification and more consistent use of applied games terminology within and across fields.

As certain intervention paradigms can be used for multiple contexts (eg, ABMT), the range of mental health and well-being domains we observed is also likely to be an underestimate of the range of domains, both within mental health and well-being and across all aspects of health and well-being, to which gamification can potentially be applied. Similarly, as the focus of this review was the improvement of mental health and well-being, apps and technologies that used gamification for other mental health and well-being–related purposes such as measurement were excluded from the review.

Finally, as the primary aim of this review is to provide a record of all reported gamified apps and technologies for improving mental health and well-being within the past 5 years (2013-2018), we did not collect any information on the included apps or technologies’ efficacy or effectiveness on any evaluation metric. However, given that a previous review has identified the relative lack, and low level of quality, of evidence for the effectiveness of gamification for health and well-being [6], this analysis may be premature. Furthermore, although this review investigates individual gamification elements, we acknowledge and argue that gamification is best implemented and evaluated holistically, as implied by Huotari and Hamari’s definition of gamification [13]. Instead of evaluating individual gamification elements, a more practical and informative approach may be to evaluate individual (gamified) intervention principles [65].

Conclusion and Future Directions

This paper reports the results of a systematic review on all applications of gamification to improving mental health and well-being reported in the literature in the past 5 years (2013-2018). A total of 12 databases and journals were searched for qualifying papers, and from the search results, we identified 50 qualifying apps and technologies. Results suggest that gamification is being applied to a greater range of mental health and well-being domains compared with previous reviews and that a greater diversity of gamification elements is being used.

http://mental.jmir.org/2019/6/e13717/
Our results also suggest that in the context of improving mental health and well-being, gamification is not being implemented in the behaviorist fashion focusing mostly on positive reinforcement that has been observed and criticized in the wider literature [19]. Importantly, however, our results are only reflective of gamified apps and technologies reported within the academic literature. Future research can conduct a review of commercially developed gamified apps and technologies for improving mental health and well-being and compare and contrast findings with those derived from the academic literature. Similar reviews can also be conducted for serious games and commercial games (potentially including both video games and nondigital games) with mental health themes.

This review also found that certain gamification elements, such as randomness, artificial challenge, artificial assistance, exploratory or open-world approaches, and social cooperation, are underutilized for the improvement of mental health and well-being and that further research (ideally with rapid prototyping methods such as agile development [27]) is needed to identify how best these elements can be applied to improving mental health and well-being, if at all. There is also a need to consider and evaluate how gamification may promote a wider variety of drivers for health behavior change. Although current applications of gamification in improving mental health and well-being are primarily for improving motivation (to engage with the intervention or change behavior), future applications should consider how gamification can serve other behavior change drivers such as capability and opportunity [22,29]. It is also important to evaluate whether gamification may lead to unintentional, harmful effects, and in what circumstances this may occur [1,55]. For example, what would be the effects and ethical implications of using randomness in a substance use disorder intervention, given that they both involve dopamine?

Finally, most researchers in health technology probably share the fundamental goal of developing interventions that enable and empower the greatest improvement in health and well-being for the greatest number of people in the target population. To achieve this, there is an urgent need to describe the implementation of gamification to health interventions in more explicit and precise detail and to standardize applied games terminology (including gamification, serious games, and other types of applied games) within and across fields. It may also be fruitful to take a step back from the single-minded focus on engagement that has been characteristic in academic literature on the gamification of health and well-being until now [6,30], and consider more broadly how gamification can enhance the basic functionality of a mental health and well-being intervention. Identifying a mental health and well-being intervention’s goals and intentionally designing gamification to support them in novel and pragmatic ways may be the best way to achieve rapid progress in this field.

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Conflicts of Interest
IBH was an inaugural Commissioner on Australia’s National Mental Health Commission (2012-2018). He is the Co-Director, Health and Policy at the Brain and Mind Centre (BMC), University of Sydney. The BMC operates an early intervention youth services at Camperdown under contract to headspace. Professor Hickie has previously led community-based and pharmaceutical industry-supported (Wyeth, Eli Lilly, Servier, Pfizer, AstraZeneca) projects focused on the identification and better management of anxiety and depression. He was a member of the Medical Advisory Panel for Medibank Private until October 2017, a Board Member of Psychosis Australia Trust, and a member of Veterans Mental Health Clinical Reference group. He is the Chief Scientific Advisor to, and an equity shareholder in, Innowell. Innowell has been formed by the University of Sydney and PwC to deliver the Aus $30 million Australian government–funded Project Synergy. Project Synergy is a 3-year program for the transformation of mental health services through the use of innovative technologies. None of the other authors declare any conflicts of interest.

Multimedia Appendix 1
Final coding frame for gamification elements (Research Question [RQ] 1), mental health and well-being domains (RQ2), and reasons for applying gamification for improving mental health and well-being (RQ3).

[PDF File (Adobe PDF File), 71KB - mental_v6i6e13717_app1.pdf]

Multimedia Appendix 2
Summary of each app or technology, including description, mental health and well-being domain(s), and gamification elements.

[PDF File (Adobe PDF File), 142KB - mental_v6i6e13717_app2.pdf]

References

http://mental.jmir.org/2019/6/e13717/

http://mental.jmir.org/2019/6/e13717/


Abbreviations

ABMT: attentional bias modification training
OIT: organismic integration theory
RQ: research question

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Sexting, Web-Based Risks, and Safety in Two Representative National Samples of Young Australians: Prevalence, Perspectives, and Predictors

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Abstract

Background: The rapid uptake of information and communication technology (ICT) over the past decade—particularly the smartphone—has coincided with large increases in sexting. All previous Australian studies examining the prevalence of sexting activities in young people have relied on convenience or self-selected samples. Concurrently, there have been recent calls to undertake more in-depth research on the relationship between mental health problems, suicidal thoughts and behaviors, and sexting. How sexters (including those who receive, send, and two-way sext) and nonsexters apply ICT safety skills warrants further research.

Objective: This study aimed to extend the Australian sexting literature by measuring (1) changes in the frequency of young people’s sexting activities from 2012 to 2014; (2) young people’s beliefs about sexting; (3) association of demographics, mental health and well-being items, and internet use with sexting; and (4) the relationship between sexting and ICT safety skills.

Methods: Computer-assisted telephone interviewing using random digit dialing was used in two Young and Well National Surveys conducted in 2012 and 2014. The participants included representative and random samples of 1400 young people aged 16 to 25 years.

Results: From 2012 to 2014, two-way sexting (2012: 521/1369, 38.06%; 2014: 591/1400, 42.21%; \(P<.03\)) and receiving sexts (2012: 375/1369, 27.39%; 2014: 433/1400, 30.93%; \(P<.001\)) increased significantly, not sexting (2012: 438/1369, 31.99%; 2014: 356/1400, 25.43%; \(P<.001\)) reduced significantly, whereas sending sexts (2012: n=35/1369, 2.56%; 2014: n=20/1400, 1.43%; \(P>.05\)) did not significantly change. In addition, two-way sexting and sending sexts were found to be associated with demographics (male, second language, and being in a relationship), mental health and well-being items (suicidal thoughts and behaviors and body image concerns), and ICT risks (cyberbullying others and late-night internet use). Receiving sexts was significantly associated with demographics (being male and not living with parents or guardians) and ICT risks (being cyberbullied and late-night internet use). Contrary to nonsexters, Pearson correlations demonstrated that all sexting groups (two-way, sending, and receiving) had a negative relationship with endorsing the ICT safety items relating to being careful when using the Web and not giving out personal details.

Conclusions: Our research demonstrates that most young Australians are sexting or exposed to sexting in some capacity. Sexting is associated with some negative health and well-being outcomes—specifically, sending sexts is linked to suicidal thoughts and behaviors, body image issues, and ICT safety risks, including cyberbullying and late-night internet use. Those who do sext are less likely to engage in many preventative ICT safety behaviors. How the community works in partnership with young people to address this need may be a multifaceted approach, where sexting is positioned within a wider proactive conversation about gender, culture, psychosocial health, and respecting and caring for each other when on the Web.
Sexting Prevalence

International research has primarily focused on sexting prevalence among adolescents and young adults; however, this has yielded broad variability in results. Recent systematic review evidence suggests that internationally, only a minority of young people engage in sexting—with an average of 1 in 7 sending sexts and 1 in 4 receiving sexts (which varies by age, reporting year, and method of sexting) [2]. Within the Australian context, the prevalence estimates are higher and remain variable, particularly for those who have received sexts. Specifically, 43% to 49% of young people report sending sexts, 42% to 67% report that they have received sexts, and 40% to 46% report having sent or received sexts [6,7,11,12]. Variability in results is at least partially attributed to inconsistencies in sampling techniques [1,13]. For example, all previous Australian studies reporting prevalence have employed convenience or self-selected sampling techniques. Research that applies nationally representative and random sampling survey techniques is clearly needed.

Variability in prevalence rates has been partially explained by inconsistencies in definitions and measurement of sexting behaviors [1,13,14]. Previous Australian research has measured the lifetime experience of sexting, as opposed to sexting frequency over a specific period. This measurement approach poses challenges when comparing adolescent with young adult sexting prevalence, as young adults will have had more opportunities to engage in sexting. Another common issue when considering sexting prevalence in Australia is that measures of sending and receiving sexts have frequently been presented as 1 sexting variable. This creates challenges in comparing sexting prevalence and correlates between studies, either nationally or internationally. Addressing these issues relating to the operationalization and measurement of sexting warrants focus.

Sexting and Information and Communication Technology Use

Research examining technology use and sexting has reported associations between sexting and time spent texting [16], problematic smartphone use [22], having a Facebook account, and Web-based video chatting with strangers [23]—but not hours spent on the internet daily [17]. Sexting predominately occurs through smartphone apps, such as Snap Inc.’s Snapchat—with these apps being perceived by participants as a more “...convenient, safe, and informal means of sexting communication than other mediums, such as e-mail or Facebook, regardless of the actual risk of unauthorized distribution” [24]. How young Australians practice ICT safety when using such technologies and forming an understanding of how ICT safety practices relate to different types of sexting behaviors (i.e., sending, receiving, two-way, and not sexting) has not, to our knowledge, been researched.
This Research

This study extends the Australian literature to provide sexting prevalence and correlates among young Australians using the results from the 2012 and 2014 Young and Well National Surveys, which include representative and random samples of 1400 young people aged 16 to 25 years. This research directly addressed the research gaps within the Australian context, including the reliance on convenience or self-selected samples, and the lack of comprehensive reporting on the relationship between sexting and other factors such as sociodemographics, mental health and well-being items, and ICT risks and ICT safety practices.

This study has 4 main aims, including the assessment of (1) the changes in the frequency of young people’s sexting activities from 2012 to 2014; (2) young people’s beliefs about sexting; (3) the association of demographics, health and well-being items, and internet use with sexting activity; and (4) the relationship between sexting and ICT safety skills.

Methods

Participants and Recruitment

This study received ethics approval from The University of Sydney human research ethics committee (2012 Protocol No. 2012/1640; 2014 Protocol No. 2014/741) and was a partnership between the authors who were associated with the Young and Well Cooperative Research Centre (CRC; 2011-16) and The University of Sydney’s Brain and Mind Centre (BMC). The survey was run using computer-assisted telephone interviewing (CATI). These telephone interviews were conducted by an independently contracted company—the Social Research Centre (Melbourne, Victoria)—that was commissioned by the authors to run the CATI. Respondents were randomly selected using random digit dialing (RDD) and included 700 young men and 700 young women aged 16 to 25 years. RDD has been cited as the historical gold standard for population-based control recruitment when conducting epidemiologic research [25]. Stratification was used to ensure that the samples were representative of the general population in terms of age, gender, and geographic location across all Australian states and territories. Participation was voluntary, and verbal consent was obtained at the start of the telephone interview. The respondents were excluded if they had English language difficulties or if they were uncomfortable with the interview being conducted in English. For all respondents aged 16 or 17 years, consent was obtained at the start of the telephone interview. The respondents were asked (1) whether they considered sexting a serious problem for young people, (2) whether they had seen or received images or messages of a sexual nature in the previous 12 months, (3) whether they had sent messages or images of a sexual nature in the last 12 months, and (4) reasons for sexting and beliefs about sexting adapted from the study by Henderson [31] (2012 National Survey only). For the cyberbullying component, participants were asked (1) whether they considered sexting a serious problem for young people, (2) the frequency for which they had been cyberbullied in the previous 12 months, and (3) the frequency for which they had cyberbullied others in the previous 12 months.

Analysis

Data were analyzed using SPSS 22.0 for Windows [32]. Univariate descriptive and frequency statistics were used to describe all demographic, clinical, and internet use items. Chi-square analysis assessed changes in sexting activity rates from 2012 to 2014. Phi was used to determine the effect size. Frequency statistics were used to describe young people’s beliefs about sexting. Binary logistic regression analyses were used to investigate possible predictors of sexting (2 way, sending, receiving, and no sexting), reported as adjusted odds ratios (AORs) at a 95% confidence interval (CI). Pearson bivariate correlations determined the relationship between sexting groups (2 way, sending, receiving, and no sexting) and ICT safety items. No missing data were imputed for any analysis.

Results

Sample Characteristics

In both 2012 and 2014, half of the 1400 young people who participated were male (2012: 700/1400, 50.00%; 2014: 705/1400, 50.36%). Approximately one-third of the respondents...
were from each target age group: 16 to 18 years (2012: 484/1400, 34.57%; 2014: 499/1400, 35.64%), 19 to 21 years (2012: 466/1400, 33.28%; 2014: 464/1400, 33.14%), and 22 to 25 years (2012: 450/1400, 32.14%; 2014: 437/1400, 31.21%). In both surveys, the majority (2012: 1086/1400, 77.57%; 2014: 1107/1400, 79.07%) of the respondents did not speak any language other than English. Rates of identification with Aboriginal or Torres Strait Islander descent (2012: 30/1400, 2.14%; 2014: 48/1400, 3.43%) were reflective of national census rates [33]. The majority of young people lived in major cities (2012: 1047/1400, 74.79%; 2014: 1048/1400, 74.86%) and lived with at least one of their parents or guardians (2012: 1031/1400, 73.64%; 2014: 1057/1400, 75.50%). In addition, over half of them described education as their main current activity (2012: 869/1399, 58.18%; 2014: 814/1398, 57.79%) and one-third of respondents were employed in some capacity (2012: 493/1399, 35.24%; 2014: 474/1398, 33.86%). Changes in sociodemographics, mental health and well-being, and internet use between 2012 and 2014 are presented in Multimedia Appendix 1.

### Sexting Prevalence

Young people’s overall sexting activities from 2012 to 2014 changed significantly; a breakdown of these changes by type of sexting activity is presented in Table 1. From 2012 to 2014, young people most commonly endorsed being reciprocal two-way sexters (2012: 521/1369, 38.06%; 2014: 591/1400, 42.21%), and this increased significantly from 2012 to 2014 (\(P=0.03\)). The number of young people reporting only receiving sexts increased significantly from 2012 to 2014 (2012: 375/1369, 27.39%; 2014: 433/1400, 30.93%; \(P<0.001\)), whereas those only sending sexts did not change significantly over time and was the least endorsed sexting behavior (2012: 35/1369, 2.56%; 2014: 20/1400, 1.43%). The proportion of young people reporting that they were a nonsexter reduced significantly from one-third to a quarter of respondents between 2012 and 2014 (2012: 438/1369, 31.99%; 2014: 356/1400, 25.43%; \(P<0.001\)).

A more detailed breakdown of the specific types of sexting activities that young people engaged in is presented in Table 2.

#### Table 1. Prevalence of sexting between 2012 and 2014.

<table>
<thead>
<tr>
<th>Sexting category</th>
<th>Yes in 2012 (N=1369), n (%)</th>
<th>Yes in 2014 (N=1400), n (%)</th>
<th>Chi-square (df)</th>
<th>(P) value</th>
<th>Phi</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two-way sexting</td>
<td>521 (38.06)</td>
<td>591 (42.21)</td>
<td>5.0 (1)</td>
<td>0.03</td>
<td>0.04</td>
</tr>
<tr>
<td>Only sending sexts</td>
<td>35 (2.56)</td>
<td>20 (1.43)</td>
<td>2.6 (1)</td>
<td>0.11</td>
<td>-0.03</td>
</tr>
<tr>
<td>Only receiving sexts</td>
<td>375 (27.39)</td>
<td>433 (30.93)</td>
<td>19.3 (1)</td>
<td>&lt;0.001</td>
<td>0.08</td>
</tr>
<tr>
<td>Nonsexter</td>
<td>438 (31.99)</td>
<td>356 (25.43)</td>
<td>14.6 (1)</td>
<td>&lt;0.001</td>
<td>-0.07</td>
</tr>
</tbody>
</table>

#### Table 2. Frequency of young people’s sexting behaviors.

<table>
<thead>
<tr>
<th>Sexting behavior</th>
<th>Yes in 2012 (N=1369), n (%)</th>
<th>Yes in 2014 (N=1400), n (%)</th>
<th>Chi-square (df)</th>
<th>(P) value</th>
<th>Phi</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Receiver</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Been sent sexual message</td>
<td>552 (40.32)</td>
<td>644 (46.00)</td>
<td>9.1 (1)</td>
<td>0.003</td>
<td>0.57</td>
</tr>
<tr>
<td>Seen a sexual message posted where others could see it</td>
<td>490 (35.79)</td>
<td>598 (42.71)</td>
<td>13.9 (1)</td>
<td>&lt;0.001</td>
<td>0.104</td>
</tr>
<tr>
<td>Seen other people perform acts of a sexual nature</td>
<td>361 (26.37)</td>
<td>540 (38.57)</td>
<td>47.0 (1)</td>
<td>&lt;0.001</td>
<td>0.130</td>
</tr>
<tr>
<td>Been asked to talk about acts of a sexual nature with someone</td>
<td>365 (26.66)</td>
<td>489 (34.93)</td>
<td>22.2 (1)</td>
<td>&lt;0.001</td>
<td>0.089</td>
</tr>
<tr>
<td>Been asked for a photo or video showing yourself nude or nearly nude</td>
<td>266 (19.43)</td>
<td>435 (31.07)</td>
<td>49.6 (1)</td>
<td>&lt;0.001</td>
<td>0.134</td>
</tr>
<tr>
<td>None</td>
<td>473 (34.55)</td>
<td>376 (26.86)</td>
<td>19.3 (1)</td>
<td>&lt;0.001</td>
<td>-0.083</td>
</tr>
<tr>
<td>Refused</td>
<td>1 (0.07)</td>
<td>4 (0.29)</td>
<td>1.7 (1)</td>
<td>0.19</td>
<td>0.025</td>
</tr>
<tr>
<td><strong>Sender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>813 (59.39)</td>
<td>789 (56.36)</td>
<td>2.6 (1)</td>
<td>0.11</td>
<td>-1.07</td>
</tr>
<tr>
<td>Talked about acts of a sexual nature with someone</td>
<td>465 (33.97)</td>
<td>513 (36.64)</td>
<td>2.2 (1)</td>
<td>0.14</td>
<td>0.028</td>
</tr>
<tr>
<td>Sent someone a sexual message</td>
<td>398 (29.07)</td>
<td>449 (32.07)</td>
<td>2.9 (1)</td>
<td>0.09</td>
<td>0.033</td>
</tr>
<tr>
<td>Sent someone a photo or video showing yourself nude or nearly nude</td>
<td>140 (10.23)</td>
<td>237 (16.93)</td>
<td>26.4 (1)</td>
<td>&lt;0.001</td>
<td>0.098</td>
</tr>
<tr>
<td>Asked someone for a photo or video showing themselves nude or nearly nude</td>
<td>122 (8.91)</td>
<td>170 (12.14)</td>
<td>7.7 (1)</td>
<td>0.006</td>
<td>0.053</td>
</tr>
<tr>
<td>Posted a sexual message posted where others could see it</td>
<td>41 (2.99)</td>
<td>24 (1.71)</td>
<td>5.0 (1)</td>
<td>0.03</td>
<td>-0.042</td>
</tr>
<tr>
<td>Refused</td>
<td>2 (0.15)</td>
<td>8 (0.57)</td>
<td>3.5 (1)</td>
<td>0.06</td>
<td>0.062</td>
</tr>
</tbody>
</table>

\(^a\)Arranged from most to least commonly endorsed item by receiver and by sender from the 2014 data.
In both 2012 and 2014, when asked about the type of sexts being received, the most frequently reported item was being sent a sexual message (2012: 552/1369, 40.32%; 2014: 644/1400, 46.00%). Overall, the rates of endorsement of items relating to being a receiver of sexts increased significantly between 2012 and 2014 across all items, whereas endorsement of none fell significantly. Significant increases in endorsement rates between 2012 and 2014 for 4 items relating to the type of sexts being sent were found (sent someone a sexual message, sent someone a photo or video showing yourself nude or nearly nude, asked someone for a photo or video showing themselves nude or nearly nude, and posted a sexual message posted where others could see it). However, for all respondents, the most commonly endorsed item relating to sending sexts was none (2012: 813/1369, 59.39%; 2014: 789/1400, 56.36%).

**Beliefs About Sexting**

Consistently in both 2012 and 2014, over half (2012: 691/1369, 50.47%; 2014: 707/1268, 50.50%) of the respondents thought sexting was a serious problem for young people ($\chi^2=1.2; P=.27$). The reasons for sexting and beliefs about sexting were explored in the 2012 survey and are presented in Table 3 and 4, respectively. The most commonly reported reason for sexting was “to get attention from a dating partner” (1217/1369, 88.90%). Sexting causing “serious negative consequences” was endorsed by nearly all respondents (1263/1369, 92.26%), and the vast majority believed that “messages usually end up being seen by more than just those to whom they were sent” (1157/1369, 84.51%).

**Sexting Predictors**

The associations between sexting activity and demographic, health and well-being items, and internet use were examined. AORs for the 2014 data are presented in Table 5. Additional crude risk ratios showing the strength of the relationships between each variable and sexting behavior are presented in Multimedia Appendix 2.

### Table 3. Young people’s reasons sexting in 2012 (N=1369).

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>To get attention from a dating partner</td>
<td>1217 (88.90)</td>
</tr>
<tr>
<td>To be fun and flirtatious</td>
<td>1111 (81.15)</td>
</tr>
<tr>
<td>To be sexy or initiate sexual activity</td>
<td>1093 (79.84)</td>
</tr>
<tr>
<td>They feel pressured to by friends or a dating partner</td>
<td>959 (70.05)</td>
</tr>
<tr>
<td>A form of self-expression</td>
<td>677 (49.45)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>22 (1.61)</td>
</tr>
<tr>
<td>Other reason</td>
<td>9 (0.66)</td>
</tr>
</tbody>
</table>

*a* Items not asked in 2014.

*b* Arranged from most to least commonly endorsed item.

### Table 4. Young people’s beliefs about sexting in 2012 (N=1369).

<table>
<thead>
<tr>
<th>Item</th>
<th>Agree/strongly agree, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>It can cause serious negative consequences</td>
<td>1263 (92.26)</td>
</tr>
<tr>
<td>Messages usually end up being seen by more than just those to whom they were sent</td>
<td>1157 (84.51)</td>
</tr>
<tr>
<td>Females have to worry about messages being viewed by someone other than the person they had originally intended it for, more than males do</td>
<td>1067 (77.94)</td>
</tr>
<tr>
<td>There is pressure among young people to sext</td>
<td>824 (60.19)</td>
</tr>
<tr>
<td>Males have to worry about messages being viewed by someone other than the person they had originally intended it for, more than females do</td>
<td>413 (30.17)</td>
</tr>
<tr>
<td>It’s no big deal</td>
<td>359 (26.22)</td>
</tr>
</tbody>
</table>

*a* Items not asked in 2014.

*b* Arranged from most to least commonly endorsed item.
Table 5. Adjusted odds ratios of the association of demographics, health and well-being items, and internet use with sexting activity (2014; N=597).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sexting activity versus all others</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Two-way</td>
<td>Sender&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Receiver&lt;sup&gt;b&lt;/sup&gt;</td>
<td>No sexting</td>
<td></td>
</tr>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender (male vs female)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)&lt;sup&gt;f&lt;/sup&gt;</td>
<td>0.63&lt;sup&gt;d&lt;/sup&gt;</td>
<td>0.58&lt;sup&gt;d&lt;/sup&gt;</td>
<td>0.59&lt;sup&gt;d&lt;/sup&gt;</td>
<td>1.73&lt;sup&gt;d&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>95% CI&lt;sup&gt;e&lt;/sup&gt;</td>
<td>0.41-0.96</td>
<td>0.38-0.89</td>
<td>0.37-0.95</td>
<td>1.07-2.80</td>
<td></td>
</tr>
<tr>
<td>Age (16-18 years vs 19-21 years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>1.13</td>
<td>1.11</td>
<td>0.83</td>
<td>1.22</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>0.71-1.80</td>
<td>0.70-1.76</td>
<td>0.51-1.37</td>
<td>0.73-2.04</td>
<td></td>
</tr>
<tr>
<td>Age (16-18 years vs 22-25 years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>1.34</td>
<td>1.23</td>
<td>0.72</td>
<td>1.56</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>0.78-2.30</td>
<td>0.72-2.10</td>
<td>0.41-1.27</td>
<td>0.87-2.79</td>
<td></td>
</tr>
<tr>
<td>English only language spoken (no vs yes)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>1.66&lt;sup&gt;d&lt;/sup&gt;</td>
<td>1.71&lt;sup&gt;d&lt;/sup&gt;</td>
<td>1.53</td>
<td>0.62</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>1.01-2.73</td>
<td>1.04-2.80</td>
<td>0.93-2.55</td>
<td>0.37-1.03</td>
<td></td>
</tr>
<tr>
<td>Indigenous (no vs yes)</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>AOR Exp (B)</td>
<td>0.74</td>
<td>0.93</td>
<td>0.93</td>
<td>0.7</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>0.23-2.37</td>
<td>0.30-2.94</td>
<td>0.23-3.80</td>
<td>0.14-3.65</td>
<td></td>
</tr>
<tr>
<td>Location (major city vs regional, rural, or remote)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>1.01</td>
<td>1</td>
<td>0.97</td>
<td>1.05</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>0.66-1.56</td>
<td>0.65-1.54</td>
<td>0.59-1.59</td>
<td>0.63-1.74</td>
<td></td>
</tr>
<tr>
<td>Currently in education (no vs yes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>0.72</td>
<td>0.8</td>
<td>0.66</td>
<td>1.32</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>0.36-1.42</td>
<td>0.41-1.59</td>
<td>0.29-1.50</td>
<td>0.58-3.02</td>
<td></td>
</tr>
<tr>
<td>Currently in employment (no vs yes)</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>1.36</td>
<td>1.57</td>
<td>1.05</td>
<td>0.76</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>0.68-2.74</td>
<td>0.78-3.16</td>
<td>0.45-2.45</td>
<td>0.32-1.81</td>
<td></td>
</tr>
<tr>
<td>Live with at least one parent or guardian (no vs yes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>0.88</td>
<td>0.79</td>
<td>0.53&lt;sup&gt;d&lt;/sup&gt;</td>
<td>2.36&lt;sup&gt;f&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>0.54-1.44</td>
<td>0.48-1.28</td>
<td>0.29-0.93</td>
<td>1.28-4.36</td>
<td></td>
</tr>
<tr>
<td>Currently in a relationship (no vs yes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>2.16&lt;sup&gt;g&lt;/sup&gt;</td>
<td>2.11&lt;sup&gt;g&lt;/sup&gt;</td>
<td>1.14</td>
<td>0.9</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>1.47-3.19</td>
<td>1.43-3.09</td>
<td>0.73-1.76</td>
<td>0.57-1.41</td>
<td></td>
</tr>
<tr>
<td><strong>Health and well-being</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological distress (K10&lt;sup&gt;h&lt;/sup&gt;: low/moderate vs high/very high)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>0.68</td>
<td>0.67</td>
<td>1.36</td>
<td>0.72</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>0.39-1.17</td>
<td>0.39-1.15</td>
<td>0.74-2.49</td>
<td>0.39-1.35</td>
<td></td>
</tr>
<tr>
<td>Suicidal ideation and or acts (PSFS&lt;sup&gt;i&lt;/sup&gt;)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>1.86&lt;sup&gt;d&lt;/sup&gt;</td>
<td>2.21&lt;sup&gt;d&lt;/sup&gt;</td>
<td>1.1</td>
<td>0.63</td>
<td></td>
</tr>
<tr>
<td>95% CI</td>
<td>1.00-3.46</td>
<td>1.19-4.10</td>
<td>0.53-2.33</td>
<td>0.28-1.41</td>
<td></td>
</tr>
</tbody>
</table>

Mental health diagnosis (no vs yes)
<table>
<thead>
<tr>
<th>Variable</th>
<th>Sexting activity versus all others</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Two-way</td>
</tr>
<tr>
<td>AOR Exp (B)</td>
<td>0.92</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.57-1.51</td>
</tr>
<tr>
<td>Alcohol or other substance misuse diagnosis (no vs yes)</td>
<td>AOR Exp (B)</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.38-36.96</td>
</tr>
<tr>
<td>Personal concern: Alcohol (no vs yes)</td>
<td>AOR Exp (B)</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.58-1.87</td>
</tr>
<tr>
<td>Personal concern: Body Image (no vs yes)</td>
<td>AOR Exp (B)</td>
</tr>
<tr>
<td>95% CI</td>
<td>1.33-3.19</td>
</tr>
<tr>
<td>Personal concern: Bullying (no vs yes)</td>
<td>AOR Exp (B)</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.80-2.34</td>
</tr>
<tr>
<td>Personal concern: Stress (no vs yes)</td>
<td>AOR Exp (B)</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.71-1.73</td>
</tr>
<tr>
<td>Personal concern: Depression (no vs yes)</td>
<td>AOR Exp (B)</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.35-1.12</td>
</tr>
<tr>
<td>Personal concern: Drugs (no vs yes)</td>
<td>AOR Exp (B)</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.91-3.75</td>
</tr>
<tr>
<td>Personal concern: Self-harm (no vs yes)</td>
<td>AOR Exp (B)</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.31-1.25</td>
</tr>
<tr>
<td>Resilience (BRCS&lt;sup&gt;j&lt;/sup&gt;)</td>
<td>AOR Exp (B)</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.96-1.12</td>
</tr>
<tr>
<td>Social support (SSCS&lt;sup&gt;k&lt;/sup&gt;)</td>
<td>AOR Exp (B)</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.88-1.04</td>
</tr>
</tbody>
</table>

Internet use and Web-based communication risks

| Has been cyberbullied in the past 12 months (no vs yes)                  | AOR Exp (B) | 1.11  | 1.07            | 4.61<sup>f</sup> | 0.22<sup>f</sup> |
| 95% CI                                                                  | 0.61-2.02 | 0.59-2.94 | 1.85-11.50       | 0.09-0.56    |

| Cyberbullied others in the past 12 months (no vs yes)                    | AOR Exp (B) | 5.28<sup>g</sup> | 4.79<sup>g</sup> | 1.4             | 0.87       |
| 95% CI                                                                  | 2.20-12.65 | 2.00-11.44       | 0.41-4.83         | 0.25-3.02    |

Average time spent on internet
Two-way sexting and sending sexts yielded similar results. Specifically, being male (two-way: \( P=0.01 \); sender: \( P=0.01 \)), speaking any language other than English (two-way: \( P=0.046 \); sender: \( P=0.03 \)), being in a relationship (two-way: \( P<0.001 \); sender: \( P<0.001 \)), experiencing suicidal thoughts and behaviors (two-way: \( P=0.048 \); sender: \( P=0.012 \)), reporting body image concerns (two-way: \( P=0.001 \); sender: \( P=0.002 \)), cyberbullying others (two-way: \( P<0.001 \); sender: \( P<0.001 \)), and late-night internet use (two-way: \( P=0.003 \); sender: \( P=0.004 \)) were associated with significantly greater AORs of both two-way sexting and sending sexts. Receiving sexts was significantly associated with being male (\( P=0.03 \)), being cyberbullied (\( P=0.001 \)), late-night internet use (\( P<0.001 \)), and lower rates of living with parents or guardians (\( P=0.03 \)).

Not sexting was significantly associated with being female (\( P=0.03 \)) and living with parents or guardians (\( P=0.006 \)) and lower rates of drugs being a personal concern (\( P=0.03 \)), being cyberbullied (\( P=0.001 \)), and late-night internet use (\( P<0.001 \)).

**Sexting and Information and Communication Technology Safety Skills**

Sexting and its relationship with ICT safety items were measured with bivariate correlations. As presented in Table 6, all sexting activities (two-way, sending and receiving) had a significantly positive relationship with respondents “removing content they had posted online” (\( P<0.001 \)) and “sharing particular kinds of information about themselves so that people won’t ask them about their real feelings or desires” (\( P<0.001 \)). All sexting activities (two-way \( P<0.001 \), sending \( P<0.001 \), and receiving \( P=0.002 \)) had a negative relationship with endorsing that people should not give out a personal address or phone number. Sending sexts (\( P=0.002 \)) and two-way sexting (\( P=0.002 \)) were negatively correlated with endorsing that people should keep their computer in a public room and being careful with what one posts online.

Being a receiver of sexts demonstrated a strong positive correlation with reporting a person or incident to a site master (\( P<0.001 \)) and ignoring threatening or offensive behavior toward both themselves (\( P<0.001 \)) and others (\( P=0.003 \)). Being a nonsextor was significantly negatively correlated with not posting because of future concerns (\( P=0.02 \), removing content (\( P<0.001 \)), limiting information shared (\( P=0.009 \)), reporting others (\( P<0.001 \)), and ignoring threatening or offensive behavior toward themselves (\( P<0.001 \)) or others (\( P=0.007 \)). However, nonsexeters were more likely to endorse not using a real name (\( P=0.04 \)), not giving out an address or phone number (\( P<0.001 \)), and being careful with what one should post online (\( P=0.009 \)).
Table 6. Bivariate correlations between sexting and information and communication technology safety items.

<table>
<thead>
<tr>
<th>Information and communication technology safety items</th>
<th>Sexting activities, Pearson r</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Two-way</td>
</tr>
<tr>
<td>Used the profile settings on your online profiles to protect your privacy and security (N=670)</td>
<td>.001</td>
</tr>
<tr>
<td>Limited what certain friends or community members can or cannot see (N=671)</td>
<td>.046</td>
</tr>
<tr>
<td>Decided not to post something online because you were concerned it might reflect badly on you in the future (N=669)</td>
<td>.066</td>
</tr>
<tr>
<td>Tried to remove content you posted online (N=668)</td>
<td>.150&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>Taken steps to try to limit the amount of information available about you on the Internet (N=673)</td>
<td>.003</td>
</tr>
<tr>
<td>If you’ve seen someone being cruel or mean online, looked for or asked someone for advice about what to do (N=667)</td>
<td>.025</td>
</tr>
<tr>
<td>Reported a person or incident to a site master (N=672)</td>
<td>.064</td>
</tr>
<tr>
<td>Reported a person or incident to an authority, eg, a teacher, police (N=674)</td>
<td>-.021</td>
</tr>
<tr>
<td>Ignored threatening or offensive behavior toward you (N=668)</td>
<td>.083&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td>Ignored threatening or offensive behavior toward someone else (N=663)</td>
<td>.091&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td>Used settings to manage what you share across apps and platforms (N=664)</td>
<td>-.019</td>
</tr>
<tr>
<td>Shared particular kinds of information about yourself so that people won’t ask you about your real feelings or desires (N=660)</td>
<td>.14&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Internet rules that some people follow<sup>g</sup>

<table>
<thead>
<tr>
<th></th>
<th>Two-way</th>
<th>Sending</th>
<th>Receiving</th>
<th>Nonsexter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your computer in a public room (N=1355)</td>
<td>-.080&lt;sup&gt;f&lt;/sup&gt;</td>
<td>-.085&lt;sup&gt;f&lt;/sup&gt;</td>
<td>-.032</td>
<td>.039</td>
</tr>
<tr>
<td>Remember people may not be who they say they are (N=1355)</td>
<td>.031</td>
<td>.035</td>
<td>.039</td>
<td>-.044</td>
</tr>
<tr>
<td>Don’t use your real name online (N=1355)</td>
<td>-.056&lt;sup&gt;d&lt;/sup&gt;</td>
<td>-.057&lt;sup&gt;d&lt;/sup&gt;</td>
<td>-.053</td>
<td>.055&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td>Don’t give out your address or phone number (N=1355)</td>
<td>-.112&lt;sup&gt;e&lt;/sup&gt;</td>
<td>-.115&lt;sup&gt;e&lt;/sup&gt;</td>
<td>-.08&lt;sup&gt;f&lt;/sup&gt;</td>
<td>.089&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>Be careful with what you post online (N=1355)</td>
<td>-.083&lt;sup&gt;f&lt;/sup&gt;</td>
<td>-.086&lt;sup&gt;f&lt;/sup&gt;</td>
<td>-.066&lt;sup&gt;d&lt;/sup&gt;</td>
<td>.071&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>Know how to block people online (N=1355)</td>
<td>-.011</td>
<td>-.016</td>
<td>.042</td>
<td>-.038</td>
</tr>
<tr>
<td>None (N=1355)</td>
<td>.019</td>
<td>.014</td>
<td>.036</td>
<td>-.032</td>
</tr>
</tbody>
</table>

<sup>a</sup>Includes all respondents who reported sending sexts in any form.
<sup>b</sup>Includes all respondents who reported receiving sexts in any form.
<sup>c</sup>2014 data.
<sup>d</sup>Correlation is significant at the .05 level (2 tailed).
<sup>e</sup>Correlation <.001 (2 tailed).
<sup>f</sup>Correlation is significant at the .01 level (2-tailed).
<sup>g</sup>2012 data.

Discussion

**Research Summary**

This is the first Australian study to examine sexting behaviors using 2 representative random samples of young people. The research presents changes in sexting prevalence, beliefs about sexting, predictors of sexting, and the application of ICT safety skills by young people who engage in different types of sexting activities. Importantly, the results are examined using 4 sexting categories to include nonsexters, receivers of sexts, senders of sexts, and two-way sexters, which is recommended as best practice when conceptualizing sexting [17].

**Sexting Prevalence**

The research found that from 2012 to 2014, not engaging in any form of sexting reduced significantly from one-third to a quarter of respondents. Meaning that three-quarters of young Australians had recently engaged in, or been exposed to, some form of sexting activity by 2014. This prevalence is high when compared with other Australian research using nonrepresentative or convenience samples [6,7,11,12].
By 2014, there was a significant increase in two-way sexting—approximately 2 in 5 young people reporting that they had sent and received sexts. In the Australian sexting literature, this is the only known research to report on the prevalence of young people engaging in two-way sexting, so no direct comparisons can be made. When considering why so many young people are two-way sexting, research has reported that most young people share sexts within a dating relationship [17,34]. Therefore, it is possible that this finding reflects the reciprocal nature of sexting between sexual or presexual partners. Indeed, sexting today is increasingly viewed as a part of normal developmental behavior between young people [14,35].

Young people reporting only sending sexts remained minimal (<3%) between 2012 and 2014, whereas those only receiving sexts significantly rose—with almost one-third of young people experiencing this by 2014. Although young people were not directly asked the reasons for only receiving sexts, it is possible that this rise reflects that more young people in 2014 were not reciprocating sexting despite being sent sexts intended for them. Another more widely reported explanation in the literature is that young people may have received photos that were originally intended for someone else (ie, the sext had been forwarded to them) [17].

**Sociodemographic Predictors of Sexting**

Previous research has predominately reported that young people in committed relationships are more likely to sext [34,36-38], whereas associations between gender and sexting have yielded mixed findings [16]. Some research examining interactions between both argue that relationship status, compared with gender, is significantly better at explaining interactions with sexting [34,39]. In this research, we examined 4 types of sexting activities and found that after adjusting for all variables, both gender and relationship status were associated with sexting. Specifically, two-way sexting, sending sexts, and receiving sexts were significantly associated with being male, whereas not sexting was associated with being female. In addition, two-way sexting and sending sexts were associated with relationship status. An explanatory reason for our findings can be drawn from previous sexting literature, which has reported that sexting can be socially riskier for certain individuals, such as females and those who are single [36]. These groups report stronger negative expectations about sending and receiving sexts. Furthermore, the abovementioned secondhand sexting research has suggested that forwarded sexts can result in bullying or reputational damage of the individual who sent the original sext, particularly for young women [24,40-42], and young men are more likely to receive secondhand sexts [17]. This idea is further supported in our research findings that 78% of respondents believed that “females have to worry about messages being viewed by someone other than the person they had originally intended it for, more than males do,” whereas only 30% of them endorsed the opposite viewpoint.

Individuals who spoke a second language had elevated odds of sending sexts and two-way sexting. Other research reports that being from a racial and ethnic minority is associated with sexting [16,43-45], although this may vary by the individual’s ethnic background [46]. An additional finding from this study concerning the family composition was that young people who lived at home with their parents were less likely to receive sexts and more likely to be nonsexters, as compared with those who lived out of home. To our knowledge, this variable has not been previously researched [1]. However, the finding could be related to parental involvement—for example, parental restriction of mobile use has been previously found to be associated with lower sexting among young people [47]. Following this rationale, it is likely that those who live at home are more exposed to parental guidance and restrictions on their technology use and thus have less opportunity to sext.

**Health and Well-Being Predictors of Sexting**

In the literature, although the research is scant, sexting has been associated with a greater likelihood of contemplated or attempted suicide [16] and suicidal ideation [48]. In this study, after adjusting for multiple sociodemographic, health and well-being, and ICT risk behaviors, two-way sexting and sending sexts were significantly associated with reporting suicidal thoughts and behaviors in the past 12 months. This research is neither able to demonstrate a causal relationship among variables nor can it determine whether sexting is an antecedent or result of suicidal thoughts and behaviors. However, an explanatory rationale for this is that sexting is a risk behavior for young people [49,50]. Previous research, for example, has drawn significant links between sexual risk behaviors, such as unprotected sex, and suicidal ideation and behaviors [51,52]. Another possible explanation is that young people experiencing mental health issues may sext to feel wanted [16]. Conversely, other researchers have suggested that both the lack of control over a sext once it is sent and possible pressure to sext when in relationships may contribute to psychological distress [17]. Indeed, in this study, the vast majority of respondents thought young people sexted as they “feel pressured to by friends or a dating partner” and that “messages usually end up being seen by more than just those to whom they were sent.”

Another well-being factor that the sexting literature has implicated is body image—with young people using sexting as a vehicle for obtaining feedback and reinforcing their body image [53,54]. This process of body image reinforcement has been cited as one of the major motivations for engaging in consensual sexting. However, research including body image concerns as a predictor of sexting is lacking. This research adds to the sexting literature by showing that body image concerns are a significant predictor of both two-way sexting and sending sexts. Some female-focused research has emphasized that sexual objectification of young women in general (ie, not digitally per se) is associated with depression, low self-esteem, eating distress, and negative body image [55,56]. This study suggests that body image may be a concern for both males and females who engage in 2two-way sexting and only sending sexts, as body image remained significant even after adjusting for all other variables including gender. Possible explanatory factors as to why young people with body image concerns have higher rates of sending sexts comes from research by Bianchi et al [54], who link young people with elevated body objectification with greater anxiety around sexuality and sexual intercourse.
They argue that sexting may offer a way for these young people to experience sexuality despite their body-related concerns as it provides greater body image control, allows the sender to disengage emotionally, and be more assertive. Conversely, the same research acknowledges that body image–related motivations for sending sexts could expose a young person to suffer Web-based bullying and cyber victimization [54], which can exacerbate body image concerns.

Information and Communication Technology Risk Predictors of Sexting

Although late-night internet use is a key risk factor for problematic internet use [57], previous research has not to our knowledge examined its association with sexting. In this research, all types of sexting activity (two-way, sending and receiving) were significantly associated with late-night internet use. Scholars argue that the technology capabilities of the smartphone, which enable the selfie combined with late-night use, make it easier than ever for young people “to cross the line from selfie to sext” [58]. Similarly, cyberbullying has also been reported to peak in frequency during the evenings [59].

Previous research has reported that those who engaged in sexting were more likely to experience cyber victimization [21]. This study extends this literature as it demonstrates that even after adjusting for all variables, receiving a sext is associated with being cyberbullied, and two-way sexting and sending sexts is significantly associated with cyberbullying others—whereas being a nonsexter is associated with reduced odds of being cyberbullied. Generally, research suggests that sexting can transform into cyberbullying when the sext is shared by the receiver without the sender’s consent [60]. In this study, it was the respondents who were more likely to be sending sexts (two-way and sending) that were engaging in cyberbullying. It is acknowledged that in this research, the survey did not distinguish between consensual sexting between intimate partners and nonconsensual sexting (such as sending secondhand sexts), which may influence the findings—particularly as relationship status predicted two-way sexting and sending sexts. Nevertheless, whether the sexts themselves form part of how respondents defined their cyberbullying experience is unknown, and further investigation is warranted—particularly given the link with serious concerns, including suicidal thoughts and behaviors.

Sexting and Information and Communication Technology Safety Practices

Young people in this study who are sexting (two-way, sending, and receiving) appear to engage in more post hoc ICT safety behaviors. For example, correlations demonstrated that respondents who sexted were more likely to have tried to remove content they had posted and ignore threatening or offensive behavior toward themselves or others. Young people who sexted (two-way, sending and receiving) were also less likely to endorse preventative ICT safety strategies, including being careful about what they post on the Web and protecting their identity by not providing others on the Web with their real name, address, and phone number. Interestingly, nonsexters were significantly less likely to engage in many of the ICT safety items personally but were more likely to endorse protecting their identity and being careful about what they post on the Web. This may suggest that nonsexters are exposing themselves less to risky behaviors on the Web and are thus less likely to need to personally protect themselves using ICT safety strategies. Whether this is because they have received better ICT safety education is unknown, but it does appear that their beliefs about protecting themselves when on the Web are more in line with ICT safety education practices, compared with those who do engage in sexting.

Implications for Policy and Practice

The research highlights the reality that there is a large proportion of young Australians sexting in some capacity. Although in Australia legal outcomes vary by state and territory and are addressed on a case-by-case basis [61], legal reforms in New South Wales have been implemented to reflect the view that sexting may be a normal part of sexual development and experimentation among many young people. Specifically, as a result of the Royal Commission into Institutional Responses to Child Sexual Abuse in 2018 [8], a legal exception has been introduced for children under 18 years who take, share, or possess nude photographs of themselves and others to minimize the risk of consenting children being convicted of possessing child pornography.

As sexting among young people is now more widespread, countries such as the United Kingdom have highlighted that a harm minimization approach, rather than an abstinence approach, may be the most appropriate path forward [62]. There have been calls in Australia to shift the sexting conversation, from ones focused predominantly on risk and prevention to one that focuses on ethics, respect, and responsibility [63]. The importance of educating young people about what it means to be an ethical user and consumer of technology is underscored [64]. Ensuring that young people’s views are incorporated, and their agency and decision making is respected is important [65], particularly as the voices of young people themselves are often ignored in the development of sexting guidelines and educational responses, despite this being a crucial step in ensuring that such initiatives are appropriate and relevant [66-68].

In line with other research [68], these results emphasize that sexting needs to be positioned within a wider conversation that involves in-depth exploration on topics such as consent, trust, gender, culture, psychological health, body image, and cyberbullying in the context of both technology and social media. Of particular importance relating to this research is sexting’s association with suicidal thoughts and behaviors and body image concerns. Currently, the Australian eSafety Commissioner’s lesson plans for teachers do not directly discuss with students how psychological and emotional well-being interacts with sexting [69]. Instead, there is greater focus placed on the potential social and legal consequences of sexting. In future, the sexting dialogue could be enriched by acknowledging and supporting young people, and those around them, in understanding and examining ways to address these issues. It should be emphasized that this is not solely engaging in risk-focused conversations but a proactive and in-depth dialogue exploring how young people can look after their own and each other’s physical, social, and emotional well-being on the Web.
The associations between sexting and other variables, including living with parents and late-night internet use, found in this research may demonstrate the important role parents and guardians play. However, parental monitoring of Web-based activities and handling conversations relating to sexting requires care and consideration—particularly as reviews of the digital safety literature [70] suggest that monitoring has the potential to force young people into becoming secretive in their online behaviors if not handled appropriately. Indeed, young people who sexted (two-way and sending) were less likely to endorse keeping a computer in a public room. Overall, a balance between safe sexting and independence needs to be found, and a focus should be placed on arming young people with ICT safety skills, particularly for when they no longer live at home. Both education and the cultivation of open, honest lines of communication with young people are seen as a crucial step in promoting ICT safety [70]. A challenge lies in the fact that research has implicated parents’ and teachers’ perceived lack of knowledge and skill relating to digital technologies as a barrier to meaningful conversations about sexting with young people [68]. Young people themselves have emphasized that parents also require greater educational support around sexting [68]. In line with previous research [71], providing support to adults so they can feel more confident in guiding young people through their cyber interactions is recommended. Online programs and apps may perform a key role in reducing the harms associated with sexting by empowering young people and adults to have better conversations around safe sexting and digital safety. These apps and electronic tools can be designed for specific groups of people. For example, apps such as the Australian Multicultural Foundation’s CyberParent [72] provide culturally and linguistically diverse parents with digital safety tools.

**Strengths and Limitations**

There were numerous strengths of the study, which included the surveys comprising large Australia-wide randomly selected stratified samples representative of gender, age groups, and geographical location across 2 time points. The research captured the sociodemographics, mental health, and risk behaviors of young people. Validated measures for psychological distress and suicidal thoughts and behaviors were used, which is often a limitation of sexting research [73]. The sexting surveys captured more in-depth questions relating to the direction (two-way, sending, receiving, and none) and the types of sexts sent (eg, talking about acts of a sexual nature and sending photos or videos showing yourself nude or nearly nude). These factors are especially noteworthy given that previous Australian research has relied on convenience and self-selecting samples and has demonstrated inconsistencies in definitions and the measurement of sexting behaviors [6,7,11,12]. Indeed, recent systematic reviews have concluded that the lack of a uniform definition of sexting is a problem that severely limits generalizability between studies [74]; by separating the direction and type of sexting, our research addressed this common concern.

However, the results demonstrated that three-quarters of young Australians had recently engaged in, or been exposed to, some form of sexting activity—which is high when compared with other Australian research [6,7,11,12]. This high prevalence rate may be a function of these CATI surveys including numerous sexting items, which is a more inclusive approach compared with single-item measures that comprise both sending and receiving sexts into the 1 variable. When compared with other Australian research, which used convenience samples (conducted at similar time points to these CATIs), this higher sexting prevalence rate may be attributed to a social desirability effect to some extent. Our previous research has shown that items that are more sensitive in nature, such as sexting, are more prone to underreporting in the presence of a telephone interviewer compared with online [75]. It is highly probable that the presence of a face-to-face interviewer in previous research [6,12] may further compound this social desirability effect, whereby respondents may minimize endorsement of embarrassing or unpleasant disclosures to maximize social acceptability and respectability as compared with a telephone interview. Hence, the rates presented in this paper may be a more accurate reflection of sexting prevalence.

Limitations in terms of survey length restricted the number of in-depth questions that could be asked; for example, we did not explore consensual versus nonconsensual sexting. Furthermore, in our examination of reasons for sexting and beliefs about sexting, we analyzed all senders and all receivers of sexts rather than senders only and receivers only—which resulted in a substantial overlap between two-way sexters and senders because of the small sender only sample size (2014, n=20). This must be taken into account when interpreting results. When doing so, the results still provide highly useful comparisons between all types of sexting activity (two-way, sender, receiver, and no sexting).

Another research limitation is that we asked about sexting behaviors over the past year; although this is arguably not as problematic as asking respondents to report lifetime sexting, the lengthy period may produce issues with respondent recall. However, as highlighted in previous research [76], shorter periods that gauge current (30-day) sexting can be problematic as it is an insufficient period to assess the full impact of sexting—such as possible mental health consequences.

**Conclusions**

Our research clearly demonstrates that the majority of young Australians sext or are exposed to sexting. Trends over time suggest that the phenomenon of sexting is unlikely to go away. How a young person navigates this brave new world of sexual relationships in this digital landscape is complex, particularly as this research found sexting to be associated with negative health and well-being concerns, including suicidal thoughts and behaviors, body image issues, and cyberbullying. How the community works in partnership with young people to address this in future needs to be a multifaceted approach where sexting is positioned within a wider proactive conversation about gender, culture, psychosocial health, and respecting and caring for each other on the Web.
Acknowledgments
This project was carried out through a partnership between the Young and Well CRC (2011-16) and The University of Sydney’s BMC, with funding provided by the Young and Well CRC. The authors would like to thank the Youth Mental Health and Technology team at the BMC, with special mention to Hannah Yee.

Conflicts of Interest
IBH was an inaugural Commissioner on Australia’s National Mental Health Commission (2012-18). He is the Co-Director, Health and Policy at the BMC, University of Sydney. The BMC operates an early intervention youth service at Camperdown under contract to headspace. Professor Hickie has previously led community-based and pharmaceutical industry–supported (Wyeth, Eli Lily, Servier, Pfizer, and AstraZeneca) projects focused on the identification and better management of anxiety and depression. He was a member of the medical advisory panel for Medibank Private until October 2017, a Board Member of Psychosis Australia Trust, and a member of Veterans Mental Health Clinical Reference group. He is the Chief Scientific Advisor to, and an equity shareholder in, Innowell. Innowell has been formed by The University of Sydney and PwC to deliver the AUS $30 million Australian Government-funded Project Synergy. Project Synergy is a 3-year program for the transformation of mental health services through the use of innovative technologies. Professor JMB is Chair of the National Advisory Council for Open Arms, Veterans and Families Counselling Service. She is a well-being and digital health consultant to Bupa, a member of the Veterans Mental Health Clinical Reference group and a Chief Investigator and author of the Defence and Veterans Transition and Wellbeing Study. She is the Founder of, and an equity shareholder in, Innowell. She is Professor of Social Innovation and Chair of the Centre for Mental Health at Swinburne University and Adjunct Professor of Social Impact and Entrepreneurship at RMIT. None of the other authors declare any conflicts of interest.

Multimedia Appendix 1
Sociodemographic and well-being changes from 2012 to 2014.

[PDF File (Adobe PDF File), 103KB - mental_v6i6e13338_app1.pdf]

Multimedia Appendix 2
Crude adjusted odds ratios and adjusted odds ratios of the association of demographic, health and well-being items, and internet use with sexting activity (2014 data).

[PDF File (Adobe PDF File), 109KB - mental_v6i6e13338_app2.pdf]

References


Abbreviations

AOR: adjusted odds ratio
BMC: Brain and Mind Centre
CATI: computer-assisted telephone interviewing
CRC: Cooperative Research Centre
ICT: information and communication technology
RDD: random digit dialing