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# Exploring How People Affected by Methamphetamine Exchange Social Support Through Online Interactions on Facebook: Content Analysis

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## Abstract

**Background:** Methamphetamine is an illicit and addictive psychostimulant that remains to be a significant cause of economic burden in Australia. Social media is increasingly being used by nongovernment organizations and health services to encourage the growth of social support networks among people with health-related issues. Several studies have investigated the utility of social media in providing social support to groups of people with health-related issues. However, limited research exists that explores how people who have been directly or indirectly affected by methamphetamine use social media for social support.

**Objective:** This study aimed to determine the types of social support being sought and provided by people affected by methamphetamine when interacting with others on a Facebook page.

**Methods:** A total of 14,777 posts were collected from a Facebook page and transferred into an Excel document for content analysis. The posts were manually coded into categories of social support using an adapted version of Cutrona and Suhr's Social Support Behavior Code. Posts could be coded into more than one category. Saturation was reached at 2000 posts, which were used to draw inferences.

**Results:** Emotional support was the most offered support type, with 42.05% (841/2000) of posts providing this form of support. This is followed by esteem support, which was provided in 40.40% (808/2000) of posts. Overall, 24.20% (484/2000) of posts offered informational support. Network support and tangible support were the least offered support types, with 2.25% (45/2000) and 1.70% (34/2000) of posts offering these types of support, respectively.

**Conclusions:** This study suggests that online social support groups can be effective in challenging stigma by encouraging people affected by methamphetamine to connect with each other and talk about their struggles. This in turn represents an important step toward successful rehabilitation.

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**KEYWORDS**

methamphetamine; social media; social support

## Introduction

### Methamphetamine Use in Australia

Methamphetamine is an illicit psychostimulant that is available in 3 distinct forms: powder (speed), base methamphetamine (base), and crystalline methamphetamine (ice or crystal meth), with crystal methamphetamine being the most potent form [1]. Findings of the 2016 National Drug Strategy Household Survey showed that 1.4% of Australians aged 14 years or older reported recent use of methamphetamines [2]. Despite the overall decline in methamphetamine use between 2013 and 2016, the use of crystal methamphetamine in Australia increased from 0.4% to 0.8% between 2010 and 2016 [2]. Furthermore, the findings of

the Illicit Drug Reporting System's 2017 National Report show that crystal methamphetamine remains the most commonly used form of methamphetamine among illicit drug users in Australia [3]. The report also indicates that most participants consider all forms of methamphetamine to be easy to obtain [3]. Taken together, these findings indicate that methamphetamine use remains a prevalent issue in Australia. Research has shown that methamphetamine use is associated with higher prevalence of anxiety, major depression, and suicide than the general population [4,5]. Moreover, unlike opioids, such as heroin, methamphetamine can induce psychosis, which is characterized by auditory or visual hallucinations and persecutory delusions [5,6]. The symptoms of methamphetamine psychosis are typically brief, but severe cases can lead to hospitalization [5,7]. Chronic methamphetamine-induced psychosis is difficult to distinguish from the symptoms of schizophrenia on hospital presentation, and it can take days for clinicians to distinguish a case of methamphetamine-induced psychosis from schizophrenia [4,8]. As such, methamphetamine-related hospital presentations require prolonged admissions and substantial resources, placing a significant economic burden on the Australian health care system [8]. In addition, psychosis is sometimes accompanied by aggressive behavior [9]. Psychotic symptoms, particularly persecutory delusions, can make nonthreatening situations appear threatening to a methamphetamine user and can result in violent resolutions [9]. The difficulty in dealing with methamphetamine-related violence places a resource burden upon emergency frontline services [10]. Methamphetamine-related violence is also prevalent in the form of criminal activity [10] and domestic violence [9,11]. Thus, methamphetamine has negative impacts not only on users but also on family and the people around them.

## Social Support and Mental Health

Social support has been defined as the information that an individual receives from family, friends, peers, or strangers, which makes them feel loved, valued, or part of a wider network [12]. It has also been defined as the network of family, friends, neighbors and community members, which is available in times of need to provide psychological, physical, and financial help [13]. Previous research has examined social networks in terms of 2 main dimensions: a structural dimension, which considers network size and frequency of social interactions, and a functional dimension, which considers the emotional and practical components of a social interaction [13]. Although the quality and quantity of social networks are both important, most studies have found that the quality of relationships is a better predictor of mental health [13]. The literature indicates that social support is essential to maintaining psychological well-being. Increased social support appears to function as a protective buffer against stress from adverse life events, thereby enhancing resilience to stress [14]. Social support has also been found to be a key factor in decreased risk of depression [15,16]. Previous research found that a lack of adequate social support and smaller social networks were linked to higher levels of stress and risk of depressive symptoms [14,17].

Furthermore, 2 main explanations have been put forward to explain how social support enhances resilience to stress. The first explanation is that social support fosters healthier coping strategies and provides the individual with knowledge, improving the individual's self-efficacy and enabling the individual to deal with stress more effectively [14,15]. The second explanation is that social support helps individuals overcome feelings of loneliness, which enables them to experience hope [14,18]. Although the exact neurobiological mechanisms of social support are not completely understood [13], it is clear from the literature that social support can positively impact mental health.

## Social Media and Online Support Groups

Social media can be defined as a group of internet-based apps that allow the creation and exchange of user-generated content [19]. The use of social media has become commonplace in Australia, with 79% of the population maintaining a social media profile [20]. Facebook is the most popular social media platform in Australia, with 95% of social media users maintaining a profile [20]. Although many people use social media to connect with family and friends, social media has also been used to form communities of specific interest [21]. Online support groups are one such example of this. With the rise of social media, an increasing number of people have turned to online support groups as an alternative to face-to-face support.

Several studies have shown that online support groups possess many advantages over face-to-face support, which explain its widespread use. Social media is accessible to anyone with an internet connection. This makes online support groups especially useful for people with limited mobility because of disability [22]. Online support groups also take place without the constraints of time, distance, and social status [22,23]. This allows for individuals to reply to messages at their own pace, which is not only convenient but also empowering for people who find face-to-face communication difficult.

Furthermore, online support groups provide individuals with safe, nonjudgmental places where they may express negative feelings that may be viewed as objectionable [16]. The option of anonymity can also facilitate greater self-disclosure because of less fear of stigmatization [15,23]. Finally, social media enables individuals to communicate with a varied range of people offering diverse perspectives and information [23]. In some cases, online support groups may be a more preferable option than family, as they are able to receive support while maintaining a comfortable emotional distance [21].

## Category Systems of Social Support

A number of studies have developed category systems to investigate the types of social support sought by individuals by using online support groups. Cobb [12] constructed a simple system that categorized social support into 3 main categories: emotional support (information signifying that one is cared for and loved), esteem support (information signifying that one is valued), and network support (information that gives one a sense of belonging). House [24] created a matrix that defined 4 broad categories of support: emotional support, appraisal support (affirmations or feedback), informational support (advice or suggestions), and instrumental support (financial or physical aid). Kalichman et al [25] constructed a similar system that categorized social support into 3 categories: emotional,

informational, and instrumental support. Cutrona and Suhr's [26] Social Support Behavior Code (SSBC) is a widely used category system that was developed to measure the frequency of supportive behaviors. The SSBC comprises 23 supportive behaviors that are encompassed by 5 broad categories of support: informational, emotional, esteem, network, and tangible support. The items were developed using previous studies of social support and were validated in a study of dyadic interaction among college students [26]. The SSBC has been adapted to studies focusing on people with disabilities [22], Huntington's disease [23], HIV/AIDS [15], cancer [27], autism spectrum disorder [28], depression [29], and bariatric surgery patients [30].

### Methamphetamine and Social Media

Numerous studies have investigated how people use online support groups for social support. The majority of the literature indicates that informational and emotional support tend to be the most frequently offered support types, with tangible support tending to be the least frequently offered type of support [15,23,28,30]. With regard to drugs, at least one study has examined how individuals use social media to exchange information about novel psychoactive substances [31]. However, there appears to be little research focusing on how people affected by methamphetamine use online support groups for social support. Social media holds much potential for use in health care, providing people affected by methamphetamine with access to social support. The first advantage of social media is its ability to reach a specific audience regardless of location. This is especially relevant in the case of methamphetamine addiction, which is notably more prominent among Australians living in rural and remote areas. Findings of the 2016 National Drug Strategy Household Survey indicated that people in remote and very remote areas were 2.5 times as likely to use methamphetamines than those living in major cities [2]. Griffiths and Christensen's [32] systematic review of 2 Australian Web-based mental health programs (MoodGYM and BluePages) indicated that Web-based mental health interventions are effective in reducing depressive symptoms. A study that was included in the review indicated that 20.5% of spontaneous MoodGYM users are from rural or remote areas, suggesting that Web-based interventions are relevant to people living in rural and remote areas [32]. Therefore, social media may prove useful for people living in rural and remote area, who are seeking social support for methamphetamine addiction. The second advantage of social media is its potential to challenge stigmatization, another issue that is relevant to methamphetamine addiction. Chalmers et al's [33] study found that increases in stigmatizing media attention toward crystal methamphetamine in Australia were associated with underreporting of lifetime methamphetamine use in population surveys. Moreover, individuals affected by methamphetamine addiction in Australian Aboriginal communities often experience intense shame, which has prevented some individuals and their families from seeking help [34]. In turn, social media could provide people with access to social support without fear of stigmatization. Previous research shows that people with diseases that are considered stigmatizing, such as HIV and prostate cancer, were more likely to use online support groups for social support than people with diseases that were not stigmatizing [35]. It is reasonable to believe that people affected by methamphetamine may be willing to engage with online support groups.

Finally, research shows that social media can play an important role in changing health behavior. In Maher et al's [36] systematic review of studies focusing on health behavior change interventions using Web-based social networks, 9 of the 10 included studies were found to have reported significant improvements in some aspect of health behavior change. This may be because of the interactive nature of social media. As social media users are required to actively generate content, social media is able to achieve higher rates of user engagement than traditional websites [36]. Taken together, these points demonstrate the potential of social media in providing people affected by methamphetamine with access to social support, which represents the first step toward rehabilitation.

### This Study

The objective of this study was to explore how people who have been directly or indirectly affected by methamphetamine use an online support group to provide social support to each other. A content-analysis approach will be used to determine the types and amounts of support exchanged by people affected by methamphetamine. On the basis of previous findings in the literature, it is hypothesized that informational support and emotional support will be the 2 most frequently offered support types and that tangible support will be the least frequently offered support type. Exploring the types of support being exchanged on the Web by people affected by methamphetamine may reveal unique insights that could be useful in developing social media resources tailored to individuals, families, and communities affected by methamphetamine.

## Methods

### Participants

The participants of this study were members who posted messages on the Facebook page *Never Give up Giving up Ice, Drugs*. This page was chosen, as it was popular at the time it was active and contained a large amount of information and experiences, which made it suitable for content analysis. The page was created by an Aboriginal Australian individual who overcame methamphetamine addiction, and it was intended to be used as a space on the Web where individuals and family members affected by methamphetamine could connect with each other. Participants were required to have a Facebook profile to post on the page and were able to request for the page administrator to post their messages anonymously, if desired. The posts themselves were available to the public and able to be read by those without a Facebook profile. Interactions on the Web took place in the form of opening posts and responding posts. The page was active from December 2014 to February 2017, and it generated a total of 14,777 posts. 5719 unique usernames were identified, which included individuals' names, organization names, and posts labeled "Never Give up Giving up," which were made by the administrator of the page, either for himself or on behalf of others. Owing to the Web-based nature of the data, sociodemographic characteristics of the

participants were unable to be obtained. All posts were collected from the page and placed into an Excel document for content analysis.

### Ethical Considerations

Research involving social media can be an area of ethical concern because of issues of privacy, consent, and the potential for data to be misused. Researchers who have commented on these issues have acknowledged Facebook groups that require specific registration or passwords as private domains that require individual consent from participants [37]. Conversely, data from Facebook groups that do not require specific registration are considered to be in the public domain. For this study, data were collected from a Facebook page that did not require specific registration or a password. The data were available to the public, and ethics approval was therefore not required. All data have been deidentified to ensure anonymity of participants and prevent misuse of data.

### Data Analysis

Content analysis was used to determine the types and amounts of support being exchanged within the posts. Cutrona and Suhr's [26] SSBC was adapted for use in this study. This model was chosen, as it has been used in several previous studies examining social support exchanges on social media. The 5 categories of social support and their definitions in this study were the following: informational support (ie, posts that provided advice or knowledge), emotional support (ie, encouragement or empathy), esteem support (ie, compliments or validation), network support (ie, emphasizing companionship), and tangible support (ie, offering physical or financial aid). Each category also contained a number of subcategories. A comprehensive table of all 23 subcategories and their definitions are provided in Multimedia Appendix 1. Posts were manually coded according to these categories, and these could be coded into more than one category of support. Saturation was reached at 2000 posts, at which no new information appeared to be emerging from the data.

## Results

### Overview

A total of 2000 posts were coded. Table 1 shows the frequency counts for each support category. As can be seen, emotional support was the most offered support type, with 42.05% (841/2000) of posts providing this form of support. Esteem support was also commonly offered, appearing in 40.40% (808/2000) of posts. Overall, 24.20% (484/2000) of posts offered informational support. Network support and tangible support were the least offered support types, with 2.25% (45/2000) and 1.70% (34/2000) of posts offering these types of support, respectively. In addition, 27.15% (543/2000) of posts contained information that did not fit into any of these 5 categories, and these were coded as *other*.

**Table 1.** Frequencies and percentages of posts for each support category (N=2000).

| Support category and subcategory | Posts, n (%) |
|---|---|
| **Informational support** | 484 (24.20) |
| Advice | 279 (13.95) |
| Referral | 29 (1.45) |
| Situation appraisal | 43 (2.15) |
| Teaching | 37 (1.85) |
| Other (informational) | 96 (4.80) |
| **Emotional support** | 841 (42.05) |
| Relationship | 30 (1.50) |
| Physical affection | 109 (5.45) |
| Confidentiality | 0 (0.00) |
| Sympathy | 23 (1.15) |
| Empathy | 64 (3.20) |
| Encouragement | 360 (18.00) |
| Prayer | 18 (0.90) |
| Other (emotional) | 237 (11.85) |
| **Esteem support** | 808 (40.40) |
| Compliment | 371 (18.55) |
| Validation | 429 (21.45) |
| Relief of blame | 8 (0.40) |
| Other (esteem) | 0 (0.00) |
| **Network support** | 45 (2.25) |
| Access | 7 (0.35) |
| Presence | 23 (1.15) |
| Companionship | 15 (0.75) |
| Other (network) | 0 (0.00) |
| **Tangible support** | 34 (1.70) |
| Loan | 0 (0.00) |
| Perform direct task | 2 (0.10) |
| Perform indirect task | 5 (0.25) |
| Active participation | 26 (1.30) |
| Express willingness | 1 (0.05) |
| Other (tangible) | 0 (0.00) |
| **Other** | 543 (27.15) |
| Anti-ice sentiment | 40 (2.00) |
| Congratulations | 108 (5.40) |
| Inaccessible | 24 (1.20) |
| Shared post | 51 (2.55) |
| Situation details | 44 (2.20) |
| Thanking | 162 (8.10) |
| Unrelated | 114 (5.70) |

### Informational Support

Informational support was separated into 5 subcategories: (1) advice, (2) referrals, (3) situation appraisals, (4) teaching, and (5) other. Advice included posts that provided guidance in dealing with challenges. A common situation that participants sought advice for in opening posts was dealing with a partner addicted to methamphetamine, which involved issues, such as domestic violence and the uncertainty of knowing whether their partners were clean (not using methamphetamine). Some examples of advice that participants provided in responding posts included the following:

> *Keep yourself and yr kids safe too...get legal advice and hopefully everything falls into place…good luck.*
>
> *Write down all the reasons to stay with him, and all the reasons to leave him. Then make a decision.*
>
> *Contact your local family violence service. You, and your children, are victims. If not for yourself, do it for them.*
>
> *Buy a test on the day you think he might be on it and ask him to do it he wouldn't refuse if he has nothing to hide best of luck.*

Advice was also provided for individuals considering rehabilitation. For example, a participant expressed the importance of immediate rehabilitation in the reply below:

> *Rehab now. It only gets worse. Relapsing is easy, getting clean is hard. The longer the wait, the harder the work. It's going to be hard no matter what. Anything worth having is worth the work.*

Advice was also sought in opening posts for dealing with relapses. Below is a responding post to an individual who felt demotivated after experiencing a relapse of methamphetamine use:

> *You were and are doing so well. Relapses happen and the worst thing you can do is wallow in your mistake. I often feel the way you do and sometimes only not having the means is the only thing to stop uou so delete numbers and contacts related to it! Block n delete anyone that can/will get it for you if you ask n beg! Get tid off all paraphanalia, anything that remins you or enbles you and keep going! You can do it! Take this time to rest n self care, you'll need it for tomorrow, it's a new day and you've got work and you want to keep that going :).*

Referrals included posts that directed individuals to a source of expertise. Participants often recommended websites to individuals in their replies:

> *We're running a couple of sessions of our free Methamphetamine Family First Aid program later in October. The program has been developed together with affected family members. See our website for details.*
>
> *Have a look at the Get Off Drugs Naturally page 'Anonymous.' They appear to have excellent results with a remarkably high success rate. Also read some of the success stories from those who've completed the program. Probably your best bet I reckon.*

Participants also recommended professionals and rehabilitation programs to individuals, as seen in the replies below:

> *[name de-identified] & the TIMP team plus Transform Your Life! They're wonderful people & may be near you if you are in Victoria. Best wishes,it's tuff stuff but it's worth it!*
>
> *I highly recommend Teen Challenge. I went through the Program there & have been clean for 4 years. I was a Speed Addict for 17 years. There is a Re hab called Cyrenian House in Wa and that has a Mothers Program where u can live with ur Child while u do Re hab. Praying that your daughter get the help she needs.*

Situation appraisals included posts that reassessed a situation in a manner that aimed to help the recipient view the situation more positively or reveal new information that could be helpful. This was commonly offered to individuals dealing with relapse, as seen in the replies below:

> *It's amazing the love & care that comes from being part of these lovely pages,hey? Relapse-just a learning curve not a life sentence...keep punching mate!!*
>
> *It's a lapse only, remember a lapse is part of recovery. Keep going and remember how far you have come already.*

Teaching included posts that provided factual information. Participants offered this in reply to individuals who wanted to know how to determine whether their partners were clean:

> *You can tell if an addicts clean by just looking at them; there not twitching; restless; moving or anxious; there skin and eyes come back to life and they just look healthier; most addicts are easily red.*
>
> *72 hours for ice rm thats min.*
>
> *Urine tests are more accurate than blood tests because the drugs are excreted through the urine thus more concertrated for testing.*

Other (informational) included posts that were categorized as informational support but did not fit into any of the preexisting subcategories. These posts tended to provide insights on the basis of personal experience. For example, a participant posted in a reply to another individual seeking information about rehabilitation centers:

> *Rehab is not a magic fix, it's a place addicts can go to be supported through a big lifestyle change it all depends on the person if you truely want to be clean you will be, I went to rehab and have been clean almost a year, I've never wanted something so bad, and never been so proud of myself.*

Another participant posted the following reply to an individual seeking help in dealing with a partner who had relapsed:

> *I only quit when I hit rock bottom and had lost contact with everyone close to me. Up until that point I would dismiss having a problem, and only promised to*

*change- with no intentions. He has to want to quit first.*

### Emotional Support

Emotional support was separated into 8 subcategories: (1) relationship, (2) physical affection, (3) confidentiality, (4) sympathy, (5) empathy, (6) encouragement, (7) prayer, and (8) other. Posts in the relationship subcategory included messages that emphasized closeness and love with the recipient and were often posted by participants to family members:

*My beautiful girl it kills me 2 c u so lost like this. U need 2 fight this battle once and for all. We need our beautiful strong daughter back ur gorgous boys need ther mum back. U can fight this devil. U can get ur life back. We will always hold ur heart with us, and the best of u hasnt gone its just a little lost so please fight this devil dont let it win. We no u r trying i no it will take 1 day at a time, wher not going anywhere we will b rite here with you, for you. Luv u my daughter with al my heart & sole. Please come back 2 us xxx.*

*More proud than you will ever know...love you my precious son xxx.*

Physical affection included posts that expressed physical contact verbally. Posts that contained hugs and kisses ("X" and "O") were included and comprised most of the posts in this subcategory. To illustrate, a participant provided support to another individual dealing with a partner addicted to methamphetamine by posting the reply below:

*Good on you for staying clean even though you are in the middle of it! That proves you have strength. now you just need to use that strength to do whats best for you and your baby. Big hugs xxx.*

Confidentiality included posts that promised to keep recipients' problems and situations in confidence. In the data, no examples of confidentiality were found. Sympathy included posts that expressed compassion or sorrow for the recipient. To illustrate, a participant provided sympathy to another participant dealing with domestic violence caused by methamphetamine addiction:

*I so feel for you, makes me so so sad. You really need to stay away from him, let him hit rock bottom, because until then he will continue to hurt, lie, steal & all the rest of the heart ache that comes along from this drug, it will be hard for you, tomorrow is a new day.*

Empathy included posts that expressed understanding or emphasized the similarity of the recipient's situation to one's own experience. The post below is a response that was provided by a participant to an individual seeking support for a partner undergoing rehabilitation while refusing to keep in contact:

*I am in the same hell mate. I was kicked to the curb for much the same. My partner will never take me back sometimes things fail for more than one reason. U need to be a bit selfish mate and make yourself happy.*

Encouragement was the most frequently offered subcategory (360/2000, 18.00%) of emotional support, and this included posts that were intended to instill hope and confidence in the recipient. Encouragement was offered by participants in most situations. For example, a participant encouraged an individual to persevere in looking after the individual's children as a single parent:

*Hang in there mate as long as there dad is there to love them and care for them that's the main thing. Most the time it's around the other way, my kids dad is the same as girlfriend. I hope she wakes up & smells the roses before its to late.*

Prayer messages were occasionally offered by some participants to individuals who were undergoing difficult situations. The following is an example:

*Oh you poor darlin some times your heart rules every thing...keep him at bay honey enough is enough surely you must see the warning signs you sound like a strong loving girl dont change just keep one step ahead, keeping you in my thoughts and praying this man seeks help good luck xxx.*

Other (emotional) included posts that did not fit into any of the preexisting subcategories. These posts mainly included messages that expressed supportive sentiments (ie, "all the best" and "good luck"), but these also included those that expressed concern or used emojis (ie, smileys). The following is an example:

*Omg your amazing...l hope your life is full to the brim with happiness thk you for sharing xx.*

### Esteem Support

Esteem support was separated into 4 subcategories: (1) compliments, (2) validation, (3) relief of blame, and (4) other. Compliments represented the second-most frequently offered subcategory of all support categories (371/2000, 18.55%) and included posts that conveyed a positive assessment of the recipient's efforts or qualities. Compliments were a common response to individuals posting about their triumphs in overcoming methamphetamine addiction:

*Far out the difference you look amazing mate keep it up...I know it hard keep doing what your doing.*

*Good job keep it up u look fantastic now :).*

*Well done you...You have great strength & a winning attitude. So lovely to hear positive news. Thankyou.*

Validation posts were the most frequently offered subcategory of all support categories (429/2000, 21.45%), and these included posts that expressed agreement with the recipient's beliefs, actions, thoughts, emotions, or perspectives. As with compliments, validation was commonly offered as a response to individuals posting about overcoming methamphetamine addiction:

*Good on you mate.*

*Proud of you--looking good--keep it up x.*

*Congratulations, well done, keep up every one will be proud of you.*

The relief of blame subcategory included posts intended to alleviate the recipient's feelings of guilt about a particular situation. In comparison with compliments and validation, relief of blame posts were extremely uncommon and almost exclusively offered to an individual who felt demotivated after experiencing a relapse. For example, a participant posted the following:

> *Don't be to hard on yourself honey. Don't give up. Work tmrw, be strong. It will all be good again yl see. Xxxxxx*

Other (esteem) included posts that did not fit into any of the preexisting subcategories. Posts that could be coded in this subcategory were not found in the data.

### Network Support

Network support was separated into 4 subcategories: (1) access, (2) presence, (3) companionship, and (4) other. Access included posts that intended to provide recipients with means to new contacts and companions who may share similar interests or concerns. For example, a participant posted the following:

> *If you need some support from others in the same position as you msg me :) I run a support group for family members of ice addicts. It's a private group and it's a safe place to get advice :).*

Presence included posts where participants offered their own presence, in the form of listening, for example, to another individual for support. This was occasionally offered by participants in various situations. Several participants offered presence in their replies to an individual who left their partner because of methamphetamine-related violence:

> *Im in QLD, if you feel like chatting pm me, I'm busy with kids but will msg back when I can :).*
>
> *Inbox me if u need a talk love.*
>
> *Good on you for turning your life around!!!:) you should be really proud of yourself. I'm really sorry though, the group I run is strictly to support family members of addicts. Feel free to msg me privately if you need someone to talk too.*

Companionship included posts that emphasized the availability of other people who have similar interests or experiences. This differs from access posts, which were often written in the form of an invitation. Companionship was often offered by participants in their responses to individuals posting about overcoming methamphetamine addiction. The following is an example:

> *We are all here for you guys and gals.....you are absolutely wonderful - get those heads up, smile on your dial and song in your voice x.*

Other (network) included posts that did not fit into any of the preexisting subcategories. Posts that could be coded in this subcategory were not found in the data.

### Tangible Support

Tangible support was support was separated into 6 subcategories: (1) loans, (2) perform direct task, (3) perform indirect task, (4) active participation, (5) express willingness, and (6) other. Loans included messages that offered to lend recipients a material object or money. Examples of loans were not found in the data. Direct and indirect task messages included posts in which participants offered to handle a task that was either directly or indirectly related to the cause of the recipient's stress. Only 2 examples of participants offering direct assistance were found. A participant was a professional offering services free of charge to any of the other members who wanted to overcome methamphetamine addiction. The other participant was a member who offered to help an individual find support for domestic violence, which is shown in the reply below:

> *Where in Victoria are your family? I could find a support service that could help get you out of QLD and back to Victoria, back to support and people that can help. Even get the police to help they are really good when you need support. You've done the right thing I just hope you can find the strength to keep going the way you are!! much love your way xxxooo.*

A total of 5 posts were categorized as indirect task messages. A total of 1 of these posts was a request from a participant to a family member to tag another family member to the page. The other 4 were requests for an individual to present as a guest speaker in a particular area:

> *The Riverland is in need. Are you coming this way.*
>
> *Come to Perth.*
>
> *Logan needs u we got nothing up here in QLD.*
>
> *WA needs you too brother.*

Active participation included posts that contained offers to join an individual in an activity. A majority of the posts in this subcategory were requests for other members to share websites, videos, experiences, and requests for petition signatures:

> *This, is a really hard thing to talk about...Please share and watch this...The feels are real, the Situation is real...ICE ADDICTION...*
>
> *Please keep putting your stories out there people, this drug destroys lives! Thankyou.*
>
> *I would like to submit my PETITION & put my hat in the ring to be a community member on the QLD TASK FORCE...would you PLEASE SIGN & SHARE - TIME IS TICKING - Petition for the Qld Premiere for change on how Meth (ICE) addiction is being managed in our State. The Detox/Rehabs, Mental Health Services and Judicial Systems are failing. Families of Addicts have minimal resources or support in our Qld communities. Internally Grateful <3.*

Express willingness included posts that expressed readiness to help without specifying the exact nature of help that will be given. Only 1 post was found for this subcategory, which was an opening post directed to the page administrator:

> *Hi you are a great man person coming from the darkesnt too the light so proud of you cheers hope I can help you coming too Tasmania in any way.*

Other (tangible) included posts that did not fit into any of the preexisting subcategories. Posts that could be coded in this subcategory were not found in the data.

### Other

Posts that contained information that did not fit into any of the 5 preexisting support categories in Cutrona and Suhr's SSBC were coded as *other*. Most of these categories were not forms of support from an individual to another. Anti-ice sentiment refers to posts that expressed negative views of methamphetamine. These were not directed at any particular individual and expressed opinions that were often shared by other members of the page. Congratulatory posts were posted by participants to individuals who posted about their successes in overcoming methamphetamine addiction and remaining clean. Inaccessible refers to posts that contained links that were no longer accessible. Shared posts refers to posts in which a participant tagged another individual to direct the individual to the page. Situation details refers to posts in which a participant provided information on the participant's situation. Thanking refers to posts where participants expressed their gratitude to another individual. Unrelated refers to posts that were not relevant to methamphetamine or the provision of social support.

## Discussion

### Principal Findings

The findings indicated that emotional and esteem support were the 2 most frequently provided support types, whereas tangible support was found to be the least frequently provided support type. As such, partial support was found for the hypothesis that informational support and emotional support would be the most frequently offered support types, as only emotional support was found to be one of the 2 most frequently offered types. The findings provided support for the hypothesis that tangible support would be the least frequently provided support type.

Informational support was noticeably less prominent in this study compared with previous studies [15,23,30]. This may be because the needs of these participants were more emotional in nature, considering the difficult and personal situations that many participants had to face. Informational support appeared to be particularly sought after by and offered to participants experiencing domestic violence and participants who relapsed into methamphetamine use. Advice may have proved especially useful to these participants in empowering them with the self-efficacy needed to handle their situations. The prominence of the posts that were categorized as informational (other) was also notable. These posts often provided insights by disclosing personal experiences. Similar findings were also noted in Evans et al's [16] content analysis study examining postpartum depression in women. In their study, the participants tended to provide informational support in the form of personal accounts rather than refer to traditional sources of information, such as pamphlets or websites [16]. As suggested by their study, sharing personal stories may be effective, as it establishes commonalities among participants while providing information at the same time. This decreases the sense of isolation experienced [16].

The prominence of emotional support reflected previous findings in the literature [15,23,30]. This may be because of the fact that a majority of posts on the page were constructed as self-disclosure. In Wang et al's [38] study of online social support among people with cancer, it was found that self-disclosure led to the perception of emotional needs, which elicited emotional support-type responses. In contrast, asking questions led to the perception of informational needs, eliciting informational support-type responses [38]. However, it must be noted that the 3 most prevalent subcategories found in this study were encouragement, emotional (other), and physical affection. Encouragement was particularly salient, and this is likely because of the nature of the page, which was set up for people affected by methamphetamine to connect with and support each other in their efforts to overcome addiction. Emotional (other) was largely represented by messages, such as "all the best," and physical affection was similarly expressed through *X* 's and *O* 's. It is more likely that the prominence of emotional support is explained by how ubiquitous these expressions were. Nonetheless, these subcategories were important, as they appeared to play an important role in building close relationships on the Web.

The prominence of esteem support was a finding that appeared to be unique to this study. Esteem support was predominantly offered in the form of validation or compliments, both of which were found to be the most frequently offered subcategories of all 22 types established in Cutrona and Suhr's SSBC. It may be that that esteem support was salient in this study, as people affected by methamphetamine are unable to find this type of support easily in their everyday lives because of the stigma of methamphetamine [34]. As Beck et al [29] suggested in their study of online support groups, the increased need to exchange emotional support could be driven by efforts to challenge stigma. Similarly, the prominence of esteem support in this study could be the result of the participants' efforts to challenge stigma through acknowledging and celebrating each other's achievements and personal victories in overcoming methamphetamine addiction.

In comparison with the 3 support categories discussed above, network support and tangible support represented an extremely small amount of the data. Although the lower prominence of network support was expected, it was surprising to find that network support was significantly less prominent than esteem support. This finding is inconsistent with the literature [15,23,28]. A potential explanation for this is that the participants' needs for network support were already addressed by being active on the page. Coulson et al [23] also noted in their study that network support became less salient over time and suggested that this could have been because of the fact that participants' network support needs were met simply by participating in the online support group. The infrequent provision of tangible support was consistent with the literature, and this may be explained by the unfeasibility of providing such support on the Web, particularly in the case of methamphetamine addiction. As noted by Atwood et al [30], this may also reflect the unsuitability of the tangible support category, as developed by Cutrona and Suhr, to online support groups.

## Implications

The findings of this study demonstrate that online social support groups represent viable opportunities for people affected by methamphetamine to find support and provide insight into the types of support exchanged on the Web by these individuals. Esteem and emotional support appear to be the most relevant and valued types of support, and informational support was also an important function of the page. This knowledge could help inform Australian health care providers in developing Web-based resources tailored toward individuals, families, or communities struggling with methamphetamine addiction. A key implication of the findings is that these resources can be effective in challenging the stigma of methamphetamine use by encouraging people to connect with each other and talk about their struggles. Provided with a platform where they can offer each other esteem and emotional support and share personal experiences, people affected by methamphetamine can reduce their feelings of isolation and experience hope. These benefits help individuals to deal with stress, and they are also critical factors that represent the first step toward rehabilitation [34].

## Strengths and Limitations

A strength of this study was the sample size. Even though a subset of 2000 posts were used out of the total 14,777 posts, the subset was nonetheless large in quantity and resembled sample sizes used in other content analysis studies examining online social support [23,30]. A second strength of the study was the use of a validated theoretical framework of social support with well-defined categories. This ensured that posts were consistently categorized and that results were reliable. However, there are a number of potential limitations in this study, which must be taken into consideration. First, the data were coded manually, without the use of a text-mining tool. Though saturation was claimed at 2000 posts, the use of a text-mining tool might have revealed information from the data that was possibly overlooked during the manual coding process. Second, the data were not always neatly categorizable. The amount of detail in these posts meant that many provided more than one type of support. As such, a majority of posts could not simply be coded into 1 category, which was done in previous studies, using Cutrona and Suhr's SSBC framework. Third, interrater reliability was unable to be obtained for the data. This would have considerably increased the reliability of the results. Finally, the nature of the data meant that the author had to make active judgements in deciding which support categories' posts were coded into. It is inevitable that the author's personal interpretation of posts will have shaped some coding choices. Nonetheless, all efforts were made to ensure objectivity by referring to the SSBC framework.

## Conclusions

This study represents one of the first few studies to examine how people affected by methamphetamine interact with online social support groups. The findings show that people affected by methamphetamine particularly valued and benefitted from esteem and emotional support, as well as informational support. The next step for future research is to determine whether these findings are generalizable by replicating the study, ideally with the use of a text-mining tool and greater attention paid toward interrater reliability. Future research should also explore these interactions on the Web in greater depth, using a thematic analysis. This may reveal further insight that may be useful for Australian health care providers in developing Web-based resources to address families and communities affected by methamphetamine.

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## Conflicts of Interest

None declared.

Multimedia Appendix 1
Definitions of social support typology classifications.
[DOCX File 27 KB - mental_v6i10e14011_app1.docx ]

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## Abbreviations

**SSBC:** Social Support Behavior Code

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Original Paper

# An Internet-Based Cognitive Behavioral Therapy Program Adapted to Patients With Cardiovascular Disease and Depression: Randomized Controlled Trial

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## Abstract

**Background:** Depression is a common cause of reduced well-being and prognosis in patients with cardiovascular disease (CVD). However, there is a lack of effective intervention strategies targeting depression.

**Objective:** The study aimed to evaluate the effects of a nurse-delivered and adapted internet-based cognitive behavioral therapy (iCBT) program aimed at reducing depression in patients with CVD.

**Methods:** A randomized controlled trial was conducted. A total of 144 patients with CVD with at least mild depression (Patient Health Questionnaire–9 [PHQ-9] score ≥5) were randomized 1:1 to a 9-week program of iCBT (n=72) or an active control participating in a Web-based discussion forum (online discussion forum [ODF], n=72). The iCBT program, which included 7 modules, was adapted to fit patients with CVD. Nurses with an experience of CVD care provided feedback and a short introduction to cognitive behavioral therapy. The primary outcome, depression, was measured using PHQ-9. Secondary outcomes were depression measured using the Montgomery-Åsberg Depression Rating Scale–self-rating version (MADRS-S), health-related quality of life (HRQoL) measured using Short Form 12 (SF-12) survey and EuroQol Visual Analogue Scale (EQ-VAS), and the level of adherence. An intention-to-treat analysis with multiple imputations was used. Between-group differences in the primary and secondary outcomes were determined by the analysis of covariance, and a sensitivity analysis was performed using mixed models.

**Results:** Compared with ODF, iCBT had a significant and moderate treatment effect on the primary outcome depression (ie, PHQ-9; mean group difference=−2.34 [95% CI −3.58 to −1.10], $P$<.001, Cohen $d$=0.62). In the secondary outcomes, compared with ODF, iCBT had a significant and large effect on depression (ie, MADRS-S; $P$<.001, Cohen $d$=0.86) and a significant and moderate effect on the mental component scale of the SF-12 ($P$<.001, Cohen $d$=0.66) and the EQ-VAS ($P$<.001, Cohen $d$=0.62). Overall, 60% (n=43) of the iCBT group completed all 7 modules, whereas 82% (n=59) completed at least half of the modules. No patients were discontinued from the study owing to a high risk of suicide or deterioration in depression.

**Conclusions:** Nurse-delivered iCBT can reduce depression and improve HRQoL in patients with CVD, enabling treatment for depression in their own homes and at their preferred time.

**Trial Registration:** ClinicalTrials.gov NCT02778074; https://clinicaltrials.gov/ct2/show/NCT02778074

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**KEYWORDS**

cardiovascular disease; depression; cognitive behavior therapy; internet; randomized controlled trial

# Introduction

## Background

Depression is highly prevalent in patients with cardiovascular disease (CVD; ie, atrial fibrillation or atrial flutter, ischemic heart disease, and heart failure) [1], with an estimated prevalence of 20% to 40%. Patients with CVD with depression experience reduced health-related quality of life (HRQoL) and have an increased risk of cardiovascular complications and premature death [1]. Potential bio-behavioral mechanisms underlying the negative effects of depression include impairment of self-care activities and/or elevations in the stress and inflammatory response systems [1,2]. This underscores the importance of treating depression in CVD. Pharmacological treatment of depression may be an option in patients with CVD, but the effects are small [1]. Moreover, such treatment poses a challenge as adding another medication to the existing complex medical treatment may be perceived as burdensome and might increase the risk of developing side effects [3].

## Psychological Interventions for Depression in Cardiovascular Disease

One possible alternative and complementary treatment option is psychological interventions that patients with CVD also seem to prefer to antidepressant treatment [4]. A recent systematic review has reported that psychological interventions in CVD, such as cognitive behavioral therapy (CBT), have small effects on depression in patients with CVD [5]. This, however, does not necessarily mean that CBT is ineffective in CVD. One explanation for the small effects reported may be the heterogeneity of the studies included in the systematic review [5]. Many of them evaluate the complex interventions based on different multiple components, which are often poorly described. Moreover, many of the studies in the review also evaluate non-CBT interventions. It is therefore problematic to determine which types of interventions will work. Another important issue is that many psychological interventional studies of CVD have included samples irrespective of whether the patient has elevated levels of depression or not [5]. This will lead to an increased risk of a floor effect, meaning that participants with no or low levels of depressive symptoms will be unlikely to experience a decrease in depression as a response to the intervention. However, a recent meta-analysis of 12 randomized controlled trials (RCTs) evaluating the effectiveness of CBT on patients with CVD with depression and/or anxiety reported significantly lower depression scores at follow-up compared with controls, which in most cases was care as usual [6]. This suggests that interventions based on CBT or CBT principles could be a treatment option for depression in patients with CVD with increased levels of depressive symptoms. However, one barrier to the implementation of CBT in current clinical and cardiac care is low access to psychotherapists, leading to a *treatment-demand gap*. A solution could be internet-based CBT (iCBT), which can be provided at low cost and has been proven effective in patients with depression [7,8]. iCBT can be delivered in a guided format (ie, support and/or encouragement and/or feedback on homework assignments [9]) or unguided; however, guided iCBT tends to be more effective [10]. One important aspect that may facilitate the implementation of guided iCBT in clinical care is that it can be delivered by health care professionals with little or no specific training, without reducing the effect of the treatment [11]. Another advantage of iCBT is that it enables patients with CVD to access CBT in their own homes and at a time that suits them. However, generic iCBT programs may not be optimal for targeting depression in patients with chronic diseases, as these programs are not tailored to the context of the disease [12,13].

## Objectives

In this study, we therefore aim to evaluate the effect of a nurse-delivered, tailored iCBT program designed to reduce depression in patients with CVD.

# Methods

## Study Design and Population

In this RCT, we recruited patients from medical and cardiology clinics at 4 hospitals in southeastern Sweden. Invitations were sent by post to all patients with at least one diagnosis of atrial fibrillation or atrial flutter (International Classification of Diseases [ICD] codes I48 or I49), coronary heart disease (ICD codes I20 or I25), or heart failure (ICD codes I42 or I50) and at least one outpatient visit or hospitalization during the previous year. Recruitment took place in 3 different rounds in January 2017 (hospital 1), October 2017 (hospital 2), and February 2018 (hospitals 3 and 4), and a total of 11,992 patients were approached. Patients interested in participating were instructed to register on the study website (Multimedia Appendix 1), which is a secure website requiring 2-factor authentication to access the study platform [14]. No compensation was provided for participating in the study.

Patients were eligible for inclusion if they were aged 18 years or above and were receiving CVD treatment according to the current guidelines for heart failure, coronary artery disease, and atrial fibrillation from the European Society of Cardiology [15-17], had stable CVD (New York Heart Association [NYHA] class I-III), with no hospitalization related to CVD in the past 4 weeks, and suffered at least mild depressive symptoms (Patient Health Questionnaire–9 [PHQ-9] score ≥5 [18]). Furthermore, patients needed to have regular access to a computer with an internet connection, have access to a mobile phone, and be willing to participate in a treatment program for their depression. The exclusion criteria were severe CVD (ie, NYHA IV) or another comorbid life-threatening disease as assessed by a study nurse, severe depression assessed as requiring acute treatment, and not being willing to dedicate 3 to 4 hours per week to participate in the program.

Patients who had registered on the study website were asked to complete a Web-based screening form that collected data about depression as assessed by PHQ-9, demographics, smoking and alcohol habits, CVD diagnosis, time since diagnosis of CVD, NYHA classification, comorbidities, and medications for CVD, depression, sleep problems, and anxiety. Patients assessed as potential participants (ie, had CVD and scored ≥5 on the PHQ-9, including the presence of at least one of the two core symptoms of depression—depressed mood and/or loss of interest) were contacted by telephone by study nurses, with clinical experience of psychiatric and cardiac care, who gave information about the study, answered questions, and checked any uncertainties about the screening form. They also assessed the severity of CVD and depression. During the telephone interview, the Mini International Neuropsychiatric Interview (MINI) version 5 panel A (ie, depression) and panel C (ie, suicidal ideation) were used to establish the presence of at least mild depression and severity (ie, the presence or absence of core symptoms, depression severity, and suicidal ideation). Those who fulfilled the inclusion criteria and did not exhibit any of the exclusion criteria were included in the study. All included participants signed a paper to give written informed consent. Self-reported data were collected via a set of questionnaires that were completed through the study website. Data were collected at baseline and after study completion at 9 weeks. The study was approved by the regional ethical review board in Linköping, Sweden (number 2016/72-31) and is registered at clinicaltrials.gov (NCT02778074).

## Randomization and Masking

The randomization was performed by a study team member (GM) who was blinded to screening and baseline data. None of the telephone interviewers had access to the random sequence. Patients were randomized 1:1 to the 9-week iCBT program (intervention group) or an online discussion forum (ODF; active control group) generated by an independent statistician using Stata version 13 proc Ralloc (StataCorp LLC) with a block size of 2. Masking of patients was not possible as the intervention is a cognitive behavioral intervention. It was not necessary to mask outcome measures as these were automatically collected via the study platform.

## Procedures

The intervention group participated in a 9-week iCBT program that was initially adapted to fit patients with heart failure and depression and had undergone pilot testing. Its theoretical underpinnings have been described in previous publications [19,20]. The iCBT program, which emphasizes behavioral components, comprises 7 modules: goal setting, psychoeducation, problem solving, behavioral activation part 1 (2 weeks) and part 2 (2 weeks), and a summary module. For this study, the program was further developed to fit a broader group of cardiac patients by adding psychoeducative modules about coronary artery disease, atrial fibrillation, and atrial flutter. Each module comprised a text, short videos, and weekly homework assignments. A table overview of the content of the iCBT program and screenshots of different modules and homework assignments can be found in Multimedia Appendix 2. No changes were made to the program during the trial. Written feedback was provided on each assignment at the end of each week by 3 nurses (PJ, JL, and MW) from the study team, who had experience in cardiology and psychiatry and had taken a short course in iCBT. The nurses participated in a 2-day course about the foundations and uses of iCBT, recent research, practical training in the use of iCBT, and how to give feedback to participants. The nurses were also provided with a handbook about iCBT [21]. The course was run by a well-recognized company specializing in education in psychological treatment. No formal assessment of the nurses' learning was undertaken. The feedback focused on encouragement, and confirming and reflecting upon the patients' homework assignments, preparing for the next module [9], and, when required, discussing psychoeducative CVD-related issues (eg, sexuality, treatment side effects, and symptoms). Participants in the iCBT group also had the opportunity to ask questions about the feedback or the content of the module using a message function on the study platform. These questions were answered within 24 hours during working days. The nurses had the opportunity to consult each other, as well as a clinical psychologist (GA) or a cardiologist (UA), if needed. Participants who did not complete the homework assignments received a maximum of 3 written reminders by email during a consecutive period of 2 weeks.

As recommended in a systematic review [13], we used an active control group, who participated in a Web-based moderated discussion forum (ie, ODF group), where new discussion topics were presented each week over a 9-week period. During participation in the ODF, no individual feedback was provided. However, participants could contact the moderator for support regarding how to use the ODF and for technical support. The topic was introduced without any extended background in a presentation comprising statements and questions such as: What are the symptoms of CVD? Do you have any tips you would like to share on how you can handle the symptoms of CVD? How do you think that depressive symptoms and CVD affect the relationship between you and your significant others? Do you have any suggestions about how to handle problems related to feeling depressed or downhearted? The discussion took place in writing. One of the members of the study group (ie, GM) was responsible for monitoring the ODF. The monitoring of the ODF focused on assessing whether there was a good atmosphere between the discussants and to control and correct if a discussant suggested management strategies that could be seen as harmful. After 9 weeks, the participants in the ODF were offered the iCBT program. This information was provided in writing on the study homepage and orally during the telephone interview.

For safety issues, and as requested by the ethical review board, we screened weekly for suicidality and worsening of depressive symptoms using the Montgomery-Åsberg Depression Rating Scale–self-rating Scale (MADRS-S) both in the iCBT and the ODF [22]. Patients who scored 5 or higher on MADRS-S item 9 (zest for life) were contacted by the research team and, if necessary, advised to seek acute psychiatric care.

## Assessments

Participants who did not complete the questionnaires received a maximum of 3 automated reminders.

### *Primary Outcome*

PHQ-9 was used to measure the level of depression at baseline and at 9-week follow-up. The instrument comprised 9 items rated on a 4-point scale (not at all, several days, more than half the days, and nearly every day) providing a summary score ranging from 0 to 27 [23]. A score of 0 to 4 indicates no or minimal depressive symptoms, scores of 5 to 9 suggest mild depressive symptoms, scores of 10 to 14 indicate moderate depressive symptoms, and scores >15 indicate severe depressive symptoms. The PHQ-9 has been found to be reliable and valid for detecting depression [18,23] and also in patients with CVD (ie, heart failure) [24]. The PHQ-9 has also been found to be valid in the computerized format [25].

### *Secondary Outcomes*

MADRS-S [22] was used as a security measurement for depressive symptoms and suicidal thoughts during the intervention. MADRS-S comprises 9 items rated on a 7-point scale with a maximum score of 54. Higher scores indicate more symptoms of depression. Scores of 0 to 12 on the MADRS-S have been proposed to indicate no depression, scores of 13 to 19 suggest mild depression, and scores of 20 to 54 indicate moderate or severe depression [26]. MADRS-S has been found to be a valid and reliable tool when administered over the internet [27].

HRQoL was measured using the Short Form 12 (SF-12) survey [28] and EuroQol Visual Analogue Scale (EQ-VAS) [29]. The SF-12 measures HRQoL via 12 items selected from the Short Form-36 [28]. Results of the SF-12 are summed into the physical component score (PCS) and the mental component score (MCS). The instrument has been used in a large number of studies and populations, including patients with CVD [30]. The EQ-VAS is a visual analog of HRQoL scale with endpoints labeled “the best health you can imagine,” marked as 100, and “the worst health you can imagine,” marked as 0.

Adherence was determined by the number of completed modules (iCBT group) and the number of activities in the ODF (ODF group), which was provided by the study platform. As recommended, we have also reported the time spent for feedback on homework assignments and responses to messages sent from the participants [13]. This was measured by clocking time from the start to the end of each feedback session or message sent.

### Statistical Analysis

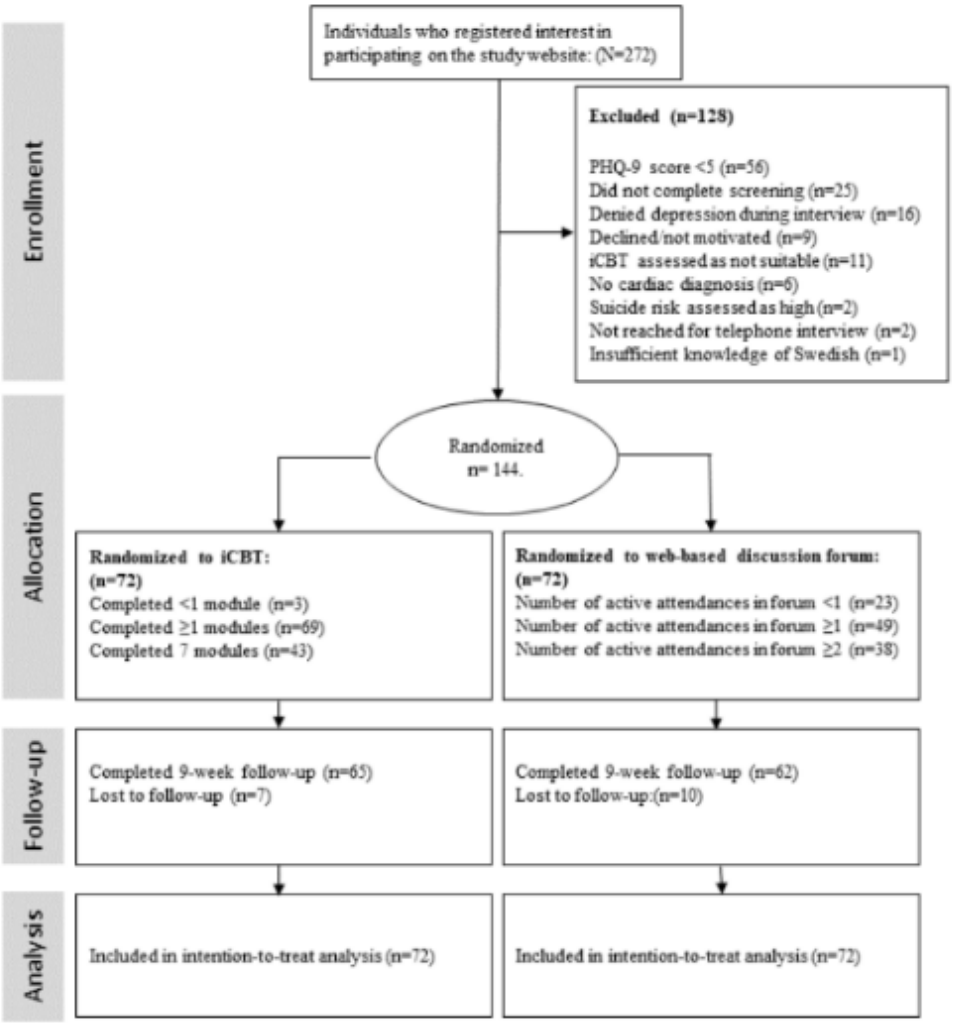
A power calculation based on effect size in the meta-analysis of iCBT [31] showed that a total of 122 participants would be needed to detect at least a moderate effect size on depression (effect size=0.5, alpha=.05 [$z$=1.96], power=0.80 [$z$=0.84]). Owing to expected dropouts, the size of the study sample was set to 140 patients. The characteristics of patients’ baseline data were analyzed using descriptive statistics. Primary and secondary outcome data were checked for normal distribution by visual inspection or Q-Q plots. All variables were found to be suitable for parametric analysis. The primary analysis for comparison between groups (ie, iCBT vs ODF) was made on an intention-to-treat basis. We followed the recommendations of the European Medicines Agency for statistical analysis [32] and used analysis of covariance (ANCOVA), which allows adjusting for baseline scores and regression to the mean [33]. Missing data in the ANCOVA were imputed using last observation carried forward (LOCF) as no consensus on how to best pool $F$ statistics was available [34]. However, LOCF has received criticism [35]; therefore, we also applied mixed-models analysis with multiple imputed data as a sensitivity analysis. A total of 40 imputations were performed using the outcome variables and variables from baseline characteristics that had a correlation $r \geq 0.5$ with the outcome variables as predictors [36]. Multiple imputed datasets, as well as raw data on primary outcome are available in Multimedia Appendix 3. Effect sizes were calculated using Cohen $d$, with a small effect considered to be a value between 0.20 and 0.49, a moderate effect between 0.50 and 0.79, and a value above 0.80 considered to be a large effect. A per-protocol analysis was performed to evaluate categorical improvements in depression as measured by minimal clinically important change, defined by a decrease of 5 points or more on the PHQ-9 [37]; the proportion of nondepressed participants (ie PHQ-9 score <5) at 9-week follow-up; and the proportion of nondepressed or mildly depressed participants (ie, PHQ-9 score <10) at 9-week follow-up. On the basis of these analyses, the numbers needed to treat (NNT) were calculated. We also calculated NNT for MADRS-S as a categorical variable (no depression=MADRS-S score 0-12; depression=MADRS-S score ≥13). A per-protocol analysis was also performed to analyze and compare the change in levels of depression in relation to the number of CBT modules and the number of activities in the ODF completed (ie, adherence to the program). Statistical analysis was performed using IBM SPSS version 23. $P$ value <.05 was considered as significant

## Results

### Population

Out of 11,992 invitations sent to potential participants, 272 (2.26%) registered interest and were screened. Out of these, 144 were included and randomized to either iCBT (n=72) or ODF (n=72). The main reasons for exclusion were a screening score of <5 on PHQ-9 (20%, n=56), not completing the screening form (9%, n=20), or denying depression during the telephone interview (6%, n=16; Figure 1). The number of patients who did not complete the 9-week trial period was similar in the 2 groups (iCBT: 10%, n=7, ODF: 14%, n=10).

**Figure 1.** Trial profile. PHQ-9: Patient Health Questionnaire–9; iCBT: internet-based cognitive behavioral therapy.




Baseline characteristics (Table 1) were similar between the 2 groups. The mean age was 63 (SD 12) years (age span 26-87 years), 38% (n=55) were women and 49% (n=70) had a college or university level of education. With regard to cardiac diagnosis, 56% (n=81) had atrial fibrillation or atrialflutter, 44% (n=65) had coronary heart disease, and 26% (n=38) had heart failure. More than one-quarter of the total population had 2 or more cardiac diagnoses (ie, 28%, n=40). In addition, 53% (n=76) had hypertension, 15% (n=21) had diabetes, and 13% (n=19) had a previous stroke or transitory ischemic attack. With regard to pharmacological treatment for CVD, 76% (n=110) were on beta-blockers, 48% (n=67) were on renin-angiotensin-aldosterone system blocking agents, and 89% (n=110) used antiplatelets or anticoagulants. The mean score on PHQ-9 was 10.47 (SD 4.78) and 14% (n=20) had been prescribed antidepressant treatment.

**Table 1.** Baseline characteristics of participants randomized to internet-based cognitive behavioral therapy or online discussion forum.

| Characteristics | Internet-based cognitive behavioral therapy (n=72) | Web-based discussion forum (n=72) |
|---|---|---|
| **Sex, n (%)** | | |
| Male | 47 (65) | 42 (58) |
| Female | 25 (35) | 30 (42) |
| Age (years), mean (SD) | 61 (13) | 64 (12) |
| **Education, n (%)** | | |
| Elementary | 7 (10) | 12 (17) |
| Upper secondary/high school | 16 (22) | 21 (29) |
| Postsecondary vocational education | 12 (17) | 6 (8) |
| College/university | 37 (51) | 33 (46) |
| **Occupation, n (%)** | | |
| Working | 26 (36) | 18 (25) |
| Sick leave/disability pension/unemployed | 9 (13) | 10 (14) |
| Retired | 32 (44) | 36 (50) |
| Other | 5 (7) | 8 (11) |
| Living alone, n (%) | 19 (26) | 19 (26) |
| **Smoking, n (%)** | | |
| Never | 33 (46) | 36 (50) |
| Ex-smoker | 37 (51) | 33 (46) |
| Smoker | 2 (3) | 3 (4) |
| **Alcohol consumption, n (%)** | | |
| 0-4 units per week | 51 (71) | 58 (80) |
| 5-9 units per week | 17 (24) | 10 (14) |
| 10-14 units per week | 3 (4) | 4 (6) |
| 15 or more units per week | 1 (1) | 0 (0) |
| **Cardiovascular disease, n (%)** | | |
| Myocardial infarction/angina | 34 (47) | 29 (40) |
| Atrial fibrillation | 40 (56) | 41 (57) |
| Heart failure | 18 (25) | 20 (28) |
| **Number of cardiac diagnoses, n (%)** | | |
| 1 | 52 (72) | 52 (72) |
| 2 | 15 (21) | 17 (24) |
| 3 | 5 (7) | 3 (4) |
| **Time since cardiac diagnosis, n (%)** | | |
| <6 months | 7 (10) | 9 (13) |
| >6 months | 61 (85) | 62 (86) |
| Do not know | 4 (5) | 1 (1) |
| **Comorbidities, n (%)** | | |
| Hypertension | 36 (50) | 40 (56) |
| Diabetes | 8 (11) | 13 (18) |
| Pulmonary disease | 7 (10) | 8 (11) |
| Stroke and/or TIA[a] | 9 (13) | 10 (14) |
| Renal disease | 3 (4) | 2 (3) |

| Characteristics | Internet-based cognitive behavioral therapy (n=72) | Web-based discussion forum (n=72) |
|---|---|---|
| Cancer | 7 (10) | 9 (13) |
| Other psychiatric disorder | 4 (6) | 8 (11) |
| **NYHA[b] class, n (%)** | | |
| 1 | 23 (32) | 18 (25) |
| 2 | 25 (35) | 28 (39) |
| 3 | 24 (33) | 26 (36) |
| **Cardiovascular disease medications, n (%)** | | |
| RAAS blockade[c] | 34 (47) | 35 (49) |
| Beta-blocker | 55 (76) | 55 (76) |
| MRA[d] | 5 (7) | 6 (8) |
| Neprilysin inhibitor | 0 (0) | 1 (1) |
| Antiplatelet/anticoagulants | 63 (88) | 65 (90) |
| Statins | 36 (50) | 33 (46) |
| Diuretics | 14 (19) | 19 (26) |
| Nitroglycerine | 15 (21) | 15 (21) |
| Rhythm stabilizing agents | 9 (13) | 8 (11) |
| **Depression medications, n (%)** | | |
| Antidepressants | 7 (10) | 13 (18) |
| Anxiolytics | 7 (10) | 12 (17) |
| Sleep medication | 23 (40) | 19 (26) |

[a]TIA: transient ischemic attack.

[b]NYHA: New York Heart Association function classification.

[c]RAAS blockade: renin-angiotensin-aldosterone system blocking agents.

[d]MRA: mineral receptor antagonists.

## Outcomes

The intention-to-treat analysis (iCBT n=72 and ODF n=72) of the primary outcome of depression as measured by PHQ-9 at the 9-week follow-up showed a statistically significant moderate treatment effect of iCBT compared ODF (mean group difference -2.34 [95 % CI -3.58 to -1.10], *P*<.001, Cohen *d*=0.62) (Table 2 and Figure 2). The mixed-model analysis based on multiple imputation data showed similar figures for the primary outcome (mean group difference -2.40 [95% CI −3.93 to −0.87], *P*=.002, Cohen *d*=0.51; Multimedia Appendix 3). In the secondary outcomes, depression measured by MADRS-S, iCBT had a significant and large effect (*P*<.001, Cohen *d*=0.86) compared with ODF. We also found significant improvements and moderate effects owing to iCBT on EQ-VAS (*P*<.001, Cohen *d*=0.62) and on the MCS of the SF-12 (*P*<.001, Cohen *d*=0.66). In the PCS of the SF-12, a small but nonsignificant improvement owing to iCBT was found (*P*=.06, Cohen *d*=0.32; Table 2). The mixed-model analysis for the secondary outcomes showed similar figures and are reported in Multimedia Appendix 3.

**Table 2.** Treatment effects for the primary and secondary outcomes. All data are imputed using last observation carried forward.

| Questionnaires | Internet-based cognitive behavioral therapy (n=72), mean (SD) | | Online discussion forum (n=72), mean (SD) | | Mean between-group treatment difference (95% CI) | *P* value | Effect size (*d*) |
|---|---|---|---|---|---|---|---|
| | Baseline | 9 weeks | Baseline | 9 weeks | | | |
| PHQ-9[a] | 10.71 (4.47) | 6.63 (4.76) | 10.22 (5.10) | 8.68 (4.60) | −2.34 (−3.58 to −1.10) | <.001 | 0.62 |
| MADRS-S[b] | 18.27 (6.98) | 10.90 (7.45) | 17.67 (6.19) | 16.10 (7.93) | −5.58 (−7.72 to −3.44) | <.001 | 0.86 |
| EQ-VAS[c] | 53.31 (20.03) | 65.11 (21.81) | 57.15 (18.10) | 56.99 (22.08) | 10.83 (5.02 to 16.64) | <.001 | 0.62 |
| PCS12[d] | 39.70 (10.07) | 41.84 (10.56) | 37.63 (10.98) | 37.80 (11.61) | 2.46 (−0.11 to 5.03) | .06 | 0.32 |
| MCS12[e] | 35.88 (9.22) | 43.41 (11.04) | 36.38 (10.02) | 38.03 (10.52) | 5.71 (2.83 to 8.60) | <.001 | 0.66 |

[a]PHQ-9: Patient Health Questionnaire–9.

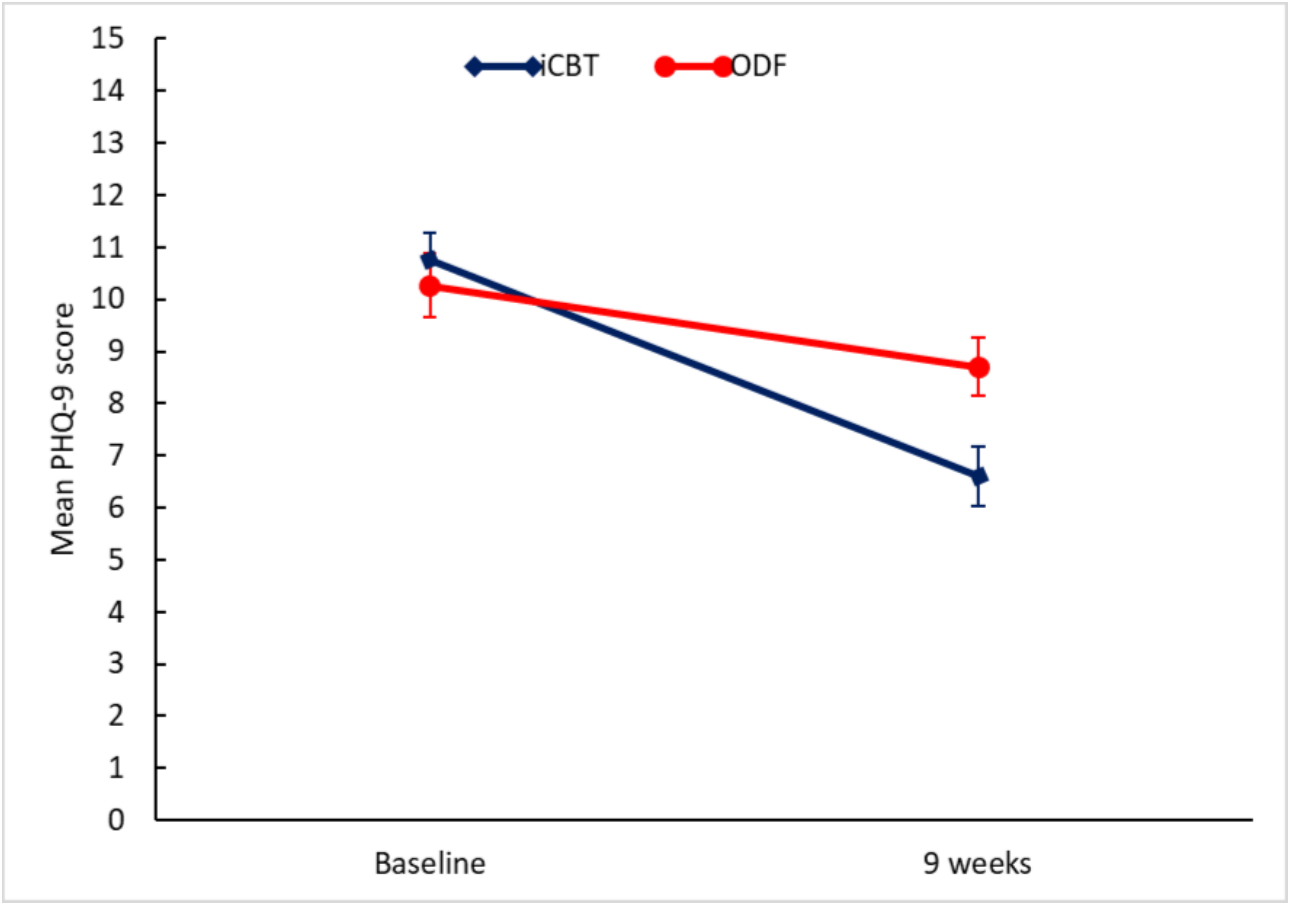
[b]MADRS-S: Montgomery-Åsberg Depression Rating Scale–self-rating version.

[c]EQ-VAS: EuroQol Visual Analogue Scale.

[d]PCS12: physical component score of the Short Form 12.

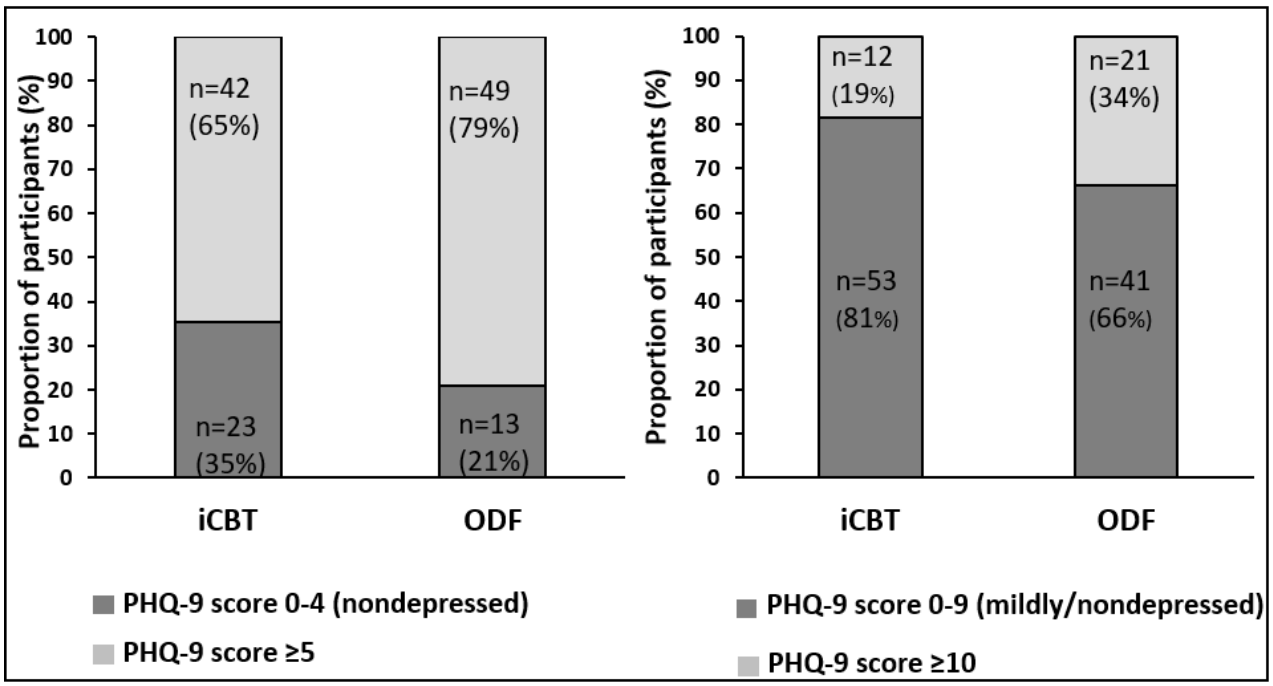
[e]MCS12: mental component score of the Short Form 12.

**Figure 2.** Effects of the internet-based cognitive behavioral therapy (iCBT) program. The figure shows the change in mean scores from baseline to 9-week follow-up as measured by Patient Health Questionnaire–9 (PHQ-9) in those allocated to iCBT (n=72) or Web-based discussion forum (ODF, n=72). Error bars show SE.




In the per-protocol analysis (iCBT n=65 and ODF n=62), which aimed to compare categorical improvements in depression at 9-week follow-up, the proportion of patients who had a clinically significant improvement in depression (ie, a decrease of ≥5 points in PHQ-9) was larger in the iCBT group than in the ODF group (43%, n=28 vs 24%, n=15; *P*=.02). There was also a significantly larger proportion of nondepressed (PHQ-9 score <5; 35%, n=23 vs 21%, n=13; *P*=.02) or mildly/nondepressed (PHQ-9 score <10; 82%, n=53 vs 66%, n=41; *P*=.049; Figure 3) participants in the iCBT group compared with the ODF group. The NNT for a clinically significant change on PHQ-9 was 5. The NNT to become nondepressed was 7, and the NNT to become mildly depressed was 6. For MADRS-S, the NNT for iCBT was 3.

**Figure 3.** Proportion of patients according to dichotomized cutoff on Patient Health Questionnaire–9 (PHQ-9) in both groups at 9-week follow-up. Patients are grouped below the cutoff for nondepression and mild depression (PHQ-9 score 0-9) and below the cutoff for nondepression only (PHQ-9 score 0-4). iCBT (n=65): internet-based cognitive behavioral therapy; ODF (n=62): Web-based discussion forum.




With regard to adherence, a total of 60% (n=43) of the iCBT group completed all 7 modules, whereas 82% (n=59) completed more than half (ie, 4 or more). In the ODF group, 27% (n=20) of the patients completed 9 or more activities (eg, reading or posting) in the forum threads. In the per-protocol analysis performed to compare the change in level of depression in relation to adherence (Multimedia Appendix 3), we first compared those who had completed at least one iCBT treatment module (n=69) with those with at least one activity in the ODF (n=49), in which a significant and moderate effect of iCBT was found ($P$<.001, Cohen $d$=0.69). In the next step, those in the iCBT group who had completed all 7 modules (n=43) were compared with those in the ODF who had at least 9 activities (n=20) and a significant and large effect of iCBT ($P$=.002, Cohen $d$=0.89) was found. The total mean time required for providing feedback to patients completing 7 modules was 113.8 (SD 46.3) min or an average of 13 min per week per patient.

With regard to safety, 1 patient in the iCBT group and 3 in the ODF group demonstrated an increase of more than 5 points on PHQ-9 when comparing individual baseline and 9-week follow-up measures. At baseline, 3 patients in each group reported a score of 2 or more on item 9 in PHQ-9 (thought about being better off dead). At 9 weeks, these numbers had decreased to 1 and 2 in the iCBT and ODF groups, respectively. On 2 occasions, 1 patient in the iCBT group scored above 4 on MADRS-S item 9 (zest for life) during the predefined weekly safety measures. The corresponding numbers for the ODF group were 3 occasions among 3 patients. These patients were contacted by telephone for an evaluation, but no patient was discontinued from the study owing to high risk of suicide or deterioration in depression.

## Discussion

### Principal Findings

To our knowledge, this is the first adequately powered RCT aimed at evaluating the effect of a nurse-delivered iCBT program for depression in patients diagnosed with CVD. We found that the program, which was adapted to fit the context of CVD, was more effective than the ODF in reducing depression and improving HRQoL.

We found a moderate effect for a nurse-delivered and adapted iCBT program on depression in patients with CVD (PHQ-9, Cohen $d$=0.62). However, measured by the MADRS-S, the effect on depression was strong (Cohen $d$=0.86). Furthermore, we also found an improved HRQoL, which is also of clinical relevance for the care of patients with chronic somatic disorders. The effects on depression are stronger than the reported small effect (standardized mean difference of 0.27) from the latest systematic review of psychological interventions for depression in patients with CVD [5]. However, our results correspond to the overall moderate effect size of 0.67 for depression reported in a recent meta-analysis [8] of iCBT studies, in which most of the patients did not have a chronic somatic disorder. The NNT in our study were 5 and 6 for a clinical improvement and being nondepressed, respectively. However, when we used MADRS-S, the NNT was 3 to become nondepressed. These NNT are comparable with the NNT of 4.6 reported in the same meta-analysis of studies using *care as usual* as a control group [8], although we used an active control group (ie, ODF), which we consider to be more active than many care-as-usual regimens. Furthermore, we included depressed patients, who thus had a risk of deterioration in depression. One strength of our study is that it was guided; the participants' levels of depression were

monitored and those with increasing scores and who were considered at risk of suicide were contacted for an assessment. This would not have been possible with an unguided program. Our results suggest that this nurse-led and adapted iCBT program was safe and provided effects on depression in patients with CVD that are comparable with the effects found in meta-analyses of iCBT studies [8].

The number of randomized controlled studies evaluating iCBT in CVD is surprisingly low. However, findings from a study [38] using a generic and unguided iCBT program on participants with self-reported high CVD risks and mild depression reported a small effect ($d$=0.15) on depression. A recent study from 2018, the U-CARE Heart study [39], reported that, surprisingly, a therapist-guided and adapted iCBT program for depression and anxiety in patients with a recent myocardial infarction (MI) was not superior to treatment as usual. Adherence in that study was low; 46% did not complete the first module and only 15% completed 2 or more. In our study, 60% completed all modules and 82% completed 4 or more. Moreover, the iCBT intervention seems to also be feasible for young and old patients with CVD. There are several possible explanations for why our iCBT program seems to be more effective and encourages greater adherence than the previously mentioned studies [38,39]. One explanation could be that the content of the iCBT program was adapted for CVD. In one study [40], depressed patients with heart failure did not describe the adapted iCBT program as a treatment for depression, but as a new way to actively learn self-care. In another study [41] conducted with patients with multiple sclerosis and comorbid depression, where iCBT was provided by a generic and automated program (ie, Deprexis), as many as 51% of the patients reported that the program required adjustments to fit the needs of patients with multiple sclerosis. On the other hand, the U-CARE [39] study used a therapist-guided and adapted iCBT program. However, in a qualitative study from U-CARE [42], the MI patients suggested that one improvement for that iCBT program could be to include the opportunity to ask medical questions to a health care professional. Thus, patients with chronic somatic disease and depression have a combination of medical and psychosocial needs that should be addressed in iCBT programs. Apart from tailoring the content, this also implies that those who deliver guidance can also address CVD-related issues when needed. Another possible explanation for our result is that feedback and support in our study were delivered by nurses with experience of CVD care, who had taken a short course in CBT. This corresponds to McCombie et al's suggestion that iCBT programs for patients with physical illness should be adapted to each individual illness and provided by the medical team caring for the patient [13]. This may also facilitate the implementation of iCBT in clinical CVD care. An alternative adapted iCBT program could be designed to incorporate a collaboration between CVD nurses, psychologists, and cardiologists, who could all respond on-demand, depending on the needs of the patients.

### Strengths and Limitations

This study has several limitations. First, patients were included on the basis of self-reported depression and not on a diagnostic depression interview. This may have increased the risk of misclassification of depression. However, to increase the probability of the presence of at least mild depression, it was not enough to only have a score above 5 on the PHQ-9 during the screening but at least one of the two core symptoms of depression (depressed mood and/or loss of interest) was also necessary. Although it should not be considered as a full, formal diagnostic interview, MINI was used during the telephone interview to assess the presence of core symptoms, as well as the severity of the depression and any presence or history of suicidal ideation. Another limitation is that we did not include high alcohol consumption as a specific exclusion criterion. If there was high alcohol consumption that might hinder participation in the study, this was assessed by the study nurses during the telephone interview. One may also direct criticism toward the design of the ODF, as the activity in the ODF group may be considered low, with only about one-third completing 9 or more activities. The intention was that the discussion between members should be the motivating factor. However, as the ODF proceeded, the activity decreased. A potential explanation is that those in the ODF were not given feedback from the study team. One might argue that the ODF is no more than care as usual and that the effect of the iCBT is thus less valid. However, in the U-CARE study [39], the depression score in the iCBT group decreased by 3.3 points and by 2.3 points in the care-as-usual group. We therefore believe that the results reported here can be seen to provide important and valid information about the effects of the iCBT program on depression. All the study nurses had clinical experience of psychiatric care and were able to consult a psychologist or the other study members when needed. The recruitment of patients was challenging as we aimed to include patients with at least mild depression, which is not always the case in other psychological interventional studies of CVD [5]. We contacted 11,992 patients with CVD by mail. However, not all of these were expected to be eligible. We calculated that approximately 20% may be depressed. Thus, 2400 of those could be potential candidates to include in the study. A potential explanation for the challenge in recruiting participants may be that cardiac patients recognize electronic health or iCBT as something different from health care [40]. This may indicate that they did not value this type of intervention as a possibility to get help. In general terms, our recruitment process may be seen as valid as it corresponds to what is common in iCBT studies [38,39,43]. Despite our limitations in diagnosing depression, we therefore believe that our study contributes to the literature. ANCOVA is often used today when analyzing the outcome of RCT. In cases of missing data, ANCOVA is limited because there is currently no consensus about how to pool multiple imputed F-statistics, and we therefore used LOCF. We are fully aware of this limitation and therefore also provided a mixed-model analysis with multiple imputed data. Regardless of the type of statistical analysis, the result is maintained. One may argue that the need to have a computer and internet access may be a limiting factor in this study. iCBT will probably never fit all CVD patients, independent of whether they have a computer or internet access. Regarding access and using the internet, this is not a major problem in Sweden. Among those aged 56–65 years, only 2 % do not use the internet. Among those aged 66–75 years, 9 % do not use the internet. However, among those aged

over 76 years, this rises to 42 %. The trend is, however, towards increasing use in all age groups within the Swedish population. Thus, iCBT can be seen as another tool in the management of depression and CVD. We argue that, if many CVD patients can be targeted with iCBT, there will also be a greater opportunity to provide face-to-face CBT to those CVD patients for whom iCBT will not fit. For those who had completed all seven modules, feedback was 13 min per week per patient. However, a limitation is that we do not have any information regarding the number of messages sent. All nurses who provided feedback were members of the study team, held specific competence in psychiatry and CVD and had a high interest in iCBT. This might be problematic if the iCBT program were to be implemented in clinical cardiac care since the ordinary healthcare personnel who may be expected to provide feedback will obviously not have all these specific competencies. However, the therapeutic part of iCBT is embedded within the text, whereas the feedback focuses more on general issues such as encouragement, confirming and reflection [9]. This suggests that feedback probably can be delivered by the vast majority of healthcare personnel within CVD care after a brief introduction to iCBT. To conclude, despite all the limitations in this study, we still believe that the results provide important and valid information about the effects of a nurse-delivered, adapted iCBT program designed to reduce depression in patients with CVD.

## Conclusions

This study has shown that a nurse-delivered and adapted iCBT program decreased depression and improved HRQoL in CVD patients with depression. A clear majority of the patients also adhered to most parts of the iCBT program. Our findings suggest that the implementation of iCBT in CVD care means that more patients, who at present might not receive adequate treatment, can now gain access to psychological treatment for depression in their own homes and at a time of their own choosing.

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## Authors' Contributions

PJ, GA, UA, AB, TJ, and JL designed the study. PJ, MW, GA, UA, GM, and JL performed the study and obtained data. PJ, MW, GA, and JL performed statistical analyses. PJ, MW, GA, UA, AB, TJ, GM, and JL performed data interpretation. PJ, MW, GM, and JL drafted the paper. PJ, MW, GA, UA, AB, TJ, GM, and JL revised the paper.

## Conflicts of Interest

None declared.

Multimedia Appendix 1
Home and log in site.
[PPTX File 1454 KB - mental_v6i10e14648_app1.pptx ]

Multimedia Appendix 2
Description of the iCBT program and examples of homework assignments.
[PPTX File 6001 KB - mental_v6i10e14648_app2.pptx ]

Multimedia Appendix 3
Supplementary results.
[PDF File (Adobe PDF File)124 KB - mental_v6i9e14648_app3.pdf ]

Multimedia Appendix 4
CONSORT‐EHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File)413 KB - mental_v6i10e14648_app4.pdf ]

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## Abbreviations

**ANCOVA:** analysis of covariance
**CBT:** cognitive behavioral therapy
**CVD:** cardiovascular disease
**EQ-VAS:** EuroQol Visual Analogue Scale
**HRQoL:** health-related quality of life
**iCBT:** internet-based cognitive behavioral therapy
**ICD:** International Classification of Diseases
**LOCF:** last observation carried forward
**MADRS-S:** Montgomery-Åsberg Depression Rating Scale–self-rating Scale
**MCS:** mental component score
**MI:** myocardial infarction
**MINI:** Mini International Neuropsychiatric Interview
**NNT:** numbers needed to treat
**NYHA:** New York Heart Association
**ODF:** online discussion forum
**PCS:** physical component score
**PHQ-9:** Patient Health Questionnaire–9
**RCT:** randomized controlled trial
**SF-12:** Short Form 12

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Review

# Potential Reduction of Symptoms With the Use of Persuasive Systems Design Features in Internet-Based Cognitive Behavioral Therapy Programs for Children and Adolescents With Anxiety: A Realist Synthesis

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## Abstract

**Background:** Internet-based cognitive behavioral therapy (iCBT) for children and adolescents is a persuasive system that combines 3 major components to therapy—therapeutic content, technological features, and interactions between the user and program—intended to reduce users' anxiety symptoms. Several reviews report the effectiveness of iCBT; however, iCBT design and delivery components differ widely across programs, which raise important questions about how iCBT effects are produced and can be optimized.

**Objective:** The objective of this study was to review and synthesize the iCBT literature using a realist approach with a persuasive systems perspective to (1) document the design and delivery components of iCBT and (2) generate hypotheses as to how these components may explain changes in anxiety symptoms after completing iCBT.

**Methods:** A multi-strategy search identified published and gray literature on iCBT for child and adolescent anxiety up until June 2019. Documents that met our prespecified inclusion criteria were appraised for relevance and methodological rigor. Data extraction was guided by the persuasive systems design (PSD) model. The model describes 28 technological design features, organized into 4 categories that help users meet their health goals: primary task support, dialogue support, system credibility support, and social support. We generated initial hypotheses for how PSD (mechanisms) and program delivery (context of use) features were linked to symptom changes (outcomes) across iCBT programs using realist and meta-ethnographic techniques. These hypothesized context-mechanism-outcome configurations were refined during analysis using evidence from the literature to improve their explanatory value.

**Results:** A total of 63 documents detailing 15 iCBT programs were included. A total of six iCBT programs were rated high for relevance, and most studies were of moderate-to-high methodological rigor. A total of 11 context-mechanism-outcome configurations (final hypotheses) were generated. Configurations primarily comprised PSD features from the primary task and dialogue support categories. Several key PSD features (eg, self-monitoring, simulation, social role, similarity, social learning, and rehearsal) were consistently reported in programs shown to reduce anxiety; many features were employed simultaneously,

suggesting synergy when grouped. We also hypothesized the function of PSD features in generating iCBT impacts. Adjunct support was identified as an important aspect of context that may have complemented certain PSD features in reducing users' anxiety.

**Conclusions:** This synthesis generated context-mechanism-outcome configurations (hypotheses) about the potential function, combination, and impact of iCBT program components thought to support desired program effects. We suggest that, when delivered with adjunct support, PSD features may contribute to reduced anxiety for child and adolescent users. Formal testing of the 11 configurations is required to confirm their impact on anxiety-based outcomes. From this we encourage a systematic and deliberate approach to iCBT design and evaluation to increase the pool of evidence-based interventions available to prevent and treat children and adolescents with anxiety.

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**KEYWORDS**

internet; cognitive behavioral therapy; computer-assisted therapy; persuasive communication; anxiety; children; adolescents; review; treatment effectiveness; clinical effectiveness; treatment efficacy; clinical

## Introduction

### Background

Anxiety is one of the most common and early emerging mental health concerns for children and adolescents [1], 20% of whom will experience an anxiety disorder in their lifetime [1]. Often presenting with a chronic and recurring course that extends into adulthood [2], anxiety disorders are associated with considerable developmental, psychosocial, and psychopathological impairments [1,3]. The effectiveness of cognitive behavioral therapy (CBT), an adaptive, skills-based psychotherapeutic approach, has been documented in numerous randomized controlled trials and is recommended as the first line treatment for children and adolescents with mild-to-moderate anxiety symptom severity [4-7]. Internet-based CBT (iCBT) aims to increase access and availability of this beneficial first line treatment [8,9] as the delivery of CBT content no longer hinges on face-to-face appointments with specialized therapists. Recent systematic reviews and meta-analyses have found iCBT to be comparably effective at reducing anxiety symptoms in children and adolescents relative to face-to-face CBT [8,10-12], and more effective in reducing symptoms than waitlist conditions [8,11,13-16]. Overall, these findings indicate that iCBT is an effective treatment option that can increase access to care.

iCBT is a complex intervention [17] and is not merely the upload of therapeutic material onto a Web page. iCBT programs incorporate 3 major components: (1) structured and standardized therapeutic content (ie, CBT), (2) technological features (ie, multimedia and email) used to deliver the content, and (3) interactions between the user and the program to engage users in iCBT content and features. These components are characteristics of a *persuasive system*—an intervention designed to change user's attitudes and behavior toward their desired health goal [18-20].

### Motivation and Objective

To date, considerable variety exists in terms of how the 3 iCBT components have been incorporated into iCBT program design. Only 2 studies of iCBT effectiveness have attempted to identify or explain what program components can be used to optimize the therapeutic gains of users and for what reasons. Calear et al [21] explored whether the expertise of the adjunct support person had an effect on intervention outcomes (teacher-only support vs teacher plus mental health education officer support [21]), and Spence et al [22] tested for a difference in adolescents' anxiety reductions because of the specificity of program content (a program with social anxiety disorder–specific content compared with generic anxiety disorder content [22]), but neither study reported a significant difference in outcomes. Therefore, an essential question that remains for the field is, "What components of iCBT work, for whom, and why?" Using realist synthesis methodology, we used a persuasive systems perspective to examine the following:

1. *What design and delivery components are described in studies of iCBT programs for children and adolescents with anxiety?*
2. *What are the components reported in studies that appear to explain the change in anxiety symptoms after completing iCBT?*

## Methods

### Study Design

The realist synthesis provided us with a mixed methods approach to generate proposed explanations (hypotheses) of how and why iCBT programs work despite variations in its design and delivery [23-25]. The synthesis was conducted using the steps recommended by Pawson and Tilley [25,26] and reported in accordance with the Realist and Meta-Narrative Evidence Synthesis: Evolving Standards II [27]. We set out to examine the technological features of iCBT (mechanisms), embedded within delivery and conditions or settings for use (program context), that produced changes in anxiety symptoms for children and adolescents (outcomes). Pawson and Tilley refer to these relationships as context-mechanism-outcome configurations. Thus, the overall purpose of the synthesis was to produce context-mechanism-outcome configurations that hypothesized when and how iCBT programs might be effective in reducing anxiety symptoms among children and adolescents with anxiety.

### Candidate Context-Mechanism-Outcome Configuration Development

We started the synthesis with the generation of a list of *candidate* context-mechanism-outcome configurations. We decided a priori to use an established, valid framework to guide the generation of candidate configurations. This also helped us maintain a consistent and streamlined approach to the synthesis (ie, extract and code data according to framework). We conducted an informal literature scan and held research team discussions to identify preexisting frameworks from the fields of psychology, pediatrics, human-computer interaction, and electronic health (eHealth). The persuasive systems design (PSD) model [28] was selected as the most appropriate framework to direct the candidate configurations and answer our research questions. It is a recent, well-studied model [29] that describes 28 technological design features that can be incorporated into a persuasive system to help the user meet his or her health goals (Multimedia Appendix 1 [30-43]). The model organizes the design features under 4 categories based on their main purpose: primary task support (assists the user in completing their target behavior), dialogue support (provides computer-human communication to guide user toward target behavior), system credibility support (increases user's perceptions of a system's credibility), and social support (leverages the interactions and influence of others).

We used the PSD model to identify PSD features (mechanisms) hypothesized to produce anxiety symptom changes (outcomes) in iCBT programs and recorded these as mechanism-outcome dyads. We then considered the program design and delivery features (context) that might support the operation of the mechanism-outcome dyads and combined them in unified but distinct configurations. The result was 8 candidate context-mechanism-outcome configurations (Multimedia Appendix 2), or initial hypotheses, that formed the basis of our analysis. We refined these configurations during the realist synthesis so that they reflected the iCBT literature. Following analysis, we considered our configurations to be fully developed hypotheses ready for future testing.

### Literature Search

We required diverse literature to inform this synthesis. We sought to include primary or secondary studies of iCBT interventions, conference proceedings, websites, program evaluations, and government or technical reports. We used 3 search strategies to identify this literature: (1) a systematic, comprehensive search of 8 electronic databases from disciplines relevant to the topic (ie, medicine and psychology)—Medline, Embase, Education Resources Information Center, PsycINFO, Cumulative Index to Nursing and Allied Health Literature, Cochrane Library, ProQuest Dissertations & Theses Global, and PubMed for the period from 1990 to 2017, conducted by an information specialist; (2) a manual search using an internet search engine (Google) and gray literature repositories (eg, Association for Computing Machinery Digital Library, Open Gray, Institute of Electrical and Electronics Engineers Digital Library, and Canadian Agency for Drugs and Technologies in Health); and (3) a hand search of medical informatics journals (*Journal of Medical Internet Research*, *Internet Interventions*, *Journal of Cybertherapy and Rehabilitation*, and *Journal of Telemedicine and Telecare*) and the reference lists of included documents and reviews (eg, systematic reviews). Medical Subject Headings terms and text words for the search were based on mental health condition (ie, anxiety and phobias), intervention modality (ie, internet-based and mobile apps), intervention type (ie, prevention and treatment), and therapeutic approach (ie, CBT; Multimedia Appendix 3). We applied the search strategies in an initial search (conducted up until February 2015) and then in 2 updated searches (conducted in November 2017 and in June 2019) to ensure the realist synthesis was current and inclusive.

### Document and Internet-Based Cognitive Behavioral Therapy Program Selection

We were interested in including documents relevant to iCBT programs that were designed for use by children or adolescents aged ≤19 years diagnosed with an anxiety disorder(s) or with anxiety symptoms associated with a disorder as classified according to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders [44]. Documents needed to include information about an iCBT program designed for treating child or adolescent anxiety and be available in English. Documents that detailed information for a transdiagnostic program (eg, treating an anxiety disorder plus depression) were eligible for inclusion but documents of programs designed solely for parent use were not. All eligible documents were grouped according to the iCBT program it represented (ie, program name). We included in the realist synthesis documents of programs that detailed its delivery context (ie, the conditions for program use), PSD mechanisms (ie, information on the technological features for how the program was proposed to work), and impact on anxiety outcomes after program delivery (ie, at least one published study of postintervention effects). These details could be described within 1 document, or across multiple documents, but needed to be available so that at least one context-mechanism-outcome configuration could potentially be generated for each iCBT program.

During the document selection progress, 2 reviewers (authors ADR and LW) independently applied the inclusion criteria using a 2-stage approach. In stage 1, titles and abstracts of documents were screened for potential eligibility (*yes*, *no*, or *unsure*). The reviewers randomly selected 100 documents to assess inter-rater agreement and found *substantial* agreement (Cohen kappa=0.74) [45]. In stage 2, the full text of *yes* or *unsure* documents were reviewed by the 2 reviewers for inclusion or exclusion in the synthesis. In both stages, they resolved discrepancies through discussion (with author ASN) until consensus was reached.

### Literature Appraisal

Quality appraisal of included documents involved assessing relevance to the synthesis objectives and, in the case of research studies, assessing methodological rigor. A total of 2 reviewers (authors ADR and LW) conducted the quality appraisal. Relevance was assessed by reviewing a document's *level of contribution*, the extent to which information was provided on (1) theory and/or the context and sequences for iCBT delivery (context), (2) PSD features, required interactions by the deliverer/user and the program, and/or other proposed program

mechanisms (mechanism), and (3) the impact of iCBT on anxiety symptoms outcomes and explanations for the findings (outcome). The level of contribution was rated *low* if little or no information was provided, *medium* if some information was provided, and *high* if information was well-described, relative to other documents for other programs.

To understand the quality of the research studies that provided outcome data for the synthesis, the methodological rigor of studies was assessed using the Mixed Methods Appraisal Tool (MMAT) [46,47]. The MMAT is a reliable, efficient, and validated tool that provides different sections for assessing studies of qualitative, randomized, nonrandomized, descriptive, and mixed methods design [46-48]. Multiple documents using the same, full dataset (ie, thesis plus published paper of the thesis) received the same MMAT score but was only counted once. MMAT scores could range from 0% to 100%, with a greater score signifying more rigorous criteria were met.

### Data Extraction and Coding

To identify context-mechanism-outcome configurations, we extracted and coded iCBT program data using a data matrix with 6 major domains: (1) document characteristics (eg, study design), (2) participant characteristics (eg, demographics) and study procedures (ie, eligibility criteria), (3) context of iCBT delivery including a program's targeted level of prevention according to the Institute of Medicine (IOM) model [49] and adjunct support details (human-derived technological or therapeutic communication complementary to program delivery), (4) program theory and principles behind iCBT program design, (5) program components or proposed mechanisms (ie, CBT content and PSD features and interactions between the user and program), and (6) pre- to postintervention change in anxiety symptoms. For outcome data, not all studies reported within-group analyses; therefore, absolute changes in anxiety symptoms among children or adolescents who received iCBT were recorded. If original authors referred to previous publications of an iCBT program, we included the document and extracted relevant data. We also extracted partial or full context-mechanism-outcome configurations, if provided by the original authors.

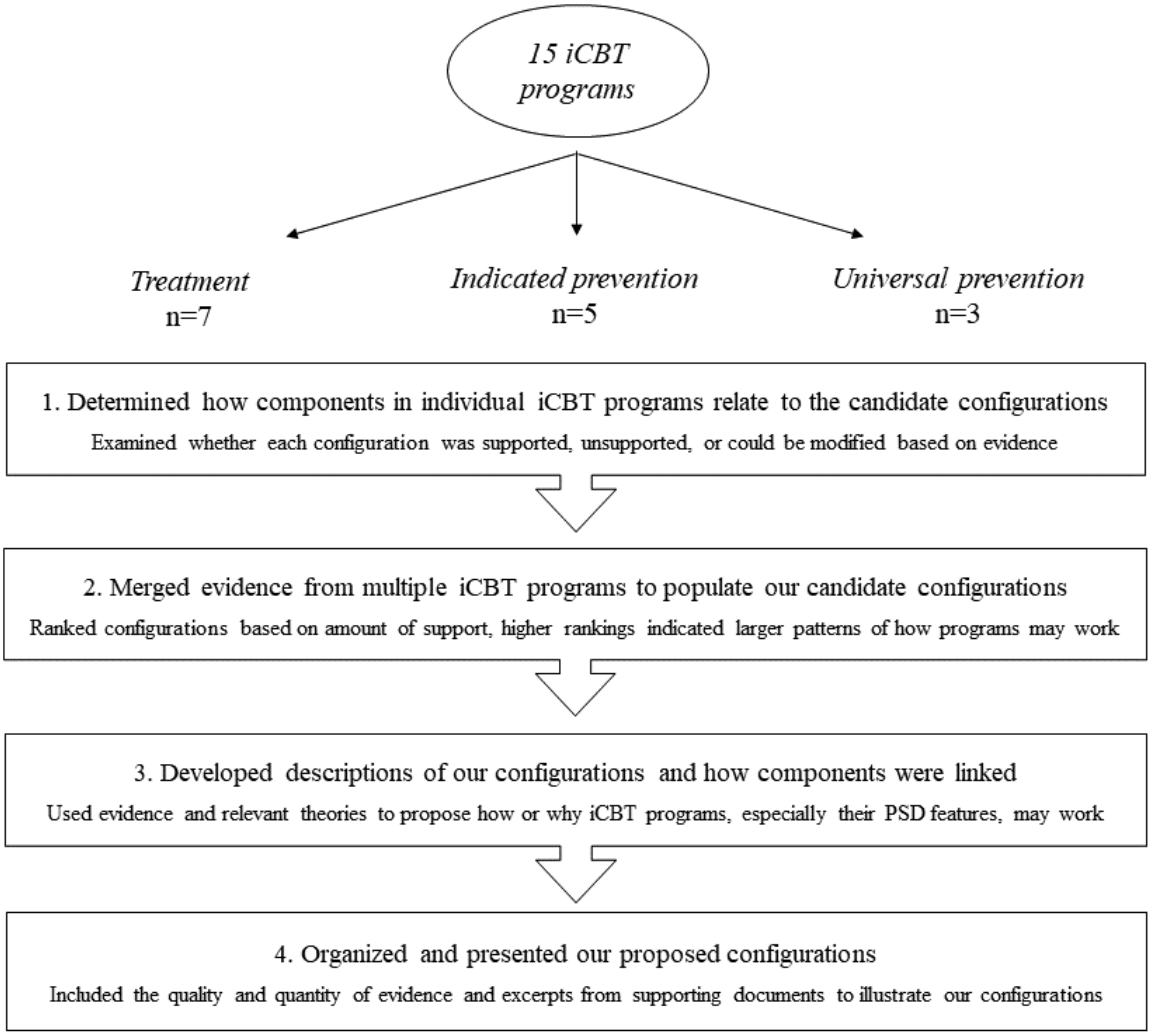
We used the PSD model [20] and a customized codebook to guide the coding process (Multimedia Appendix 1). Similar to previous studies [29,50], PSD features of iCBT programs were coded: (1) when a program feature was executed by technology (eg, video demonstration of an adolescent performing deep breathing) rather than by human action (eg, a parent demonstrating deep breathing in person) and (2) when the feature was a part of the iCBT program, not supporting research study materials, such as an informational website. We coded therapeutic content according to the 5 main CBT components found in the American Academy of Child and Adolescent Psychiatry (AACAP) practice parameter for anxiety disorders [6]: psychoeducation, somatic management skills, cognitive restructuring, exposure methods, and relapse prevention. We also extracted other therapeutic content, such as behavioral activation details and interpersonal therapy techniques [51,52]. We contacted corresponding authors associated with each iCBT program to support accurate and complete extraction and coding of the data. Overall, 80% (12/15) of original authors associated with the included iCBT programs responded to the request for more information. The interpretation of data extraction and coding between 2 reviewers (authors ADR and LW) was checked with a random sample of 10 documents and achieved consensus before the remaining documents were coded by a single reviewer (author ADR).

### Analysis and Synthesis Process

Analysis was conducted at the program level [25], which meant that multiple documents or studies relating to each unique iCBT program were grouped together for analysis of the iCBT program as a whole. Programs were grouped according to their level of prevention using the IOM model [49]—whether they were a universal prevention, indicated prevention, or treatment program (*program type*). The IOM model recognizes that the target population (ie, children or adolescents with baseline anxiety symptoms and an associated level of risk for a disorder) differs according to program type and so does the conceptual focus of the intervention, and together, these differences may influence the fundamental design and delivery of a program (ie, context and clinical techniques) and the expected degree of change users may experience (ie, outcomes) [53].

We analyzed the candidate context-mechanism-outcome configurations in 4 stages using meta-ethnographic [54,55] and realist [24-26] techniques (Figure 1). During this process, information from included documents was synthesized to refine each configuration. In stage 1, we recorded the individual components (ie, contexts, mechanisms, and outcomes) and relationships between components (eg, mechanism-outcome dyads) reported in the documents for each iCBT program. We compared the information for each iCBT program with the candidate configurations (initial hypotheses) and documented whether a candidate configuration was supported, unsupported, modified, or newly generated based on the evidence. In stage 2, reciprocal translation analysis was used to determine if common contexts and mechanisms were being described across programs. The candidate configurations were ranked from the most to least supported, based on the number of iCBT programs supporting each configuration. A configuration was required to be supported by at least two iCBT programs to proceed with the next stage of analysis. We considered configurations with the highest rankings to depict the larger patterns or trends (demi-regularities) of iCBT program components. These candidate configurations became our final hypotheses for how iCBT programs were hypothesized to work.

**Figure 1.** The 4 stages of the realist analysis and synthesis process of internet-based cognitive behavioral therapy (iCBT) programs for children and adolescents with anxiety. PSD: persuasive systems design.



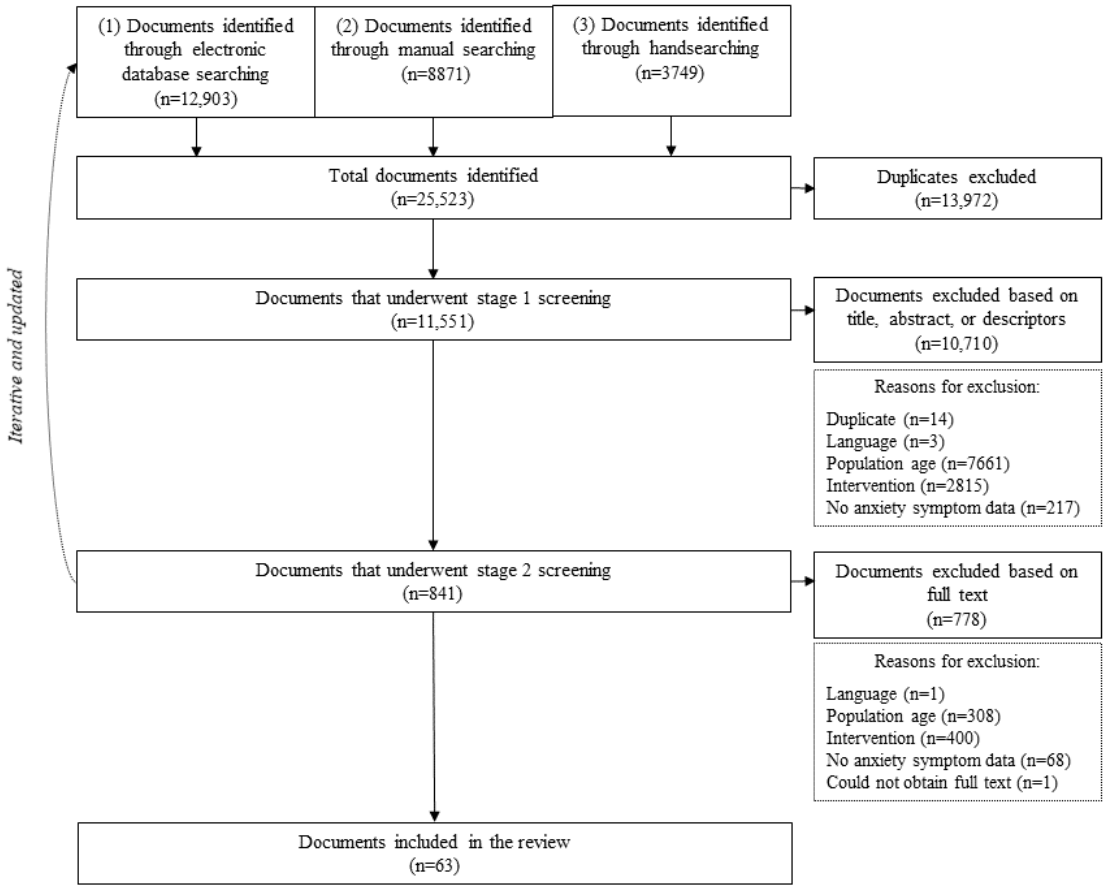

In stage 3, we developed descriptions of how the iCBT program components were linked in our configurations. The descriptions focused on the proposed function (role) of key PSD features in explaining how iCBT programs might reduce anxiety for children and adolescents. To do this, we nested the configurations within our broader understanding of the theoretical underpinnings of the PSD model and CBT, along with original authors' descriptions of the design or delivery of program features. This process allowed us to explore not only *what* iCBT program components might be working together but also *why* they might be doing so. We maintained a level of abstraction that allowed us to express the larger similarities across multiple programs while acknowledging the details that made each configuration unique (using lines-of-argument synthesis). This meant that we did not delve deeper into specific details of contexts, mechanisms, or outcomes. For example, we identified whether adjunct support was provided in programs rather than the specific amount of support provided, and we identified the direction of treatment effect rather than specific effect sizes. This approach was not only necessary because of the data available to us but also ensured that our configurations remained usable and applicable across the programs. During this stage, we also incorporated into the descriptions other factors that could help explain our understanding of the configurations (eg, multiple PSD features working together and differences in user characteristics). In stage 4, we identified the quantity (ie, number of programs) and quality (ie, relevance and methodological rigor) of support associated with each configuration. Research team meetings were used to discuss and improve the final detailed descriptions of our proposed configurations.

## Results

### Included Documents

Figure 2 is a flow diagram outlining the results of the 2-stage literature search and selection process. A total of 63 documents (30 from the initial search, 15 from the updated search conducted in November 2017, and 18 from the updated search conducted in June 2019) describing 15 iCBT programs were eligible and included in the review. The included documents were published studies (n=29), theses (n=5), registered protocols for trials (n=15), study or program websites (n=9), study flyers (n=2), and conference abstracts or posters (n=3).

**Figure 2.** Flow diagram of the literature search and selection process.




## Level of Contribution and Methodological Quality

Details of the quality appraisal are provided in Multimedia Appendix 4 [21,22,30-39,41-43,56-91,92-102]. Across documents, the most details were provided for iCBT program contexts and outcomes. Program mechanisms were not so well described in terms of what the mechanisms were (ie, technological and therapeutic features) and how they were proposed to work. A total of 8 documents were rated as having a *high* level of contribution to understanding contexts, mechanisms, and outcomes [22,31,40,56-60]. These documents were for 6 iCBT programs that provided the greatest contributions to the context-mechanism-outcome configurations we developed: BRAVE-Online, internet-delivered CBT for children with anxiety disorders, internet-delivered CBT for children with specific phobia, internet cognitive behavioral skills–based program, STAY COOL system for test anxiety, and the e-couch Anxiety and Worry program.

MMAT scores were calculated for 35 research studies: 20 randomized controlled trials, 5 nonrandomized studies, 7 quantitative descriptive studies, 1 qualitative study, and 2 mixed methods studies. A total of 22 documents met all 4 MMAT criteria (100%), 7 documents met 3 criteria (75%), 5 documents met 2 criteria (50%), and 1 document met 1 criterion (25%). Lower MMAT ratings were a result of factors such as incomplete outcome data or unacceptable response rates, high withdrawal rates, or no mention of whether groups were comparable.

## Overview of the Contexts, Mechanisms, and Outcomes of Internet-Based Cognitive Behavioral Therapy Programs for Children and Adolescents With Anxiety

### *Contexts: User and Program Delivery Characteristics*

Table 1 presents an overview of the user and program delivery characteristics of iCBT programs, organized according to program type. All programs were computer-based and included some form of adjunct support or program facilitation. Most programs (10/15 programs) were designed to solely target users with reported anxiety symptoms. There were similarities in the delivery setting, workflow, and adjunct support of iCBT programs of the same program type. Treatment programs were most often accessed at home, included 7 or more modules, and incorporated weekly Web-based therapist interaction and parent-dedicated modules. Indicated prevention programs demonstrated more variety in their use setting (eg, home, school, or clinic) and the adjunct support provided (eg, not all programs required parent participation), and the workflow tended to involve fewer modules (ie, typically 6 modules or less). Universal prevention programs were delivered with teacher facilitation in a classroom setting and incorporated the least number of modules relative to other program types. iCBT programs were based on relevant theoretical, anxiety, or CBT literature or published treatment recommendations [30,31,34,90,95], established clinic-based programs, manuals or workbooks [37,39,42,57,94], a school syllabus [35], or were adaptations of a developed iCBT program designed to target a different population or mental health condition [32,76,83,88].

**Table 1.** Overview of internet-based cognitive behavioral therapy user, program, and delivery characteristics.

| Numbered list of programs[a] | Target users' age group and symptom severity[b] | Program delivery | | Therapist support in program | | | Adjunct program support |
|---|---|---|---|---|---|---|---|
| | | Use setting | # of sessions, frequency, or duration of program | Web or email | Phone | In-person | |
| **Treatment programs: 1, 2, 3, 4, 5, 6, 7** | | | | | | | |
| (1) BRAVE-Online | Children and adolescents with an anxiety disorder | Home | 10 weekly sessions plus 2 booster sessions; 60 min each | X[c] | X | —[d] | Parent |
| (2) iCBT[e] for dental anxiety | Children and adolescents with an anxiety disorder | Home plus clinic | 12 weekly modules | X | — | — | Parent, dental professional[f] |
| (3) Internet-delivered CBT[g] for children with anxiety disorders | Children with an anxiety disorder | Home | 11 modules over a 10-week period | X | X | — | Parent |
| (4) Internet-delivered CBT for children with specific phobia | Children with an anxiety disorder | Home | 11 modules over a 6-week period; 15-45 min each | X | X | — | Parent |
| (5) Chilled Out | Adolescents with an anxiety disorder | Home | 8 modules over a 12- or 14-week period; 30 min each | — | X | — | Parent (optional) |
| (6) Group therapy supported iCBT for adolescents with social anxiety disorder | Adolescents with an anxiety disorder | Home plus clinic | 12 weekly modules | X | X | X | Parent |
| (7) iCBT for anxiety disorders among adolescent girls | Adolescents with an anxiety disorder | Home | 7 modules over a 3-month period; 1 hour daily | X | — | — | — |
| **Indicated prevention programs: 8, 9, 10, 11, 12** | | | | | | | |
| (8) Internet cognitive behavioral skills-based program | Children with moderate-to-severe anxiety symptoms | Home | 3 modules[h] with 20 sections over a 12-week period | — | X | — | Parent |
| (9) Internet-supported brief CBT for shy-socially isolated problem | Adolescents with moderate-to-severe anxiety symptoms | School | 6 modules | X | X | — | — |
| (10) STAY COOL system for test anxiety | Adolescents with mild-to-moderate anxiety symptoms | School or home | 6 modules over 8 weeks; 20-30 min for each activity | — | — | X | Researcher[i] |
| (11) Feeling Better | Adolescents with mild-to-moderate anxiety and/or depressive symptoms | Home | 4 modules[j] | X | X | — | — |
| (12) Individually tailored iCBT for adolescents | Adolescents with mild-to-severe anxiety and/or depressive symptoms | Clinic | 6-9 prescribed modules over a 6- to 18-week period | X | X | X | — |
| **Universal prevention programs: 13, 14, 15** | | | | | | | |
| (13) The e-couch Anxiety and Worry Program | Adolescents with no symptoms required | School | 6 weekly sessions; 30-40 min each | — | — | — | Teacher[k], mental health service provider[l] |
| (14) MoodGYM | Adolescents with no symptoms required | School | 5 weekly modules; 30-60 min each | — | — | — | Teacher[k] |
| (15) Thiswayup Schools for Anxiety and Depression prevention courses | Adolescents with no symptoms required | School | 6 (anxiety) or 7 (depression) weekly modules; 40 min each | — | — | — | Teacher[k] |

[a]Categorized according to the Level of Prevention Model [49]: universal prevention—target participants have not been identified on the basis of individual risk (ie, no symptoms required); selective prevention—target participants have a higher risk of developing an anxiety disorder than others; indicated prevention—target participants are at high risk, those who have anxiety signs or symptoms but do not currently meet diagnostic levels; and treatment—target

participants are diagnosed with an anxiety disorder.

[b]Children: mean study age of users ≤12 years; adolescents: mean study age of users ≥13 years. The anxiety severity reported was the severity required for study inclusion; anxiety severity was not necessarily the baseline level of symptoms participants had.

[c]This type of therapist support was incorporated.

[d]This type of adjunct support was not incorporated.

[e]iCBT: internet-based cognitive behavioral therapy.

[f]A dental professional (a dentist, dental hygienist, or dental assistant) provided exposure at a dental clinic.

[g]CBT: cognitive behavioral therapy.

[h]2 blocks of modules (containing 9 major sections) are dedicated to mothers, and 1 module block (containing 12 major sections) is dedicated to the child plus mother.

[i]Research assistant or graduate student was present to facilitate aspects of the study, such as assessment and troubleshoot technical issues.

[j]The first 4 out of a possible 12 modules were delivered for the purpose of this study: Introduction, Activity and Motivation, Thoughts and Feelings, and Stress Management [95].

[k]Program administration was facilitated by a classroom teacher. The teacher was available for general guidance but did not provide an active therapeutic role in the program.

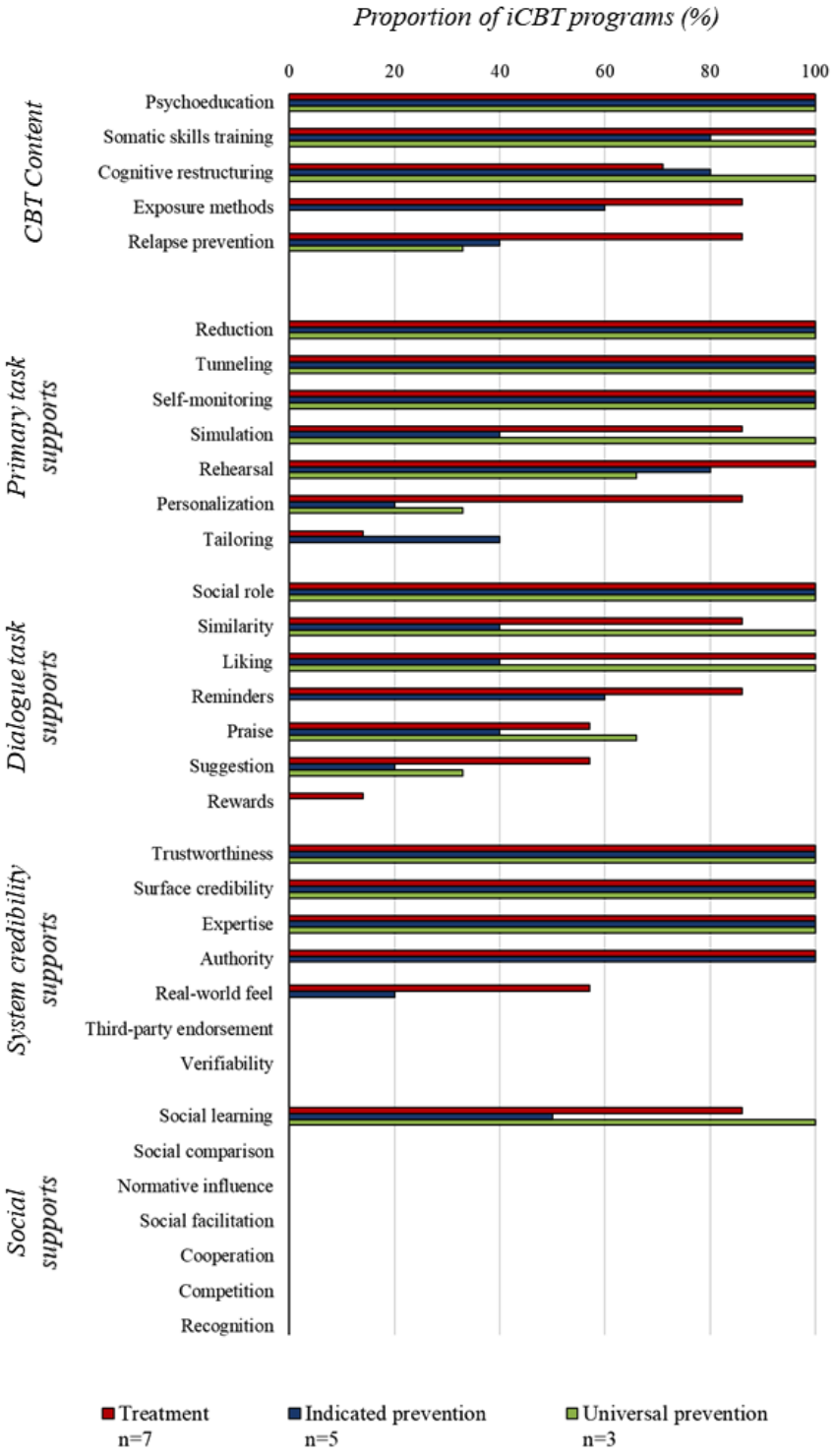
[l]A mental health service provider was present in 1 study of the program to facilitate program administration and address student questions [103].

### *Mechanisms: Therapeutic Content and Persuasive Systems Design Features*

Figure 3 provides an overview of the proportion of iCBT programs that incorporated specific CBT content and PSD features, organized according to program type. All programs described themselves as *CBT-based* and contained AACAP recommended CBT components, although considerable variability in the type and quantity of components was found based on program type and age group of target users. Many programs also integrated techniques with an interpersonal focus, such as assertiveness training and problem-solving skills, to reduce environmental stressors and enhance social support [104]. Psychoeducation and somatic skills training were found in all iCBT programs. Cognitive restructuring was reported in more than half of the treatment programs and in nearly all the indicated and universal prevention programs. Relapse prevention was incorporated in a minority of prevention-based programs. Exposure methods were not delivered to users of universal prevention preventions.

Treatment programs incorporated the most PSD features, followed by indicated prevention and then universal prevention programs. Out of the 4 PSD support categories, features from the primary task support and dialogue support categories were most widely used. In terms of primary task supports, iCBT programs of all IOM program types incorporated reduction and tunneling to regulate the logical and incremental presentation of module content to users, mimicking the progressive delivery format of face-to-face CBT. Self-monitoring of users' iCBT progress was also a primary task support feature common to all programs. Social role, a dialogue support feature, created a virtual presence of *others* in the program through Web- or email-based messaging between the user and therapist or recurring graphics or videos of real or animated peers. System credibility support features, trustworthiness, and surface credibility, although not explicitly reported, were inherent in all iCBT programs, as they were designed and delivered (tested) within a research study (ie, use of confidentiality and consent processes and declared academic affiliations). Authority features were associated with program content that was presented by a *reliable source* (ie, therapist) and was, therefore, only incorporated in treatment and universal prevention programs with adjunct therapist involvement. Social learning was the only social support feature included in iCBT programs, but not all indicated prevention programs utilized it. iCBT from different program types varied to the greatest extent on their use of personalization, tailoring, reminders, liking, and similarity features. Multimedia Appendix 1 provides additional examples of how PSD features were reported in the documents included in this synthesis.

**Figure 3.** Frequency of the cognitive behavioral therapy (CBT) content and persuasive systems design features across 15 internet-based cognitive behavioral therapy (iCBT) programs, organized according to program type.




### *Outcomes: Changes in Anxiety Post Intervention*

Across program types, there was an overall trend for reduced anxiety symptoms among children and adolescents who received iCBT. An overview of the outcomes is provided in Multimedia Appendix 5. Among treatment programs, anxiety diagnoses, clinical severity, and parent- and user-reported symptoms were reduced post intervention in 98.5% of studies. Among indicated prevention programs, anxiety diagnoses, parent- and user-reported symptoms were reduced post intervention in 100% of studies. Among universal prevention programs, user-reported anxiety symptoms were reduced post intervention in 83.3% of studies.

### Key Relationships Between Internet-Based Cognitive Behavioral Therapy Program Contexts, Persuasive Systems Design Mechanisms, and Outcomes

We found that reductions in anxiety outcomes were reported across iCBT programs with many shared mechanisms and delivery contexts. Self-monitoring, simulation, social role, similarity, social learning, and rehearsal were common PSD features across all program types; however, mechanisms for customizing program content (ie, personalization and tailoring) distinguished treatment, indicated prevention, and universal prevention programs from one another. The key aspect of iCBT context that supported the mechanism-outcome interactions was adjunct support. The adjunct support person (eg, therapist, parent, and teacher), their expertise, and the intensity and frequency of their communication (eg, weekly personalized feedback and technical troubleshooting as needed) was associated with the program type, and, therefore, also the characteristics of users, such as age and symptom severity. In this way, treatment programs received the greatest amount of adjunct support relative to indicated and universal prevention programs.

### Context-Mechanism-Outcome Configurations

The refined set of context-mechanism-outcome configurations is summarized in Table 2, according to program type. Configurations, organized by PSD mechanism, are based on included information from documents that ranged in level of contribution (low to high).

**Table 2.** Summary of the 11 context-mechanism-outcome configurations for internet-based cognitive behavioral therapy programs for children and adolescents with anxiety.

| Context—user characteristics and adjunct support | Mechanisms—PSD[a] features and proposed function | Outcomes—trend in anxiety changes, pre- to postintervention[b] | Contributing programs | Mean MMAT[c] score, % | Supporting studies where reductions of anxiety were found[d], % |
|---|---|---|---|---|---|
| **Treatment programs: 1, 2, 3, 4, 5, 6, 7** | | | | | |
| **Context: users were children diagnosed with an anxiety disorder(s); adjunct support provided by a therapist, parent and/or professional** | | | | | |
| Configuration 1 | Self-monitoring: to increase users' attention to and comprehension of anxiety-related feelings or behaviors, track and present users' program progress toward anxiety management or symptom reduction, and assess users' accumulation of program-related knowledge | Reductions in user- and parent-reported symptoms, diagnoses, and clinical severity | Programs 1-7 | 88 | 98.5 |
| Configuration 2 | Simulation + social role + similarity + social learning: to normalize users' experience of anxiety and increase motivation or willingness to improve their mood and model the application of new anxiety management skills | Reductions in user- and parent-reported symptoms, diagnoses, and clinical severity | Programs 1-6 | 91 | 97.4 |
| Configuration 3 | Rehearsal: to provide opportunities for developing fear tolerance, reduction, and/or extinction and reinforce the application of program concepts, behavioral anxiety management strategies, and problem-solving skills | Reductions in user- and parent-reported symptoms, diagnoses, and clinical severity | Programs 1-7 | 88 | 98.5 |
| Configuration 4 | Personalization + social role + trustworthiness + expertise + authority: to provide customized feedback on user's program activity to increase accurate comprehension and application of anxiety management concepts and skills | Reductions in user- and parent-reported symptoms, diagnoses, and clinical severity | Programs 1-6 | 91 | 98.5 |
| **Indicated prevention programs: 8, 9, 10, 11, 12** | | | | | |
| **Context: users were children or adolescents with mild-to-severe anxiety symptoms; adjunct support was provided by a therapist, parent and/or researcher** | | | | | |
| Configuration 5 | Self-monitoring: to increase users' attention to and comprehension of anxiety-related feelings or behaviors, track program progress toward anxiety management/symptom reduction, and assess users' accumulation of program-related knowledge | Reductions in user- and parent-reported symptoms and diagnoses | Programs 8-12 | 89 | 100 |
| Configuration 6 | Simulation + social role + similarity + social learning: to normalize users' experience of anxiety and increase motivation or willingness to improve their mood and model the application of new anxiety management skills | Reductions in user- and parent-reported symptoms and diagnoses | Programs 8 and 11 | 100 | 100 |
| Configuration 7 | Rehearsal: to provide opportunities for developing fear tolerance, reduction, and/or extinction and reinforce the application of program concepts, cognitive and behavioral anxiety management strategies, and problem-solving skills | Reductions in user- and parent-reported symptoms and diagnoses | Programs 8-12 | 89 | 100 |
| Configuration 8 | Tailoring: to adapt program content based on user's demographic or mental health condition to improve the relevance for each user | Reductions in user-reported symptoms and diagnoses | Programs 11 and 12 | 100 | 100 |
| **Universal prevention programs: 13, 14, 15** | | | | | |
| **Context: users were adolescents who are not required to have any anxiety symptoms; adjunct support was teacher-facilitated program administration** | | | | | |
| Configuration 9 | Self-monitoring: to increase users' attention to and comprehension of anxiety-related feelings or behaviors, track and present users' program progress toward anxiety management or symptom reduction, and assess users' accumulation of program-related knowledge | Reductions in user-reported symptoms | Programs 13-15 | 70 | 83.3 |

| Context—user characteristics and adjunct support | Mechanisms—PSD[a] features and proposed function | Outcomes—trend in anxiety changes, pre- to postintervention[b] | Contributing programs | Mean MMAT[c] score, % | Supporting studies where reductions of anxiety were found[d], % |
|---|---|---|---|---|---|
| Configuration 10 | Simulation + social role + similarity + social learning: to normalize users' experience of anxiety and increase motivation or willingness to improve their mood and model the application of new anxiety management skills | Reductions in user-reported symptoms | Programs 13-15 | 70 | 83.3 |
| Configuration 11 | Rehearsal: to provide opportunities for developing fear tolerance and reinforce the application of program concepts, cognitive and behavioral anxiety management strategies, and problem-solving skills | Reductions in user-reported symptoms | Programs 13 and 14 | 75 | 80 |

[a]PSD: persuasive systems design.

[b]Categorized according to type of anxiety measure used, although specific instruments varied among studies.

[c]MMAT: mixed methods appraisal tool.

[d]Percentage of studies reporting a reduction in anxiety for internet-based cognitive behavioral therapy participants from pre- to postintervention.

### *Treatment Programs, Configurations 1 to 4*

#### Configuration 1: Self-Monitoring

Treatment programs for children with an anxiety disorder, delivered with adjunct therapist, parent, or professional support and include self-monitoring, may produce postintervention reductions in user's anxiety (diagnoses, clinical severity, self-reported, and parent-reported symptoms). Self-monitoring was part of the workflow for each module of the BRAVE-Online program and included regular tracking of symptoms and interactive activities and end-of-module quizzes to "facilitate attention and comprehension of material" [36]. Chilled Out program participants were presented with a weekly progress chart based on their reports of anxiety interference in their daily lives [83]. During program tasks, self-monitoring was employed using automated *pop-ups* stating the accuracy of users' entries (ie, corrective comments) to ensure understanding of important concepts [36]. The adjunct support therapist encouraged users to self-monitor and record details of their in vivo (real world or offline) practice activities [39,41], including changes in anxiety following exposure exercises [37].

#### Configuration 2: Simulation, Social Role, Similarity, and Social Learning

Treatment programs for children with an anxiety disorder, delivered with adjunct therapist, parent, or professional support and include simulation with a social role, similarity, and social learning features, may produce postintervention reductions in user's anxiety (diagnoses, clinical severity, self-reported, and parent-reported symptoms). These features were evident in videos or animations of peers, cartoon, and real-life characters to illustrate the experience of different emotions and the application of therapeutic skills, such as goal setting, developing fear hierarchies, and completing exposure activities [36,37,41,83]. Age-appropriate characters "provided 'models' for the use of coping strategies to overcome anxiety problems" [36]. Role models were designed to be appealing and relatable to users and their anxiety-related challenges; they represented someone with whom "the child can identify [with] and will be more likely to learn from" [58] (similarity). In another treatment program [37], the development of exposure-based film scenes used for fear extinction [105,106] of dental procedures were based on the principles of observational learning and the development of self-efficacy [107]. Email communication between the user and adjunct therapist (social role) could mimic or complement simulations, as therapists provided additional anxiety management instructions, tutorials or helped users problem-solve and plan exposure activities related to their specific situation or fears [76].

#### Configuration 3: Rehearsal

Treatment programs for children with an anxiety disorder, delivered with adjunct therapist, parent, or professional support and include rehearsal features, may produce postintervention reductions in user's anxiety (diagnoses, clinical severity, self-reported, and parent-reported symptoms). Rehearsal was incorporated in brief, interactive tasks to be completed during the module (eg, drag this sentence to the correct term and drop it there) [41], quizzes for comprehension (eg, recap or summary quizzes) [58], or more in-depth, application-based worksheets at the end of the module [37,90]. For example, in BRAVE-Online, "Participants consolidate[d] learning of these [anxiety management] strategies through completion of weekly [Web-based] homework tasks, known as 'extreme challenges'" [36]. Postmodule rehearsal activities recommended users to apply their target skill in real life anxiety-provoking situations outside of the program (ie, exposure exercises) [58]. An adjunct therapist was available to help structure and monitor some of these rehearsal activities. For example, in preparation for exposure activities, a supportive telephone call or message from the therapist assisted the user in developing a suitable exposure hierarchy [36,88].

#### Configuration 4: Personalization, Social Role, Trustworthiness, Expertise, and Authority

Treatment programs for children with an anxiety disorder, delivered with adjunct therapist, parent, or professional support and include personalization, a social role, trustworthiness, expertise, and authority, may produce postintervention reductions in user's anxiety (diagnoses, clinical severity,

self-reported, and parent-reported symptoms). Personalization provided a sense of program relatedness or knowing of the user through automated or manual features based on demographic details or program activity of the user. For example, the user's name and that of his or her adjunct therapist could be populated throughout the modules [42]. Personalized *pop-ups* with immediate and specific feedback (eg, explanations for correct and incorrect answers [36]) on quizzes and tasks were also provided. In addition, the adjunct therapist (social role) monitored users' responses to tasks and homework assignments and provided personalized written feedback by email. Personalized feedback was used to "reinforce effort and success and provide corrective information if required" [36], to "answer questions and clarify treatment content, increase motivation and to help solve problems" [41], or to "[ensure] adolescents' understanding of the program elements" [83]. As the therapist could access user-specific information stored within the program, a response could be crafted with objective and supportive input through the therapist's professional lens (authority); therefore, trustworthiness and expertise were features considered to be inherent to this personalized feedback process.

### *Indicated Prevention Programs, Configurations 5 to 8*

#### Configuration 5: Self-Monitoring

Indicated prevention programs for children or adolescents with mild-to-severe anxiety symptoms, delivered with adjunct therapist, parent, or researcher support and include self-monitoring, may produce postintervention reductions in user's anxiety (diagnoses, self-reported, and parent-reported symptoms). Self-monitoring was incorporated in the Feeling Better program using standardized symptom assessments at the beginning of modules as a way "to monitor symptom change" [43] over the course of the program. For some programs, symptom tracking was an essential part of the ongoing risk management of users [32,43]. The program or the adjunct support therapist would respond (automatically or manually) to safety concerns that arose from these assessments by providing additional mental health coping resources. In addition to mood, the program tracked the user's progress toward goal achievement via homework completion. Module quizzes in some programs [31,57] were a means for users to review his or her understanding of new program concepts or skills [57].

#### Configuration 6: Simulation, Social Role, Similarity, and Social Learning

Indicated prevention programs for children or adolescents with mild-to-severe anxiety symptoms, delivered with adjunct therapist, parent, or researcher support and include simulation with a social role, similarity, and social learning, may produce postintervention reductions in user's anxiety (diagnoses, self-reported, and parent-reported symptoms). Simulation was incorporated in examples or demonstration videos of individuals (social role) "illustrat[ing] certain concepts in the program" [57], providing suggested solutions, or working through their problems (social learning) [43]. The examples and activities provided in the Feeling Better program were specific to target users and their reported *stressors* (similarity) and were employed to "encourage practice and enhance learning of material" [43].

#### Configuration 7: Rehearsal

Indicated prevention programs for children or adolescents with mild-to-severe anxiety symptoms, delivered with adjunct therapist, parent, or researcher support and include rehearsal, may produce postintervention reductions in user's anxiety (diagnoses, self-reported, and parent-reported symptoms). The STAY COOL program described including evidence-based practice activities (rehearsal) for reducing physical and cognitive test anxiety symptoms and pairing these coping activities with desensitizing exposure tasks to improve the program's effectiveness [31]. In the same program, postmodule quizzes presented users with "a less-threatening, relatively low stakes exposure by testing them on recently obtained information in an untimed scenario" [31]. In the internet-based cognitive behavioral skills program, *Talk Time* was used to prompt the mother (adjunct parental support) and child to discuss a therapy topic or work together on a task [57]. In addition, exposure hierarchies were used to guide users' practice (rehearsal) outside of the program as well. Adjunct therapists could provide rehearsal support (eg, encouragement and suggestions), if necessary, through their communications with the user.

#### Configuration 8: Tailoring

Indicated prevention programs for children or adolescents with mild-to-severe anxiety symptoms, delivered with adjunct therapist, parent, or researcher support and include tailoring, may produce postintervention reductions in user's anxiety (diagnoses, self-reported, and parent-reported symptoms). iCBT content was tailored according to the user's symptom profile. In the Feeling Better program, "A standardized assessment of symptoms of distress… [was] built into the start and end of core program modules to monitor symptom change and to help the user choose customized streams of program content specific to their emotional distress [such as anxiety, depression, or stress]" [43]. Another program had gender-specific versions (male and female), so that therapeutic examples matched the sex of the user [43]. For the individually tailored iCBT program for adolescents, the adjunct therapist used results from a baseline diagnostic interview to select module content (ie, psychoeducation and case examples) that corresponded to the user's primary anxiety concern [32]. According to Silfvernagel (2017), a tailored iCBT program was "designed to identify a participant's unique symptom profile and to provide information and skills that are likely to be helpful based on said profile" [96], aiming to improve the usefulness of the intervention.

### *Universal Prevention Programs, Configurations 9 to 11*

#### Configuration 9: Self-Monitoring

Universal prevention programs for adolescents with minimal or no symptoms, delivered with teacher facilitation and include self-monitoring, may produce postintervention reductions in user's self-reported anxiety symptoms. The MoodGYM program provided anxiety and depression quizzes (self-monitoring) before and after each module. Adolescents' answers to quizzes and other program tasks were saved in a *personal Web-based workbook* that could be accessed by them at any time [34], serving as a benchmark for which they could compare changes over the course of iCBT. Electronic questionnaires were administered to adolescent users of Thiswayup Schools who

also received notification if their scores were above average [102]. In the case of all 3 universal prevention programs, a teacher was present for iCBT administration and could provide referral advice if an adolescent's symptoms required professional follow-up [108].

#### Configuration 10: Simulation, Social Role, Similarity, and Social Learning

Universal prevention programs for adolescents with minimal or no symptoms, delivered with teacher facilitation, and include simulation with a social role, similarity, and social learning, may produce postintervention reductions in user's self-reported anxiety symptoms. Cartoon vignettes (similarity and social role) provided examples of anxiety management behaviors and responses as a regular part of the modules (simulation and social learning). For example, at the beginning of the MoodGYM program, adolescent users were "introduced to six distinct characters that form the basis of examples and discussion. Each character has a specific way of dealing with stressful situations, which [were] explored in the program." [34]. Similarly, Thiswayup Schools used a storyline of cartoon teenagers with anxiety or depression to demonstrate ways to solve real life problems [35].

#### Configuration 11: Rehearsal

Universal prevention programs for adolescents with minimal or no symptoms, delivered with teacher facilitation, that include rehearsal may produce postintervention reductions in user's self-reported anxiety symptoms. The e-couch Anxiety and Worry program included rehearsal exercises *to help users understand themselves and others better* [99]. The MoodGYM program also provided opportunities for users to apply therapeutic strategies to their own situation. Both quizzes and homework exercises were incorporated for users to practice their skills. User's answers were recorded in their Web-based workbook and could be accessed at any time [34]. Rehearsal activities appeared to focus on cognitive restructuring, problem-solving, and interpersonal skills.

## Discussion

### Principal Findings

Our study systematically documented important similarities and differences in the design and delivery of iCBT components across 15 existing programs, which to our knowledge, is the first study of its kind for children or adolescents with anxiety. Anxiety reductions were reported in more than 98% of studies we reviewed. Our use of realist synthesis methods enabled the development of 11 context-mechanism-outcomes configurations that hypothesized the PSD features (technology-based mechanisms) that might contribute to the observed reductions in anxiety symptoms (outcomes), as they relate to key user and delivery features (context). Our results point to the need for increased emphasis on PSD in the development, evaluation, and reporting of iCBT programs for children and adolescents with anxiety concerns and further research designed to establish their relationship with improved anxiety symptomatology.

### Design and Delivery Components of Internet-Based Cognitive Behavioral Therapy for Children and Adolescents With Anxiety

The 11 configurations included PSD features from all 4 support categories. However, some category features were more often linked to iCBT program effects than others. Our findings highlight the central role of primary task supports in iCBT interventions for children and adolescents with anxiety, followed by dialogue support and system credibility support categories. Only 1 social support feature was supported by our analysis. These findings are in line with others [29,109] who also found primary task supports to be the most frequently reported persuasive features in technology-based health interventions. As primary task support features are considered to "aid users in completing their tasks and tracking and achieving their goals" [110], they have a similar aim to the goal-directed nature of iCBT programs. Dialogue support features keep "the user active and motivated in using the system" [111], so the user has more time and opportunities to complete their intended behavior(s) in the program. Both primary task support and dialogue support features have been linked to intervention effectiveness in previous studies in other fields [112-114].

### Toward Explanatory Persuasive Systems Design—Informed Models of Internet-Based Cognitive Behavioral Therapy Effects With Children and Adolescents With Anxiety

All iCBT programs in this study contained multiple PSD features. Although detailing the frequency of PSD features in iCBT provides some insight into what a user does within a program (activity), this information does not describe the important patterns or combinations of PSD features or explain why a program may or may not be effective. However, our findings suggest that (1) no PSD feature is applied in isolation and will likely not *work* as such (ie, some synergy is expected and essential) and (2) different PSD features have different functions, so we cannot assume that more features are better. We identified features from within and across different PSD support categories that were employed simultaneously, suggesting some synergistic or additive effect in their grouping (eg, simulation—a primary task support + social role—a dialogue support + similarity—a dialogue support + social learning—a social support). There have been attempts to examine the quantity and combination of PSD features in relation to the effectiveness of other health-based programs [29,109,111,115-117], but the literature is inconsistent and inconclusive. Wildeboer et al [111] indicated a positive relationship between effect sizes and the number of PSD features used in an intervention [111]. Additive or synergistic effects between multiple features, such as simulation and rehearsal, have been reported [117]. In contrast, other features together may negate or interfere with their persuasive potential [117], depending on the features and what persuasive support category they are from [111]. Future studies are needed to systematically assess the use and combination of multiple features as they relate to program effects to optimize the design of programs.

Overlap with the proposed context-mechanism-outcome configurations we generated and the literature on internet-based

interventions indicate larger patterns for how these features operate. For example, others have hypothesized that self-monitoring might be used to increase user's knowledge, self-awareness, and ability to monitor and manage their health [118,119]. Simulation allows users to cognitively or physically play out hypothetical situations [120], such as health-related decision making [121], to observe their effects before applying strategies to the real world [122]. In face-to-face CBT studies, rehearsal promotes skill acquisition [123], self-efficacy, and confidence with health management techniques [124,125]; rehearsal has been critical to the cognitive improvements found during treatment [126-128]. We propose that rehearsal may have a similar function in iCBT to that in face-to-face CBT, justifying its use in iCBT programs.

The consistent incorporation of specific key PSD features (rehearsal, self-monitoring, and simulation) in configurations across all program types indicates that these may be *signature features* that appeared to be particularly effective at producing the desired effects of iCBT regardless of the program type—perhaps because of the mental (psychological) activity and the interactions (effortful, suggestive, and engaging) between the user, the program content, and its features they incite. Our proposed key PSD features may produce symptom reductions in iCBT because they initiate higher-order cognitive processes, such as information recall, mental reflexivity, and future planning, much similar to the CBT content in these programs as well (ie, cognitive restructuring) [129], that may lead to longer lasting changes in learning and behavior. This observation supports a foundational conceptualization of persuasive systems as being a medium or tool for behavior change [19,130].

Differences in key PSD features may distinguish iCBT programs of one program type from another (ie, indicated prevention programs used tailoring whereas treatment programs used personalization). It has been recognized that user characteristics (eg, symptom severity and motivation), the focus of a program (eg, technological or therapeutic elements incorporated and the *at risk* behaviors targeted), and expected benefits (eg, degree of reduction in anxiety) differ depending on program type (eg, universal prevention, indicated prevention, and treatment) [53]. It may be that as the risk level and severity of symptoms of users increases from universal prevention (general population) to indicated prevention (low to high risk) to treatment programs (a diagnosed disorder), so does the program's ability to adapt to user characteristics to improve its applicability and potential effectiveness (eg, providing relevant content based on user's age and providing individual feedback on user's practice activities). We believe maintaining the program type categorization is important in future testing of the PSD-based hypotheses as this categorization may help account for the distinct design and delivery components and the measures of effectiveness used (eg, primary outcomes, instruments, and significance level) across program types. Taking the unique contexts, mechanisms, and outcomes across program types into consideration will also help prepare the evidence base for implementation efforts of iCBT for anxious children and adolescents, for example, identifying important aspects of delivery setting, program support, or intervention features that may influence program effects [76,131,132].

## The Context-Mechanism Relationship

Realist synthesis methods focus on uncovering both the mechanisms of a complex intervention and their relationship to context [17,133-135]. We observed the important effect that the delivery context had on the PSD mechanisms that were included in iCBT programs, further confirming the importance of examining iCBT programs of a similar *program type* together. For example, we found that the context of all universal prevention programs involved widespread delivery in schools, during regular class periods, to all students in attendance, by a teacher with no specialized mental health training. This aspect of context differed considerably from indicated prevention and treatment programs that had a primarily *self-led* delivery format (ie, users could log into the program from any location at any time) where minimal, but some, Web- or email-based interaction with an adjunct support person was provided. PSD features could be affected by program contexts in a way that determined their presence or absence and the quality or how they were delivered. An example of this is that personalized feedback was provided to users only if an adjunct therapist was available to craft and deliver the message—a feature provided to users of treatment and indicated prevention programs. Another example is, in terms of iCBT practice, at-home or clinic-based delivery of programs required users to complete Web-based homework (rehearsal), whereas with some school-based universal prevention programs, paper-based homework (non-Web-based) was assigned to users during class.

School-based universal prevention programs have aspects of context (ie, setting of program use) that are different from indicated prevention and treatment programs, making their design and delivery unique [136]. In this study, we did not include the setting (home, clinic, or school delivery) in the proposed configurations as an understanding of how this context relates to specific PSD features to affect users' anxiety did not emerge in our analyses. However, indications of a relationship between use setting, adjunct support, and program type (eg, the self-led delivery format of treatment and indicated prevention programs) was evident, indicating that the consideration of the impact of setting in future studies is warranted.

## Strengths and Limitations

We took a high-level perspective to develop hypotheses that may explain the effects of iCBT as a complex intervention. To our knowledge, this is the first study to systematically describe what and how PSD features may relate to symptom reductions in iCBT across programs for children and adolescents with anxiety. Although our findings may be similar to those of adult-based studies of internet-based interventions (eg, rehearsal [117] and self-monitoring [118]) or intuitive to researchers and developers in the iCBT field, no formal exploration of the effects of the PSD features on iCBT program outcomes for children and adolescents has previously been conducted. Our study acknowledged that there might be PSD features unique to programs designed for users within our age range (eg, social learning and peer demonstrations, ie, simulation, seemed especially important for children and adolescents using iCBT).

Previous research suggests that the age and developmental stage of program users (eg, cognitive development: autonomous thinking and socioemotional: theory of mind) can affect the acceptability of an intervention [16,137,138] and intervention features (eg, tailoring, interactivity, and reinforcement) [139-141], indicating that there are unique iCBT design and delivery considerations to account for with children and adolescents that cannot be presupposed based on the adult literature [142,143].

This review has several strengths. We followed established and rigorous methods for conducting and reporting realist syntheses [24,26,27]. We included diverse, high-quality evidence from published and gray literature and used mixed methods for our analysis. Our approach to program evaluation was *inward-looking* in that it used data from iCBT programs and its users only. This allowed us to focus our analytic efforts to uncovering the within-iCBT relationships between design and delivery features (program contexts and mechanisms) that may produce the outcomes observed. With increasing emphasis being placed on the need for theory to guide internet-based intervention development [144-146], especially theories that consider intervention content, technology, and context together [147], our findings may inform theoretical developments in the field by providing new ideas around intervention processes and elements to test in future clinical trials of program effectiveness. We took some important first steps in the theory-building process (laying a foundation of evidence) by bringing together the fragmented and diverse data of iCBT programs, attempting to clearly define and report iCBT design and delivery features, highlighting important relationships between variables [24,148], and creating generalizable hypotheses. Another strength of this study is our use of the PSD and IOM models to organize the collection, analysis, interpretation, and presentation of data [149]. Although not applied by the original authors of the included documents, the models helped us identify and link contexts, mechanisms, and outcomes in a systematic way within and across programs.

Several challenges placed limitations on our findings. The 11 context-mechanism-outcome configurations we developed were dependent on the level of detail provided in the documents included in this synthesis. iCBT program descriptions were brief and details around therapeutic or technological features used (and associated theory or justification) were limited. Thus, the specifications of each technological (PSD) feature are not accounted for with our approach (which required a high level of abstraction) and readers should consider that the differences within features of the same type may be just as large as the differences across feature types (eg, rehearsal activities may differ among iCBT programs but these differences are not included in our configurations). We hope the hypotheses that we have generated can be applied to more detailed studies in the future that explore this important issue. In addition, few ineffective interventions (those that did not generate anxiety reductions) were identified for our review; therefore, we were unable to explore aspects of the delivery context or PSD features that might contribute to undesirable treatment effects with iCBT. As the dissemination and use of reporting standards (eg, Consolidated Standards of Reporting Trials–eHealth [150]) and requirements to document the design and delivery components for internet-based interventions become more common, we may not need to rely on additional models to operationalize data for comparisons across studies. We also acknowledge that information on other factors (ie, mediators or moderators) that may affect how iCBT programs work, such as user's psychological characteristics (eg, cognitive processing style, beliefs or attitudes, skills, and literacy [151]), user engagement (eg, adherence, satisfaction, and motivation [152]), or environmental and cultural influences (eg, health care policies, user's location, and societal perceptions of health), were not included in the configurations because of the lack of or inconsistent reporting. Thus, our proposed hypotheses for how iCBT programs for children and adolescents with anxiety work provide a constructive start to understanding their function but may not be complete. For example, once we better understand user characteristics, we may be able to identify subgroups of users who respond to iCBT, or some features of it, more than others. Although organizing our findings by program types led to a redundancy in the PSD mechanisms in configurations across program types, this redundancy also demonstrated the similarities that were universally found in iCBT programs. In the future, we recommend a more *formal* consideration of program type (ie, explicitly identifying the program's targeted level of prevention) before designing and evaluating a program, as there are important differences in the target users, program design and delivery, and outcome measures used that may have a significant impact on program effects that should not be overlooked.

## Future Directions

As more complex and sophisticated technological mediums or delivery methods (ie, mobile phones and wearables) and features (ie, gamification, virtual reality, and virtual agents) are being developed and incorporated into new technology-based treatments, we need to understand the *first principles* for how the individual and most basic applications of PSD features in iCBT programs work, so we can *scale up* our understanding of their effects in parallel with advancing technology and the complexity of program design. This review highlights 2 recommendations for future directions in the iCBT field.

First, studies designed to assess the impact and functions of identified program components and identify other components that are relevant for the design of new iCBT programs for children and adolescents with anxiety are needed. Evaluating individual program features to understand their theoretical level of action (what the feature intends to do; eg, based on CBT or the PSD model), instantiation (how the feature was executed; eg, timing and volume), quality (a distinguishing aspect of the feature; eg, degree of personalization, size, or color), and their effect (the result or consequence of a feature; eg, initiating and reinforcing behavior) [153-156] may provide insights into what the most persuasive features are and how they can be deliberately combined to support users' desired behavior change.

Evaluation of individual features requires the use of certain methodological frameworks [157,158] and study designs that allow for more timely feedback, iteration, and fewer resources for testing (ie, participants, multiple health care centers, and

funds). For example, modeling and predictor analyses [159,160], multifactorial designs [161-163], trials with multiple treatment arms [164], adaptive evaluation strategies (ie, the multiphase optimization strategy [165,166]), or the use of mixed methods and the triangulation of data [167,168] may be attractive alternatives to traditional clinical trials [169].

Second, to advance our understanding of the causal mechanisms that underpin effective iCBT programs, we will need to address what and how therapeutic content (ie, CBT skills) is delivered using PSD (technology-based) features to produce the intended and actual attitude or behavior changes. This will involve developing a framework that integrates the PSD model with the CBT framework and a theory of behavior change (for a review of theories see [170]) to identify specific combinations of therapeutic content and technological features designed to help users meet their health goals. A holistic framework by Wang et al [171] combines behavioral theories and the PSD model to provide a starting point for more theoretical and comprehensive designing, reporting, and evaluation of persuasive systems [171].

## Conclusions

Although iCBT effectiveness for children and adolescents with anxiety has been demonstrated, not all programs benefit users in the same way. This leaves room for programs to be further optimized. PSD (technological) features can be intentionally selected and incorporated into the design and delivery of iCBT programs, making it an aspect of treatment that is under the control of developers. The hypotheses that we generated suggest that multiple key PSD features may work together to help users actively engage with therapeutic content and practice newly acquired skills. The type and degree of adjunct support will vary based on the level of prevention and user characteristics (ie, symptom severity) the program was designed to target and can influence what and how certain features operate within the program. The key PSD features and aspects of context identified require formal testing to understand whether, and to what extent, they are effective and how they function. These next steps may involve new conceptualizations of effectiveness and evaluation methods. As we improve our understanding of how the components of iCBT work (their proposed purpose) and what users prefer and need, we can create programs with better objective and subjective effectiveness. This systematic and deliberate approach to iCBT design and evaluation will increase the pool of evidence-based interventions available to prevent and treat anxiety in children and adolescents.

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## Conflicts of Interest

None declared.

Multimedia Appendix 1
The persuasive systems design (PSD) model.
[PDF File (Adobe PDF File), 87 KB - mental_v6i10e13807_app1.pdf ]

Multimedia Appendix 2
The candidate Context-Mechanism-Outcome configurations.
[PDF File (Adobe PDF File), 13 KB - mental_v6i10e13807_app2.pdf ]

Multimedia Appendix 3
Document electronic search strategy.
[PDF File (Adobe PDF File), 8 KB - mental_v6i10e13807_app3.pdf ]

Multimedia Appendix 4
The level of contribution and methodological quality of documents included in the synthesis.
[PDF File (Adobe PDF File), 94 KB - mental_v6i10e13807_app4.pdf ]

Multimedia Appendix 5
Overview of the preintervention to postintervention changes in anxiety (outcomes) based on the total number of measures, studies, and iCBT programs across program types.
[PDF File (Adobe PDF File), 84 KB - mental_v6i10e13807_app5.pdf ]

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## Abbreviations

**AACAP:** American Academy of Child and Adolescent Psychiatry
**CBT:** cognitive behavioral therapy
**CIHR:** Canadian Institutes of Health Research
**eHealth:** electronic health
**iCBT:** internet-based cognitive behavioral therapy
**IOM:** Institute of Medicine
**MMAT:** Mixed Methods Appraisal Tool
**PSD:** persuasive systems design

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Original Paper

# Use of Web Conferencing Technology for Conducting Online Focus Groups Among Young People With Lived Experience of Suicidal Thoughts: Mixed Methods Research

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## Abstract

**Background:** There is an increasing interest in engaging people with lived experience in suicide prevention research. However, young people with suicidal thoughts have been described as a "hard-to-include" population due to time, distance, stigma, and social barriers.

**Objective:** This study aims to investigate whether conducting synchronous Web conferencing technology–based online focus groups (W-OFGs) is a feasible method to engage young people with lived experience of suicidal thoughts in suicide prevention research.

**Methods:** Young people aged between 16 and 25 years and living in Sydney, Australia, were recruited through flyers, emails, and social media advertisements. The W-OFGs were established using a Web conferencing technology called GoToMeeting. Participants' response rate, attendance, and feedback of the W-OFGs were analyzed to determine whether the W-OFG system is feasible for suicide prevention research. Researchers' reflections about how to effectively implement the W-OFGs were also reported as part of the results.

**Results:** In the pre–W-OFG survey, 39 (97.5%) young people (n=40) chose to attend the online focus group. Among the 22 participants who responded to the W-OFG invitations, 15 confirmed that they would attend the W-OFGs, of which 11 participants attended the W-OFGs. Feedback collected from the participants in the W-OFG and the post–W-OFG survey suggested that online focus groups are acceptable to young people in suicide prevention research. Considerations for selecting the Web conferencing platform, conducting the mock W-OFGs, implementing the risk management procedure, inviting participants to the W-OFGs, and hosting and moderating the W-OFGs as well as a few potential ethical and pragmatic challenges in using this method are discussed in this study.

**Conclusions:** The Web conferencing technology provides a feasible replacement for conventional methods, particularly for qualitative research involving vulnerable populations and stigmatized topics including suicide prevention. Our results indicate that this modality is an optimal alternative to engage young people in the focus group discussion. Future studies should compare the data collected from the Web conferencing technology and conventional face-to-face methods in suicide prevention research to determine if these two methods are equivalent in data quality from a quantitative approach.

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**KEYWORDS**

online focus group; young people; suicide; qualitative methods

## Introduction

### Background

There is an increasing consensus regarding the importance of involving people with lived experience of suicidal thoughts in the design of health care services and interventions [1,2]. However, concerns about ensuring the safety of those with lived experience as well as structural barriers to attending interviews or focus groups lead to substantial challenges for researchers when using conventional face-to-face methods to engage this population [3]. The conventional face-to-face focus group, a well-known means for collecting qualitative data in health care research [4], has long been criticized for its limitations with regard to the number of the topics that can be included in a given time as well as restrictions imposed by the geographical location where the group is conducted [5]. Lack of freedom in choosing the participatory locations can be a barrier to participation, particularly for people with lived experience of suicidal thoughts. They may worry about insufficient protection of their anonymity due to the chance of being coming from the same community [6]. These reasons could be especially true for young people, who frequently report privacy concerns and lack of money to travel long distances as two major barriers to participating in mental health research and services [7-9].

### Online Focus Groups

The rapid development of digital technology has given rise to a group of new methods for collecting qualitative data in health care, including online focus groups that can be delivered either asynchronously (ie, participants contribute to the conversation at different time) through messenger services or forums [10-12] or synchronously (ie, participants contribute to the conversation at the same time) through chat rooms or Web conferencing technology [13,14]. Through these technologies, online focus groups can operate like conventional face-to-face focus groups by providing real-time communication for multiple users from different geographical locations while saving costs for both transcription and travel [15]. Online focus groups also have greater potential than conventional face-to-face focus groups for participants to maintain anonymity. User identities can remain hidden [16] as long as a unique identification code is assigned and quoted as part of their response. This potentially increases the willingness of participants to exchange opinions about sensitive or potentially taboo topics, and there is evidence to support this in respect to sexuality [14] and domestic violence [17]. Furthermore, online focus groups may provide more "equal" chances of participation, as potentially stigmatizing personal details (eg, social status and educational background) are not as readily available. Such sociodemographic factors have been found to potentially impede equal participation in face-to-face interviews, as some participants with a perceived lower status may defer from those who were perceived to have a higher social standing [18].

Online focus groups may be particularly appealing to young people, who are familiar and comfortable with communicating and engaging in the virtual world and online apps [19,20]. Burton and Bruening [18] suggest that gathering the opinions of young people through a medium that they are familiar and comfortable with "can potentially produce data that sheds more light on the experiences of these participants than survey research or even traditional focus groups do."

### Web Conferencing Technology–Based Online Focus Group

One type of synchronous online focus groups, the Web conferencing technology–based online focus group (W-OFG), provides real-time communication between participants and moderators across various geographical locations similar to an Internet chat room. Moreover, the W-OFG has advantages over the internet chat room in enabling immediate and spontaneous communication through real-time videos and sounds via various devices that can be used, such as full-motion Webcam, microphones, and speakers. Compared to the internet chat room, the W-OFG mimics the operating environment of the conventional face-to-face focus group better by capturing more nonverbal and paraverbal cues (ie, tone, pitch, and pacing of voices), which has been suggested to be vital for focus groups [15].

In the last 4 years, the W-OFG has been used to engage male victims of partner abuse [17], university students [21], and geographically dispersed health professionals [22-25] in research. In these studies, delivering focus groups via the W-OFG was well received by both participants and researchers due to its convenience and anonymity. Importantly, the W-OFG has a similar level of data richness [26] and group interactivity [21] as conventional face-to-face focus groups.

Although several limitations of the W-OFG have been noted in the literature, including underrepresentation of the overall community due to computer usage and availability [27] and a potential high no-show rate (ie, over 50% of the people signing up but not attending the W-OFG) [22,28], the W-OFG serves as a viable alternative to comparable conventional methods. However, there have not been any published W-OFG studies in the suicide research literature, and therefore, the feasibility or efficacy of this methodology in this area is not clear.

This research study is conducted as the first step in a participatory approach to the design and development of a smartphone app for managing suicidal thoughts of young people. This paper focuses on describing young people's preferences of focus group settings, acceptability of the W-OFG, and researchers' methodological reflections on the procedure of the W-OFG. The content of the data acquired using the W-OFG and the online surveys will be the subject of a separate paper. The findings reported in this study are expected to provide the first empirical implications for the feasibility of using online interviewing methods to involve vulnerable young people in suicide research practice.

### Aims

Given the lack of published studies on W-OFG in suicide prevention research, this study aims to (1) examine young people's preference of focus group settings (face-to-face or online) in suicide prevention research; (2) describe the W-OFG procedure in a reflective way; (3) determine whether the W-OFG is feasible for suicide prevention research by analyzing young people's response rate, attendance, and feedback; and (4) discuss

the ethical implications with regard to privacy and safety of the W-OFG in suicide prevention research.

## Methods

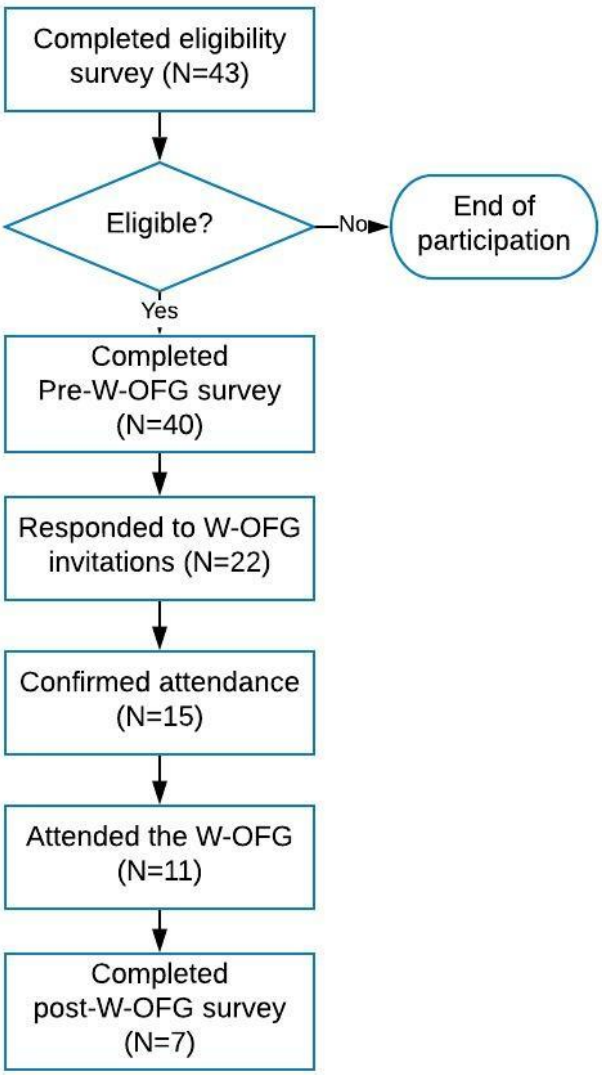
### Participant Eligibility

Participants were first screened online for their eligibility before being invited to an online survey and to attend focus groups. Participants were deemed eligible if they (1) were aged between 16 and 25 years; (2) were located in Australia; (3) were fluent in English; (4) were able to attend face-to-face focus groups in Randwick or Sydney's central business district, or were willing to do online focus groups on the scheduled dates; and (5) had lived experience of suicidal ideation. Participants were excluded if they (1) had been diagnosed with schizophrenia or a related psychotic disorder, (2) had experienced suicidal thoughts in the past 2 weeks, or (3) had attempted suicide in the past month.

### Participant Recruitment

Participants were recruited through online advertisements on Facebook and the Black Dog Institute (BDI; a medical research institute) social media channels, including Facebook, Twitter, and Instagram, through the registered volunteer network at the BDI and through flyers at the Black Dog Clinic and Headspace at Bondi Junction and Camperdown in NSW, Australia. Multiple methods were used to maximize recruitment. Targeted Facebook advertisements were used to recruit young people aged between 16 and 25 years in Sydney who were interested in mental health issues suggested by following one of the following social media accounts, including Beyondblue, Headspace, Lifeline, RUOK Day, and SANE Australia. The advertisement included a brief introduction of the study design, the eligibility criteria, and mental health support information such as a contact number of Lifeline Australia. Content was slightly adjusted to meet the word limit of different channels (ie, Facebook, Twitter, and Instagram). Thirty (75.0%) participants reported hearing about the study from Facebook advertisements; 11 (27.5%) from the BDI social media channels; 6 (15%) from the BDI clinics and Headspace; and 4 (10%) from Instagram. An AUD $100 electronic gift card was given to the participants who completed the focus group in acknowledgment of the time and internet expense related to participation. Figure 1 illustrates the participant flow in this study. Details about the procedure were described under the relevant section of the results.

**Figure 1.** Diagram of participant flow. W-OFG: Web conferencing technology–based online focus groups.



### Study Design

The research study used mixed methods to analyze the feasibility of the W-OFG in suicide prevention research. Data were drawn from two online surveys (before and after the W-OFG), and one relevant question was asked at the end of the W-OFG.

The pre–W-OFG online survey was designed to collect participants' characteristics and preference for the type(s) of focus groups. Participants were asked to choose the focus groups they were prepared to participate in, including conventional face-to-face focus groups at two local sites in Sydney, and the W-OFG, through a select-all-that-apply question. Participants were notified that the W-OFG was only available for young people aged between 18 and 25 years (ie, not for individuals aged 16-17 years) according to the ethics requirements. Other questions included those on participants' age; sex; nationality; living and relationship status; education; severity of their suicidal thoughts assessed by the Suicidal Ideation Attributes Scale [29]; the number of lifetime suicide attempts; history of suicidal thinking; general help-seeking intentions measured by the General Help Seeking Questionnaire [30]; and smartphone use habits including the devices, installed apps, and average time spent using apps.

The W-OFG focused on young people's use habits of smartphone apps, their preference of app features and designs, and how they may use apps to manage suicidal thinking. At the end of the W-OFG, participants were asked about their experience with the process by responding to a question, "We will take this chance to ask how you've found this focus group method. Any comments on that?" All participants' responses to the question are listed in the results.

The post–W-OFG online survey was designed to ensure the quality of the W-OFG and was optional. Questions about the areas of improvement of the W-OFG, motivations of participation, and undisclosed comments about the ideas raised in the focus group were asked in the post-W-OFG survey. The areas of improvement of the W-OFG were summarized and reported in the results. The results also included researchers' reflections about the procedure of the W-OFG.

### Ethics Statement

The study received ethics approval from the Human Research Ethics Committee at the University of New South Wales (protocol number: HC180646). The research was conducted in accordance with the ethical principles of the Declaration of Helsinki.

## Results

### Participant Characteristics

The online eligibility survey was automatically closed after attaining 40 eligible participants. The total sample (n=40) had a mean age of 21.2 years (SD 2.4 years, range: 16-25 years). The majority (n=37, 92.5%) were female, and all were Australian and spoke English at home as their primary language. No participants identified as Aboriginal or Torres Strait Islander. Half (n=20, 50.0%) were not married or in a relationship, and close to half (n=19, 47.5%) lived with their parents or family. Similar values have been found among those who responded and confirmed that they would attend the W-OFG (Table 1). For the participants who attended the W-OFG (n=11), the average age was 21.3 (SD 1.9) years; all of them were female, 7 (63.6%) were not married or in a relationship, and 3 (27.3%) lived with their parents or family. The target number of participants were recruited within 1 day of using the online recruiting methods.

**Table 1.** Characteristics of the participants grouped by participation.

| Characteristics | Completed the online survey (n=40) | Responded to attend the W-OFG[a] (n=22) | Confirmed the attendance (n=15) | Attended the W-OFG (n=11) |
|---|---|---|---|---|
| Age, mean (SD) | 21.2 (2.4) | 21.8 (2.0) | 21.5 (2.1) | 21.3 (1.9) |
| Female, n (%) | 37 (92.5) | 20 (90.9) | 14 (93.3) | 11 (100) |
| Never married and not in a relationship, n (%) | 20 (50) | 10 (45.5) | 8 (53.3) | 7 (63.6) |
| Living with parents or family, n (%) | 19 (47.5) | 7 (31.8) | 5 (33.3) | 3 (27.3) |

[a]W-OFG: Web conferencing technology–based Online Focus Groups.

### Pre–Web Conferencing Technology–Based Online Focus Group Survey: Examining Participants' Preference for the Types of Focus Groups

A total of 39 (97.5%) young people chose to attend an online focus group. Only one individual (2.5%) chose the conventional face-to-face focus group as the preferred format. As the majority of the surveyed young people preferred the online focus group, it was implemented in this study. One participant aged below 18 years was not eligible for the W-OFG. The moderator (NG) contacted the participant and discussed the opportunity to have a one-to-one interview to participate in the study. The participant expressed an understanding but declined the opportunity.

### Selection of the Web Conferencing Platform

In this study, a Web conferencing technology called GoToMeeting [31] was used to run two focus groups with young people who had lived experience of suicidal thoughts. It is one of the two online meeting software platforms provided by the University of New South Wales. The other option was Zoom Video Communications. The researchers tested the two Web conferencing platforms according to the modified eight criteria from Tuttas [22] for the online meeting software, which were as follows: (1) ability to accommodate up to 10 participants in the group, (2) ability to run a focus group for up to 1.5 hours, (3) ability to support real-time audio and full-motion video imaging, (4) ability to support audio and video recording of the

focus group, (5) ability to restrict the access to recordings within the research team, (6) no more than moderate technical competency required from participants, (7) no obligation to purchase and install the software, and (8) provision of access for only invited parties to enter the meeting space. Both GoToMeeting and Zoom fulfilled all criteria with the exception that Zoom only allowed 40 minutes of the meeting to be recorded for free. Therefore, GoToMeeting was selected to host the focus groups in this study.

### The Mock Web Conferencing Technology–Based Online Focus Group

As suggested by Irani [27], a mock W-OFG was conducted by the researchers in a private conference room with adequate lighting. The W-OFG moderators became familiar with the functionality of both the participant and the moderator screens under the assistance of an internal information technology helpdesk supporter. The questions for the focus group were reviewed and practiced in the mock W-OFG to estimate how long the focus group might take to complete. The accessibility of the W-OFG was tested using multiple devices, including smartphones and laptops. Automatically generated audio records and transcripts were reviewed for completeness and accuracy. An action plan was developed to manage any potential technical difficulties that may arise, and a risk management procedure was outlined to manage any psychological distress experienced by participants.

The mock W-OFG yielded important insights that required attention. First, a number of technical issues were identified. These included a slide presenting major themes that organized the questions to be asked in the online focus group and background music, indicating that the participant had successfully logged in to the system. Dialing into the focus group using mobile phones needed to be prohibited, as participants would not have been able to see the screens shared by the moderators: Only Web-based devices such as smartphones, desktops, and laptops could be used to access the W-OFG. The provision of quick guidance about the major features of the conferencing system from the moderator was helpful regardless of participants' Web literacy level. In addition, participants needed to be advised in advance that they could use the Webcam if they wanted to. Participants could text the moderator in the chatlog anytime during the focus group to inform the moderator that they were experiencing psychological distress or when they wanted to give further comments in response to questions. The information was only accessible by the moderator. The lessons we learned from the mock W-OFG were used to inform the implementation of the W-OFG.

### Risk Management Procedure

The risk management procedure was adapted from a protocol of a study among male suicide survivors who discussed their positive strategies to prevent and manage suicide in face-to-face interviews and focus groups [32,33]. It is composed of general risk management, identification of at-risk participants, and management of at-risk participants.

First, general risk management included reminding all participants at the beginning of the W-OFG that a clinical psychologist was available in the instance of distress. They could message the moderator anytime if they felt distressed or planned to withdraw the W-OFG. Second, participants were reminded to be mindful of the spoken content and limit their answers to how technologies or other skills had helped them manage prior suicidal experiences. Third, participants were asked to be respectful of each other's opinions and were informed that all the content shared in the W-OFG was confidential and sharing the Webcam content was optional. Following this, time was allocated to participants to read the participant information sheet and raise any questions or concerns orally or by message. Participants needed to provide oral consent or written consent by message before the W-OFG. Finally, at the end of the W-OFG, the moderator checked how participants were feeling, and a question regarding self-care activities was asked to all the participants.

At-risk participants were identified based on statements made by the participant during the course of the focus group, which indicated distress, or by direct disclosure of distress to the moderators. Visible signs of distress were not available during the W-OFG, as participants preferred not to use their Webcams, which is a limitation of this approach. If participants became distressed during the W-OFG, the moderator would check if they needed a break or support from the clinical psychologist. If the participant required a break, one of the moderators would keep the discussion going, while the other moderator would stay in touch with the participant. The moderator would ask the participants if they could contact support persons for the participants. At the end of the W-OFG, the at-risk participants would be messaged individually to check their safety. If they felt calm, they would be notified that they could contact the research team later if they needed help. The research team would check in on them the next day if this was consented to. If the participant still felt distressed, the moderator would offer to contact their carers or health professionals. They would be followed up the next day if they agreed. All incidents related to identifying "at-risk" participants would be recorded in the risk-management log.

### Invitation to the Web Conferencing Technology–Based Online Focus Group

Eligible participants who provided written consent were contacted by the researchers to arrange an online focus group time using the contact method they chose in the online survey. Thirty-eight (95%) of the young people chose to be contacted by email, while only two (5%) chose to be contacted by phone. No participants wanted to be contacted by short message service. Initially, three timeslots were provided to the participants. Twenty-two (55%) participants responded to the W-OFG invitations. Each timeslot received 7-10 expressions of interest (EOI). The participant flow is presented in Figure 1.

The two timeslots that received the most EOIs were confirmed with the participants by email. At this stage, 15 participants confirmed that they would attend the W-OFGs, by email or phone. All other participants who indicated that they could not attend either of the two focus groups received an email notifying them that they had been put on a waiting list. After the two W-OFGs took place, JH and NG reviewed the audio records

and agreed on content saturation. A thank-you letter was sent to the participants on the waiting list after the completion decision was made by the research group.

A unique identification code was allocated to each participant to replace their real names when logging in to GoToMeeting. The email also contained brief instructions about how to use GoToMeeting and a digital copy of the participant information sheet in which a detailed description of the study was provided. A group of help resources (eg, contact number of Lifeline) was provided at the bottom of the email. The researcher's contact information, research project Webpage link, and ethical approval number were also included in the email. It was also emphasized in the email that participants could withdraw their consent and discontinue participation at any time without any consequences.

Two reminders of the focus group were sent to the participants by email 1 day and 1 hour before the W-OFG. Of the participants who confirmed that they would attend the W-OFG, approximately 70% (5/7 and 6/8) attended each of the two focus groups. A similar level of attendance was noted in the face-to-face focus groups [34]. One of the four participants (25%) who signed up for the W-OFG but did not show up reported a time conflict. The other participants did not respond to the emails. All communication between the participants and the research team was monitored by the researchers with training in clinical psychology or counselling. Following the Recovery Oriented Language Guide [35], words such as "excluded" or "ineligible" were intentionally avoided in the communication, and the emails were worded using person-centered language. Specifically, all young people who did not meet the selection criteria received a personalized end-of-study message, including the reasons why they were ineligible at that moment. Participants who were put on the waiting list or did not attend the W-OFG were followed up by emails to notify the progress of the study and check their safety.

### Hosting and Moderating the Web Conferencing Technology–Based Online Focus Group

The two focus groups were led by the same moderators (JH and NG). Upon initiating the focus groups, the moderators framed the discussion with a message around respect for different opinions and equal opportunity of participation. This helped foster a safe environment and facilitated a connection between the moderator and participants in the absence of visual cues. Subsequently, the participants were given enough time to go through the digital participant information sheet and raise questions if they wanted to before they were asked to provide individual verbal consent for participation. The use of the Webcam was optional, and no participants chose to use the Webcam functionality.

Participants were asked to mute their microphones during the focus group to improve recording quality and avoid the interruptions in the conversation. After each question, participants who wanted to express their ideas were required to unmute their microphone and wait until their number was called by the moderator. The times each participant was invited to speak were balanced by the moderator. Participants could also text the moderator in the chatlog during the W-OFG if they were not invited to respond to the question or if they preferred input in this way. Two participants chose to use the chatlog function due to privacy concerns and a technical problem with the microphone.

Finally, the W-OFG concluded with a question focused on self-care with the aim of leaving participants feeling empowered and on a positive note. The rationale for this originated from Sharkey et al [36] who, in their online research among vulnerable young people, highlight why participants need to consider studies carefully. Therefore, the final question posed by the moderator was whether the self-care activity participants were going to engage in activities upon completion of the focus group.

### Acceptability of the Web Conferencing Technology–Based Online Focus Group

At the end of the W-OFG, young people were asked about their experience with the process by responding to a question, "We will take this chance to ask how you've found this focus group method. Any comments on that?" Three participants responded to this question orally:

> *I think it's been great, like it hasn't been glitchy at all the whole time.*
>
> *I was quite surprised at how easy this was to use, so I think it definitely a good way, especially to stay anonymous I think.*
>
> *I [think the process is] way better than Skype.*

The feedback provided by participants at the end of the W-OFG was in accordance with the comments received from the post W-OFG survey. Seven of the eleven participants filled in the survey and responded to an open-ended question: "Can we do anything to improve the way we run future focus groups?" No particular area of improvement was indicated by the participants. The exception to this was that one participant suggested that it might be better to provide the questions before the W-OFG.

### Records of the Web Conferencing Technology–Based Online Focus Group

GoToMeeting automatically generated the records of audio, the chatlog, and the automated transcript after the W-OFG. The original audio records of the W-OFG were transcribed through a paid transcribing service. The quality of the audio record was acceptable. On an average, 12 per 10,000 words were labelled as inaudible. The record of the chatlog was of good quality without missing information. User identification and time were precisely recorded. However, compared to the transcription from the paid transcribing service, less than 50% of the content was obtained by the automated transcript provided by GoToMeeting, indicating that the transcription from the former should be preferred over the latter.

## Discussion

### Principal Findings

This study reports on the process of using Web-based conferencing systems to host the W-OFG among young people with suicidal thoughts. It provides the first report on using this method in suicide prevention research and provides a basis for

further development of conducting synchronous online focus groups with people experiencing sensitive or stigmatized mental health issues such as suicidal thoughts.

Although previous studies have suggested that the "no-show" rate is often high (over 50%) in the W-OFG [18,22,28], around 70% of the participants who agreed to participate attended the scheduled W-OFG. This number is similar to the level of attendance reported in virtual focus groups (81% by video and 69% by chat) in a previous study, but lower than that in face-to-face groups (94%) [37]. Provision of incentive, delivery of reminders, themes of the focus group, and the target population may have influenced the attendance rate, but warrant further investigation. The whole process was described as surprisingly easy by the participants. Although the W-OFG is an emerging method with great potential to include participants in a less costly way, there are some issues that need to be acknowledged and addressed before implementing the W-OFG in people with suicidal thoughts.

First, we need to acknowledge that participants who participate in the W-OFG are likely to be an unrepresentative sample of the community, as the W-OFG can only include people who have access to the internet. The technology itself can be a barrier. For example, the W-OFG may be a less favored means of participating in research by elderly individuals who are unfamiliar with digital technologies or by people living in areas where the internet is expensive or less accessible. However, because of these criteria, the W-OFG may also be particularly advantageous for research topics related to digital technologies, such as developing a smartphone app, as these topics require participants to convey experiences of using technology.

Second, the safety of participants is paramount in the context of the W-OFG. The absence of nonverbal cues and lack of environmental information might hamper the immediate assessment of respondent behaviors and emotions during the focus group. This increases the difficulty of providing support during the W-OFG. For example, the meaning of periods of silence was difficult to decipher, that is, it was difficult to know if it was a sign of disengagement or distress, or simply a result of participants taking some time to think about their response to the question. Therefore, it was difficult to determine whether it was necessary to remind participants of the option to write privately to the moderator or that a clinical psychologist was available in the instance of distress. As there is limited evidence about how to manage risk among vulnerable populations in online focus groups, we propose five considerations on the basis of our experience and Irani's [27] work: (1) those conducting the online focus group consider the health status and the technological literacy of potential participants during recruitment; (2) those conducting the online focus group ensure participants know that they do not have to answer anything too painful or distressing or things that they do not want to share; (3) those conducting the online focus group create safety management procedures involving clinicians, allowing participants to withdraw at any time during the study and providing follow-up check-in if participants allowed; (4) those conducting the online focus group frame the discussion with messaging around respect for different opinions and equal opportunity of participation upon initiating the W-OFG; and (5) those conducting the online focus group conclude with the focus group by asking questions regarding self-care activities.

Third, although a potential strength of the W-OFG is to overcome potential barriers with regard to the physical location and the lack of privacy of face-to-face focus groups, there is evidence suggesting that participants in a W-OFG are less likely to elaborate on others' opinions compared to participants in a face-to-face focus group [15]. We observed a similar tendency in our W-OFGs, as participants often used simple statements such as "I agree," which can be simply substituted for nods in the conventional face-to-face focus group. In addition, it remains unknown if acknowledging others' comments is due to peer pressure, which could lead to group polarization. On the other hand, it could represent the opposite with previous studies, showing that focus groups can be a positive experience for participants due to group membership and cohesiveness [38]. Therefore, further qualitative studies are needed to distinguish between these possibilities.

Finally, although no participant expressed any concern about privacy in the W-OFG, digital data collection via a video conferencing system could raise issues of privacy and data breach. Similar to any other type of information and communication technology, video conferencing systems have inherent vulnerabilities including issues such as intentional attacks from hackers or accidental security breaches due to user ignorance or misunderstanding. For example, most video conferencing systems allow automatic audio-saving online and locally. It is therefore the researchers' responsibility to check the Web conferencing security documents provided by the video conferencing companies before using the system to minimize the chances of data being retrieved without permission.

## Limitations

Several limitations need to be addressed in this study. First, the Web conferencing platforms were compared and decided by the researchers. This could be improved by taking users' preference into consideration. Furthermore, validated measures such as the System Usability Scale [39] can be used in the future to quantify users' feedback of the system. Second, the majority of the participants involved in the study were female, suggesting that other strategies may be required to engage men. However, there is a broad issue of women being more likely to engage in research [40-42]. Overrepresentation of women in this study may also reflect the natural gender bias in suicidal risk (ie, females are more likely to ideate and attempt suicide) [43]. This sample was not representative but fulfilled the goal of attracting potential end-users to provide their perspectives on the app features that can help them manage their suicidal thoughts. Since the focus groups were also restricted to a small group of participants that had Web-based devices and could access the internet, the generalizability of these findings to the broader population of young people with suicidal ideation should be approached with caution. Lastly, no comparisons between the conventional face-to-face focus group and the W-OFG were made in this study. It remains unclear if these two types of focus groups generate similar quality data in suicide prevention research. Future studies may address this limitation by using the two methods in the same study and comparing the findings.

## Conclusions

Conduct of focus groups using digital technology is gaining popularity among researchers due to flexibility and functionality that traditional methods cannot logistically offer, including reaching out to those from diverse population groups and remote areas. Recent studies suggest that actively involving individuals with mental illness in the research process is beneficial to the participants [44]. This study provides preliminary evidence that the use of the Web conferencing technology can be a feasible replacement for conventional methods, particularly for research involving vulnerable populations and stigmatized topics including suicide prevention. Future studies need to compare the data collected from the Web conferencing technology and conventional face-to-face methods in mental health and suicide research to determine if these two methods are equivalent in data quality from a quantitative approach and to target respondents from disadvantaged social and demographic backgrounds to confirm the feasibility.

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## Conflicts of Interest

None declared.

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## Abbreviations

**BDI:** Black Dog Institute
**W-OFG:** Web conferencing technology–based online focus group


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Original Paper

# A Web-Based Alcohol Screening and Brief Intervention Training Module Within Physician Assistant Programs in the Midwest to Increase Knowledge, Attitudes, and Confidence: Evaluation Study

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## Abstract

**Background:** Preventing and reducing risky alcohol use and its side effects remains a public health priority. Discussing alcohol use with patients can be difficult; dedicated training for health care providers is needed to facilitate these conversations. A Web-based alcohol screening and brief intervention (SBI), comprising didactic and skills application training, was designed for physician assistant students.

**Objective:** This paper details experiences and outcomes in developing an alcohol SBI training curriculum and coordinating virtual encounters with standardized patients. We also explain challenges faced with developing an alcohol SBI training and a Web-based learning management site to fit the needs of 5 different physician assistant programs.

**Methods:** Training development comprised 3 phases—precourse, development, and implementation. The precourse phase included developing the initial training curriculum, building a website, and testing with a pilot group. The development phase refined the training curriculum based on user feedback and moved into a three-component module: didactic training module, guided interactive encounter with a simulated patient, and live encounter with a standardized patient. A learning management system website was also created. In the implementation phase, 5 physician assistant schools incorporated the Web-based training into curricula. Each school modified the implementation method to suit their organizational environment. Evaluation methods included pre- and postchange over time on trainee attitudes, knowledge, and skills (confidence) on talking to patients about alcohol use, trainee self-reported proficiency on the standardized patient encounter, standardized patient evaluation of the trainee proficiency during the alcohol use conversation, user evaluation of the type of technology mode for the standardized patient conversation, and overall trainee satisfaction with the Web-based training on alcohol SBI.

**Results:** Final evaluation outcomes indicated a significant ($P$<.01) change over time in trainee knowledge and skills (confidence) in the conduct of the alcohol SBI with a standardized patient, regardless of the program implementation method. Trainees were generally satisfied with the Web-based training experience and rated the use of the videoconference medium as most useful when conducting the alcohol SBI conversation with the standardized patient. Training that included a primer on the importance of screening, individual participation in the Web-based didactic alcohol SBI modules, and virtual encounters with standardized patients through a university-based simulation center was the most widely accepted. Successful implementation included program

investment and curriculum planning. Implementation barriers involved technical challenges with standardized patient encounters and simulation center logistics, and varying physician assistant school characteristics.

**Conclusions:** Development and implementation of Web-based educational modules to educate health care professionals on alcohol SBI is effective, easy to reproduce, and readily accessible. Identifying challenges affecting development, implementation, and utilization of learned techniques in practice, enhances facilitation of learning and training efficacy. As the value of technology-based learning becomes more apparent, reports detailing what has worked versus what has not may help guide the process.

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**KEYWORDS**

alcohol education; alcohol screening and brief intervention; Web-based training; standardized patient; physician assistant

## Introduction

> *I will have patients that will need alcohol counseling, and this [alcohol SBI training] helped me to approach that subject in a better way with future patients.* [Physician Assistant student 2016 pilot]

Numerous studies have found that health care providers, especially physicians, lack the knowledge and confidence to inquire about patient alcohol use behavior. Primary care professionals remain uncomfortable when talking to their patients about alcohol use [1-4]. Screening, brief intervention, and referral to treatment (SBIRT) is an evidence-based, public health approach utilized to screen patients and initiate a conversation on alcohol use, which may lead to a brief intervention. This method is recommended by the Institute of Medicine, the American College of Obstetricians and Gynecologists, the Centers for Disease Control and Prevention, the Substance Abuse and Mental Health Services Administration (SAMHSA), and many other research, policy, and public health organizations to reduce alcohol exposure and alcohol use disorders with demonstrated effectiveness [5]. However, challenges remain with the diffusion of SBIRT principles into routine practice. Research suggests finding more creative and engaging ways to teach the principles of SBIRT to ensure that primary care providers (PCPs) routinely utilize this technique in practice [6]. Therefore, a key translational research question to answer is how to address training gaps in advancing SBIRT knowledge and utilization.

As part of coordinated efforts to advance the utilization and adoption of SBIRT in primary care, researchers have focused on developing new and improved ways of teaching SBIRT to PCPs. Some of these methods have included utilizing Web-based training models [7], incorporating training materials into health care provider curricula [8,9], engaging simulated patients [10], and creating Web-based interactive platforms [11]. Although mixed results have been reported on the effectiveness of these approaches in health care education, interventions that include interactivity, continued practice exercises, repetition, and feedback appear to improve learning outcomes [12]. A recent report found that the referral to treatment component of SBIRT had not been fully implemented within practice settings and, therefore, had not been shown as effective, compared with the screening and brief intervention (SBI) components [13]. The focus of this training for the physician assistant has been on primary care screening for all patients, with greater emphasis placed on alcohol SBI as an equally effective first line of prevention for identifying at-risk alcohol use.

With the evolution of the internet as a tool for instruction, Web-based methods have been acclaimed in the literature for their benefits in academic training. These benefits, including convenience, reach, and availability, have continued to expand, providing limitless opportunities for academic development [12]. As benefits of Web-based learning for health care students have become more apparent, researchers have begun to explore the feasibility of incorporating these approaches to advance training and utilization of SBIRT in practice settings [14]. Mixed results have also been reported on the effectiveness of these approaches in terms of presenting the training material, engaging participants, and ensuring that trainees utilize this knowledge in clinical practice settings [6,15]. Further research is required to understand what aspects of Web-based trainings resonate with participants and are more likely to be helpful in continued practice.

Engaging standardized patients in the training of health care professionals is another training approach that is widely supported by the literature. Standardized patients are individuals from the community who have been trained to consistently portray patient roles and role-play health states typically found in health care practices. Evidence from several studies suggests that engaging the standardized patient in health care professional training can be beneficial in many ways, including building interactivity, collecting patient histories, building confidence, providing realistic practice scenarios within a safe space, and assessing student level of skill acquisition [9,16,17]. Some studies also suggest that SBIRT skills are reinforced when standardized patients work with health care professionals [8-10]. In their study, Lempicki et al [11] found that interprofessional teams participating in a videoconference encounter with a standardized patient enjoyed the encounter more than those participating in face-to-face encounters. Although this finding did not translate into continued utilization of this training resource, it might suggest avenues for more research exploration [11].

With the increased uptake of electronic learning (e-learning) approaches in health professional academic training, there is a need to understand what factors influence the development, implementation, and sustainability of e-learning approaches with the goal of increasing diffusion of alcohol SBI techniques. Similarly, as the benefits of utilizing standardized patients in

health care professional training continually emerge, there is a need to explore, identify, and strengthen the aspects of standardized patient encounters found most beneficial to trainees, particularly for alcohol SBI. In the Midwestern United States, many physician assistant schools have not implemented any alcohol screening training in their curriculum. Consequently, upon graduation, students may not have acquired the necessary skills to start, maintain, and conclude conversations around alcohol use with their patients. With the growing capacity—in breadth of content matter and rigor and increasing number of students—of these programs and the time required to train and learn the elements of alcohol SBI, there is an increased need to deliver training using Web-based approaches. This study sought to incorporate both e-learning approaches and standardized patients to deliver and practice SBI techniques for alcohol use. We hypothesized that combining Web-based alcohol SBI approaches and video conferencing with standardized patients would improve learning and utilization of these techniques in practice settings. In this paper, we report on lessons learned while designing a Web-based didactic alcohol SBI course that included a guided interactive experience with 2-character scenarios and virtual live encounters with a standardized patient for physician assistants, incorporated into already established student curricula. We also report on how the training was adapted to address the unique contextual factors of each academic program and challenges faced with implementing the program. And finally, we report the evaluation outcomes of the change in attitudes, knowledge, and skills in terms of confidence of trainees along with satisfaction of using e-learning methods for teaching physician assistants how to talk with their patients about alcohol use.

## Methods

### Phase 1: Precourse Development

In the original proposal, we had planned to develop the alcohol SBI education training curriculum for the physician assistant in 2 parts: a didactic component, based upon SBIRT training slides from the SAMHSA Ideas Exchange, and an experiential component, designed to be used with an avatar for virtual communication using Second Life (a platform used for avatar-based video gaming), accessed via downloadable apps. The initial version of the didactic training module was completed within the first 4 months of the 3-year grant period and submitted for faculty feedback in February 2016. The pilot cohort of physician assistant students completed the training in March 2016. In addition to the alcohol SBI education module, we created a separate SBI implementation into practice module, a learning management system (LMS) website named Catalyst Learning Center [18], and the Catalyst Central virtual world avatar experience in the first 6 months of the study.

Feedback from the first cohort of student trainees provided information on the utility, success, and challenges of learning and practicing alcohol SBI in a Web-based format. Students were asked to respond to the question, what about the training was most useful in supporting your work responsibilities? Positive qualitative comments from student experiences included:

> *It provided useful tips for communicating difficult topic areas. Also, there were several small details and beneficial pneumonics that helped to remember some of the subject [material].* [University of Missouri–Kansas City (UMKC) 68/2016]

> *I will have patients that will need alcohol counseling and this helped me to approach that subject in a better way with future patients.* [UMKC80/2016]

A simulation satisfaction survey also solicited feedback regarding the aspects of the training for improvement, inclusive of curriculum, and modality. Responses included:

> *I think that you should throw out the avatar idea altogether. I think it's more useful to look directly at a real person than do the avatar anyway. There were so many glitches with that avatar. That was somewhat frustrating.* [UMKC65/2016]

> *The training modules were very wordy…Also, I think more emphasis needs to be placed on how to proceed through the actual interview itself…when to use the ten questions from the Alcohol Use Disorders Identification Test interview and how to introduce the topic to the patient gently without offending them.* [UMKC70/2016]

The use of the Second Life platform proved to be significantly challenging for students to access and, based upon their feedback, we discontinued the use of Second Life. Subsequently, we chose to build our own experiential platform that we believed would ultimately increase the likelihood of a successful and effective experience.

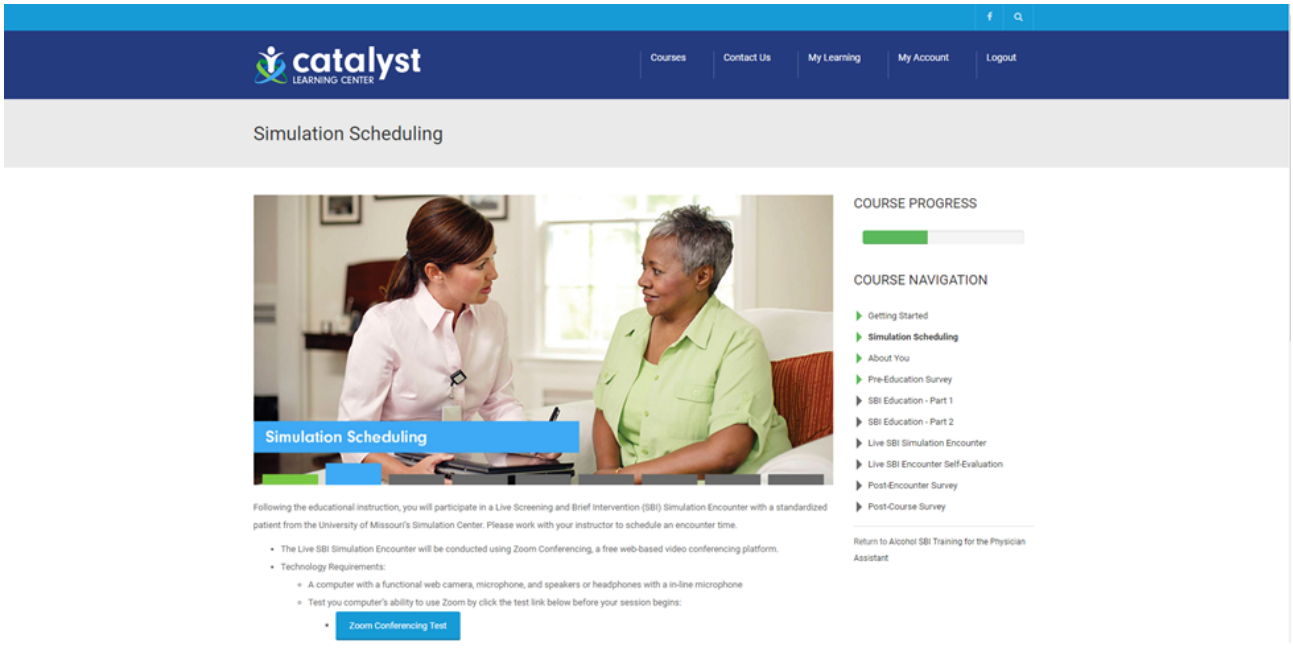
### Phase 2: Development

On the basis of initial feedback, the team made several significant changes to the alcohol SBI training curriculum. Revisions included a completely redesigned Web-based training course, alcohol SBI training for the physician assistant, with 3 components: a didactic module, an experiential module with a guided interactive alcohol SBI encounter attached to the didactic training, and a live encounter using videoconferencing with a standardized patient. The entire training course was housed at Catalyst Learning Center [18], and all users had to register to participate. The didactic module is narrated and interactive, covering the elements of screening and brief intervention; motivational interviewing; alcohol use among adults, teens, and pregnant women; and appropriate screening tools and how to use them.

The guided interactive alcohol SBI encounter included avatar-like characters and allowed the student to immediately practice the alcohol SBI skills learned during the preceding didactic course. A patient scenario is presented along with scripted options in drop-down menus (Figure 1). The trainee proceeds through a scripted alcohol SBI patient encounter and must apply technical skills, such as implementing the appropriate screening tool, understanding the format of a brief intervention, and using interpersonal skills. The third segment of the training included a scheduled live encounter with a standardized patient at a university-based simulation center using videoconferencing software (Figure 2).

**Figure 1.** Avatar-like character on the Catalyst Learning Center website walking trainees through alcohol screening and brief intervention training.

**Figure 2.** Simulation scheduling through Catalyst Learning Center website.




### *Trainee Process*

The full Web-based training course comprised a live-encounter scheduling process, pretraining evaluations, the didactic module, 2 guided interactive alcohol SBI encounters, the live alcohol SBI encounter with a standardized patient via video conference, and posttraining evaluations. At 30 days posttraining, an email was sent to the students requesting an additional follow-up evaluation to be completed at the Catalyst website [18].

### *Development and Implementation of the Catalyst Learning Center Learning Management System*

An LMS website, Catalyst Learning Center [18], was designed by contractors hired for this study. The LMS captures data on the training course, securely houses personal information, and provides certificates of completion for continuing medical education and continuing educatioN units for a wide variety of professionals. We had a contract with the Creighton University Continuing Education Department to provide approved

certification of the continuing medical education and continuing education credits for professionals.

### Phase 3: Implementation

The alcohol SBI training program was implemented in 3 accredited physician assistant programs and in a new physician assistant program in the state of Missouri and a well-established physician assistant program at South College in Knoxville (SC-Knoxville), Tennessee. The entire training program was implemented in 3 stages: (1) a precourse stage in which faculty were trained, who then taught students about the importance of alcohol screening; (2) a Web-based alcohol use didactic course plus a guided interactive alcohol SBI encounter with a simulated avatar-like patient; and (3) a face-to-face encounter with a standardized patient using videoconferencing. In one physician assistant program, a translation into practice stage was introduced with preceptors in which preceptors were taught how to integrate the training into the student curriculum. To begin training, students received guidance from the research team and their academic instructor to participate in the Web-based training module. This was followed by a discrete link provided by the academic instructor connecting students to a cohort-specific landing page at Catalyst Learning Center [18], prompting students to register and automatically enroll in the designated alcohol SBI course section. Students were given the opportunity to self-schedule for the live virtual encounter with the standardized patient ahead of a prescribed deadline and prearranged live-encounter date.

### Settings

The 5 physician assistant programs that agreed to participate in the development, implementation, and data collection for this sudy included the following: University of Missouri-Kansas City (UMKC), Missouri State University (MSU), Saint Louis University (SLU), Stephens College (SC-Columbia), and South College (SC-Knoxville). Table 1 provides the name and location of the academic program, a description of the academic program, and how the alcohol SBI training was implemented within each academic setting.

**Table 1.** Program and implementation descriptions of each physician assistant program.

| Academic program | Program description | Implementation description |
|---|---|---|
| University of Missouri-Kansas City Master of Medical Science Physician Assistant Program (Kansas City, Missouri) | 28-month program, created in 2014; urban setting; annually accepts 20 students | Alcohol SBI[a] training program occurred in year 1, semester 1, and was included as part of *Physician Assistant Professions I* course; initial 2-hour lecture provided by instructors and included a workshop on essential traits of effective communication and discussion on importance of alcohol use screening; students were given 1 week outside of class to complete the alcohol SBI training on the Web and the live standardized patient encounter; final discussion held as debriefing to discuss student experience with the training and the live standardized patient encounter |
| Missouri State University Physician Assistant Studies Program (Springfield, Missouri) | 24-month program, created in 2000; urban setting; annually accepts 30 students | Alcohol SBI training occurred in year 1, semester 1, and was included as part of the *Behavioral Medicine* course; faculty-held initial discussion on alcohol use; students were exposed to Web-based training over a 3-week period, utilizing 2 2-hour class sessions—week 1, alcohol SBI course completed on the Web; week 2, live encounter completed outside class; week 3, faculty debriefing session on student experience with Web-based training and live standardized patient encounter; during clinical year, alcohol SBI utilization was tracked using the E-value[b] system |
| Saint Louis University Master of Medical Science, Physician Assistant Program (St Louis, Missouri) | 27-month program, created in 1971; urban setting; annually accepts 46 students | Training occurred in 4th didactic semester before clinicals and was a part of the *Essential of Pediatrics* course; training participation was considered extra credit; faculty-held discussion provided preparation for the course; students completed alcohol SBI course independently and scheduled live standardized patient encounters; instructor debriefing session held during class on student perception of experience and utilization of training in subsequent clinical year |
| Stephens College Master of physician assistant Studies Program (Columbia, Missouri) | 27-month program, began in August 2016; largely urban setting; annually accepts 20 students | Live presentation by the first author on role of Physician Assistant in OBGYN[c] and FASD[d] as part of the *OBGYN Clinical* module; students completed alcohol SBI course independently following live presentation; live standardized patient encounters conducted on campus in controlled environment to decrease technical challenges |
| South College Master of Health Science in Physician Assistant Studies Program (Knoxville) | 27-month program, created in 2007; urban setting; annually accepts 85 students | Alcohol SBI training occurred in year 2 of the clinical year as part of the OBGYN Clinical module; no initial discussions held with students; live presentation by the first author on the role of a physician assistant in OBGYN and FASD; students completed alcohol SBI course independently before live standardized patient encounter, scheduled within 1 week of the in-class presentation |

[a]SBI: screening and brief intervention.

[b]E-value: E-value is a Web-based evaluation system designed to help manage one's medical education program.

[c]OBGYN: obstetrician-gynecologist.

[d]FASD: fetal alcohol spectrum disorder.

### Measurement Instruments

The evaluation plan was based on a set of questionnaires to assess the improvement in attitudes, knowledge, and skills (in terms of confidence) of trainees; how well the alcohol SBI encounter with the standardized patient occurred from the perspectives of the trainee and the standardized patient; a feedback survey on technological settings utilized for the training; and finally, a set of overall training satisfaction questions. All of the evaluation assessments were conducted on the Web using Qualtrics within the Catalyst Learning Center LMS [18] and included surveys and scales as follows.

#### *Pre- and Posttest: Attitudes, Knowledge, and Skills Survey*

Trainees completed a self-assessment on 9 attitude and knowledge statements and 5 skills (confidence) statements in the application of alcohol SBI techniques before and after the training. The attitudes, knowledge, and skills survey was scored using a Likert-type 7-point response scale, with 1=strongly disagree and 7=strongly agree with the given statement. The attitudes, knowledge, and skills survey was designed by the researchers at the UMKC. For this study, psychometric properties were measured with Cronbach alpha and revealed strong internal consistency (alpha=.80).

#### *Baseline and 1-Month Follow-Up Satisfaction Surveys*

A total of 4 items were adopted from the Center for Substance Abuse Treatment standard measurements of training satisfaction as required by the grant. The baseline and 1-month follow-up survey statements were scored using a Likert-type 5-point response scale, with 1=strongly disagree/dissatisfied and 5=strongly agree/satisfied with the given statement.

#### *Proficiency Rating Scale–Provider*

This scale was used to assess the live virtual alcohol SBI encounter between the provider (in this case, trainee) and the standardized patient, from the perspective of the trainee. A set of 11 statements assessed the trainee's perception of how proficiently they applied the skills learned in the alcohol SBI training within the simulated patient encounter with a standardized patient. A 5-point response scale was used, with 1=I did not do this; 2=I attempted but could improve on skill/technique for best practice; 3=I performed this skill/technique at a level that is approaching acceptable; 4=I did this well, with good technique; and 5=I did very well, with positive reception and engagement from the patient. In addition, 2 qualitative questions requested trainee feedback on their perspective of how well they conducted the conversation with the standardized patient. The first question asked the trainee, "what 2 things did you like about the way you conducted this intervention?" and the second question asked "what 2 ways do you feel you could improve your skills in these conversations?"

#### *Proficiency Rating Scale–Standardized Patient*

This scale was used to assess the virtual alcohol SBI encounter between the provider/trainee and the standardized patient, from the perspective of the standardized patient. A set of 10 statements asked the standardized patient to rate the trainee's proficiency in the simulated alcohol SBI encounter. A 5-point response scale was used, with 1=did not do this; 2=attempted, but could improve; 3=nearing acceptable skill; 4=done well; and 5=done very well. A separate question asked the standardized patient if "this conversation increased my motivation to cut down or quit drinking, or at least to consider doing so" and was assessed with a Likert-type scale ranging from 1=strongly disagree to 5=strongly agree. Finally, the standardized patient provided feedback on 2 positive observations about the way the trainee conducted the intervention and 2 ways the trainee could improve his/her skills in future conversations.

#### *Telecom Simulation User Evaluation Survey*

This survey asked the trainee to assess their experience with using the various types of technological settings in which to hold the alcohol SBI encounters. The three settings used included teleconference, avatar/virtual world, or a phone encounter when video conferencing was nonviable. The trainee responded to 12 statements that provided feedback on how well the use of technology fared compared with real-life or face-to-face encounters with a live standardized patient. The assessment utilized a Likert-type 5-point response scale ranging from 1=strongly disagree to 5=strongly agree. Finally, two qualitative questions asked the trainee to provide what they liked best about the training and what suggestions they had for improving the training.

### Assessment Time Intervals

Pre- and posttest attitudes, knowledge, and skills (in terms of confidence) assessments were completed immediately before and after the didactic Web-based training course. The baseline satisfaction survey was completed at the end of the entire course, whereas the 1-month follow-up satisfaction survey was completed, with a direct link sent to the student, 1 month post training. The Proficiency Rating Scale (PRS) was completed by both the trainee and the standardized patient immediately following the simulated patient encounter. The Telecom Simulation User Evaluation Survey was completed at the completion of the simulated patient encounter.

### Analytical Plan

All pre/posttest mean scores were examined using a *t* test for statistical significance. We also examined for differences between pre- and posttest assessments stratified by demographics. A mixed-models factorial analysis of variance (ANOVA) stratified by institution was used to assess any differences in terms of the training outcomes and effectiveness between institutions. Finally, we conducted a comparison of outcome characteristics between responders and nonresponders to evaluate the impact of attrition on our results. All analyses were conducted using SPSS version 25.0. The institutional review board of the UMKC reviewed and approved this evaluation study.

## Results

### Demographic Characteristics

Demographics of all physician assistant trainees who completed the training are shown in Table 2.

**Table 2.** Demographics of physician assistant trainees (N=482).

| Demographic category | n (%) |
|---|---|
| **Gender** | |
| Female | 341 (70.7) |
| Male | 141 (29.3) |
| **Race** | |
| White | 437 (90.7) |
| Black | 15 (3.1) |
| Asian | 24 (5.0) |
| Other | 6 (1.2) |
| **Education** | |
| 4-year degree | 431 (89.4) |
| Master-level degree | 48 (10.0) |
| Doctoral-level degree | 2 (0.4) |
| Some college | 1 (0.2) |
| **Year in program** | |
| Didactic | 264 (54.7) |
| Clinical | 218 (45.2) |
| **Academic institution** | |
| Saint Louis University | 54 (11.2) |
| University of Missouri–Kansas City | 72 (14.9) |
| Missouri State University | 91 (18.9) |
| South College | 227 (47.1) |
| Stephens College | 38 (7.9) |

The majority of trainees were female 70.7% (341/482), white 90.7% (437/482), had completed a 4-year degree 89.4% (431/482), and were in the first year of their physician assistant program 54.7% (264/482).

## Knowledge, Attitude and Confidence Change Over Time

Table 3 provides the comparison between the pre- and postsurvey results, showing the change in attitudes, knowledge, and skills (in terms of confidence) of the trainees. With the exception of four of the nine attitude and knowledge statements, we saw significant differences ($P<.01$) in mean scores over time in attitudes, knowledge, and skills (in terms of confidence) level of the trainees after completing the Web-based alcohol SBI training course. The overall aggregate score across all 14 statements went from a mean score of 5.06 for the pretest survey to a mean score of 5.73 in the posttest survey ($P<.01$). For the statement “Learning to screen and intervene in patients with hazardous or harmful substance use is important for me in my current/future position”, the overall mean score for the pretest was 6.48 and decreased slightly to 6.39 ($P=.70$), indicating a nonsignificant difference. For the statement “Substance use and associated risk are not appropriate topics to address with patients in my current or future practice,” the mean score for the pretest was 6.15 and decreased slightly to 6.13 ($P=.99$), indicating a nonsignificant difference. Finally, the statement “There are many nonphysicians (social workers and others) I work with who address alcohol and drug problems skillfully” resulted in a mean score of 4.86 in the pretest survey and decreased slightly to 4.80 ($P=.16$) in the posttest survey, also indicating a nonsignificant relationship.

**Table 3.** Mean scores on knowledge, attitude, and confidence pre- and posttest survey (N=482).

| Knowledge, attitude, and confidence questions | Pretest, mean (SD) | Posttest, mean (SD) | *P* value |
|---|---|---|---|
| I have a good understanding of alcohol and substance use | 5.35 (1.01) | 5.95 (1.04) | <.001 |
| Learning to screen and intervene in patients with hazardous or harmful substance use is important for me in my current/future position | 6.48 (0.77) | 6.39 (1.09) | .70 |
| Substance use and associated risks are not appropriate topics to address with patients in my current or future practice | 6.15 (1.36) | 6.13 (1.51) | .99 |
| There are many physicians I work with who address alcohol and drug problems skillfully and effectively | 4.72 (1.18) | 4.59 (1.32) | .02 |
| There are many nonphysician providers (social workers and others) I work with who address alcohol and drug problems skillfully | 4.86 (1.16) | 4.80 (1.24) | .16 |
| I am confident in my ability to screen patients for alcohol/drug problems | 4.22 (1.34) | 5.70 (0.88) | <.001 |
| I am confident in my ability to assess patients' readiness to change their behavior | 4.59 (1.19) | 5.81 (0.89) | <.001 |
| I am confident in my ability to discuss patients' substance use and advise them to change their behavior | 4.48 (1.32) | 5.78 (0.88) | <.001 |
| I am confident in my ability to refer patients with alcohol/drug problems | 4.78 (1.29) | 5.77 (0.96) | <.001 |
| It takes too much time to deal with the drinking/drug behavior of my patients | 5.59 (1.26) | 5.93 (1.18) | <.001 |
| Patients will be angry if I ask questions about their substance use | 4.03 (1.21) | 5.06 (1.25) | <.001 |
| My interaction with a patient can make a difference regarding their use of substances | 5.84 (0.97) | 6.23 (0.83) | <.001 |
| Incorporating screening, brief intervention, and referral to treatment into routine medical practice is critical for meeting health care needs | 5.52 (1.11) | 6.14 (0.91) | <.001 |
| I feel confident in my understanding of low-risk drinking limits | 4.28 (1.33) | 5.96 (0.85) | <.001 |
| Aggregate scores | 5.06 (0.61) | 5.73 (0.56) | <.001 |

## Proficiency (Skill) Rating Scale Completed By the Trainee

The PRS-provider was completed by the trainee immediately following the alcohol SBI encounter with the standardized patient. Overall, the trainees scored themselves as conducting the conversation at a performance level *approaching acceptable* (mean 3.41, SD 0.69). We note that the students rated themselves low for statement number 3 in comparison with the other elements of the PRS-provider. This statement asks about the National Institute on Alcohol Abuse and Alcoholism (NIAAA) low-risk drinking guidelines that are discussed in the training module as one of several alcohol screening instruments. Quantitative results for the PRS-provider are presented in Table 4.

The final 2 questions on the PRS-provider (trainee) asked the trainee to respond to two open-ended questions in which they reflected on how well they believed they conducted their initial conversation with a patient about alcohol use. In response to the first question "What two things did you like about the way you conducted this intervention?" a student responded:

> *I feel that I was able to look beyond just the systemic health risks associated with their increased drinking and how cutting back can improve the occurrence of accidents that put them in danger.* [SLU230/2016]

Whereas a second student responded:

> *I felt as though I was able to have a conversation as opposed to just spitting facts at the patient.* [SC-Columbia339/2017]

In response to the second question "What two ways do you feel you could improve your skills in these conversations?" a student stated:

> *I need to improve my comfort level with discussing "harder" topics with patients. This was my first alcohol discussion so I felt more nervous and need to improve my confidence and comfort level.* [MSU356/2017]

Whereas another student responded:

> *I felt like I was talking a lot more than the patient. I was focused on making sure I got all my points across that I think I should have slowed down and allowed the patient to express her thoughts a little bit more.* [SC-Knoxville540/2017]

**Table 4.** Mean scores on the Proficiency Rating Scale–Provider (n=474).

| Trainee self-reported skill level items | Mean (SD) |
|---|---|
| Ask for permission to talk about patient's alcohol use | 4.03 (0.78) |
| Assess quantity, frequency, and consequences of alcohol use | 3.72 (0.85) |
| Explain the National Institute on Alcohol Abuse and Alcoholism low-risk drinking guidelines (including *0 drinks for pregnant women* and associated health risks) | 2.56 (1.14) |
| Advise the patient to quit or cut down on alcohol use | 3.74 (0.89) |
| Help the patient think about pros and cons of his/her alcohol use | 3.19 (1.09) |
| Ask how ready s/he is to make a change | 3.70 (0.96) |
| Help the patient make a plan or set a goal for decreasing use and/or discussing further | 3.47 (1.01) |
| Explore patient's own reasons for quitting or cutting down on alcohol use | 3.01 (1.11) |
| Work with the patient as a partner in addressing his/her alcohol use issues | 3.27 (1.02) |
| Support his/her autonomy and choice regarding alcohol use | 3.49 (0.98) |
| Proficiency Rating Scale aggregate scores | 3.41 (0.69) |

## Proficiency (Skill) Rating Scale Completed By the Standardized Patient

In contrast, the PRS–standardized patient completed by the standardized patient scored the trainees at a somewhat higher performance (mean 3.77, SD 0.74). Results for the PRS–standardized patient are presented in Table 5.

For the PRS–standardized patient, the standardized patient responded to two open-ended questions, giving very detailed feedback to each trainee that might help improve their skills in having a conversation about alcohol use with their patients. In response to the first question "What two things did you like about the way the trainee conducted this intervention?", a standardized patient responded:

> *When you used the statement, "bringing to your attention..." regarding my at-risk use, I felt respected by the nonconfrontational way of bringing this up.* [Standardized patient for SC-Knoxville540/2017]

Another standardized patient provided the following feedback:

> *I appreciated how this provider responded to the discrepancy of my former OB's advice that a little alcohol in pregnancy was okay versus my current provider's recommendation that no amount of alcohol is safe during pregnancy. The student validated the former physician's recommendation by stating that "Maybe things have changed since your last pregnancy" and went on to communicate the current safe limits recommended now, which of course is no alcohol.* [UMKC128/2016]

For the second question "What two ways could this trainee improve his/her skills in these conversations?" a comment from a standardized patient to the trainee included:

> *When I asked if my glass of wine had hurt my baby, I LOVED the response, "Let's just focus on moving forward." It eliminated any guilt but also didn't give any false promises. It was a terrific way to handle that question.* [UMKC72/2016]

**Table 5.** Mean scores on the Proficiency Rating Scale–Standardized Patient (n=474).

| Proficiency Rating Scale–Standardized Patient items | Mean (SD) |
|---|---|
| Asked for permission to talk about my alcohol use | 4.00 (0.86) |
| Assessed quantity, frequency, and consequences of my alcohol use | 4.01 (0.79) |
| Explained specific National Institute on Alcohol Abuse and Alcoholism low-risk drinking guidelines and health risks to me | 3.66 (0.97) |
| Advised me to quit or cut down on alcohol use | 3.78 (0.93) |
| Helped me think about pros and cons of my alcohol use | 3.50 (1.16) |
| Asked how ready I am to make a change | 3.77 (1.02) |
| Helped me make a plan or set a goal for decreasing (or quitting) my alcohol use | 3.72 (1.09) |
| Explored my own possible reasons for quitting or cutting down on my alcohol use | 3.40 (1.22) |
| Worked with me as a partner (respectfully and nonjudgmentally) in addressing my alcohol use issues | 3.96 (0.94) |
| Supported my autonomy and choice regarding my alcohol use | 3.97 (0.89) |
| Proficiency Rating Scale aggregate scores | 3.77 (0.74) |

### Telecom Simulation User Evaluation Survey

The Telecom Simulation User Evaluation Survey measured the user satisfaction with three different types of technology used for the alcohol SBI encounter with the standardized patient and are presented in Table 6. The highest rating overall was found in the use of Zoom as a videoconferencing app (mean 4.14, SD 0.51). The second highest rating overall was found in the use of the avatar in a setting similar to the virtual world (mean 3.83, SD 0.61). The lowest rating overall was found in the use of a phone call as the medium for the alcohol SBI encounter (mean 3.41, SD 0.75).

**Table 6.** Mean scores of Telecom Simulation User Evaluation Survey (N=482).

| Telecom Simulation User Evaluation Survey items | Teleconference (Zoom; n=450), mean (SD) | Avatar/virtual world encounter (n=18), mean (SD) | Phone encounter (n=14), mean (SD) |
|---|---|---|---|
| This training mode provided a realistic provider–patient interaction | 4.26 (0.70) | 3.78 (1.11) | 3.21 (1.18) |
| Experiencing the standardized patient's voice and facial expressions was important in this interaction | 4.46 (0.67) | 3.50 (1.15) | 3.43 (1.01) |
| It was just as easy to talk with the patient about substance use in this interactive environment as it would be in real-world training | 3.77 (0.93) | 3.67 (1.08) | 3.00 (1.10) |
| This mode of interacting was distracting from the content of the conversation | 3.79 (0.98) | 3.72 (1.17) | 3.64 (0.92) |
| I noticed a delay in response time while using this method of communicating | 4.14 (1.06) | 3.72 (1.07) | 4.00 (0.87) |
| The standardized patient was skillful and natural in the patient role | 4.55 (0.69) | 4.11 (1.02) | 4.07 (1.14) |
| Feedback from the standardized patient was informative and useful to me | 4.55 (0.63) | 4.50 (0.51) | 3.86 (1.16) |
| I prefer this method training to real-life role plays or simulations | 3.14 (1.05) | 2.83 (1.29) | 3.00 (1.03) |
| Getting set up and started with technology for this simulated SBI[a] session was easy enough | 4.07 (0.91) | 3.6 (1.03) | 2.36 (1.39) |
| This mode of experiential training is an expedient method for learning how to conduct a good intervention | 4.17 (0.73) | 3.78 (0.64) | 3.14 (1.29) |
| I plan to utilize what I have learned from this training in my clinical practice | 4.52 (0.60) | 4.56 (0.51) | 3.93 (0.99) |
| Overall, the experiential training met or exceeded my expectations | 4.30 (0.74) | 4.22 (0.87) | 3.36 (1.15) |
| Satisfaction score in the aggregate | 4.14 (0.51) | 3.83 (0.61) | 3.41 (0.75) |

[a]SBI: screening and brief intervention.

### Training Satisfaction Survey

Finally, the Training Satisfaction Survey, presented in Table 7, was completed by the trainee immediately following the training (baseline) and 30 days later, at the one-month follow-up time point, resulting in essentially no change over time. The baseline mean score was 4.24 (SD 0.73), and it was unchanged after 30 days, with a mean score of 4.24 (SD 0.73).

In the examination for demographic differences in the pre/posttest mean score analysis (results not shown), we did find significant differences by gender and year in school.

In addition, owing to the significant outcomes across all schools in the pre/post mean scores, we conducted a sensitivity analysis to determine if differences in each school implementation (Table 1) had influenced school performance and if there was any statistical differences between their training outcomes. Although we did show that at the pretest assessment there was a statistical difference between SSC-Knoxville, SLU, and MSU, at the posttest assessment, those differences were resolved. Therefore, the mixed-models factorial ANOVA stratified by institution revealed no statistical difference between the 5 school implementations (data not shown).

**Table 7.** Training Satisfaction Survey baseline and 1-month follow-up scores (n=353).

| Training Satisfaction Survey questions | Baseline, mean (SD) | 1-month follow-up, mean (SD) |
|---|---|---|
| How satisfied are you with the overall quality of this training? | 4.26 (0.78) | 4.25 (0.77) |
| How satisfied are you with the quality of the instruction? | 4.21 (0.80) | 4.22 (0.79) |
| How satisfied are you with the quality of the training materials? | 4.23 (0.78) | 4.26 (0.75) |
| Overall, how satisfied are you with your training experience? | 4.28 (0.77) | 4.25 (0.81) |
| Satisfaction aggregate scores | 4.24 (0.73) | 4.24 (0.73) |

## Discussion

### Principal Findings

The development of a cohesive and inclusive Web-based training educational model for health care students is complex. We found that it involves a continuous process that requires detailed feedback mechanisms and flexibility to match emerging needs. The effectiveness of utilizing alcohol SBI in routine clinical practice is not new; however, implementing techniques to assure routine use in practice remains a challenge. In our analysis across these 5 programs, the best training sequence involved a face-to-face presentation at the participant schools, introducing the topic of alcohol SBI and importance of screening for alcohol use; providing direction on how to navigate the course website with details about pre- and postcourse expectations, followed by participation in the alcohol SBI training course; and finally, inclusion of a live session with a standardized patient via videoconferencing for a practice alcohol SBI encounter. However, although this appeared to be the best implementation method based upon satisfaction feedback, in the sensitivity analysis conducted among the 5 programs, we found no significant differences between implementation method and effectiveness of the outcomes. This would suggest that differences in program implementation did not affect the impact of the alcohol SBI Web-based training module.

In the analysis of our results compared with the population of trainees, we did find significant differences by gender and year in school. It appears that women trainees increased their knowledge and skills more, compared with men. Similarly, the students who were in their second year of the program (the clinical year) had higher mean scores at the posttest assessment compared with those in their first year of the program. The gender difference could be because of the greater number of female physician assistant students (70.7%, 341/482), compared with male physician assistant students (29.3%, 141/482) across all participant schools. The fact that students in their second year had higher mean scores would suggest that more experience with patients yields greater knowledge and makes one more comfortable in knowing how to talk with patients.

Finally, it is noted that the student/trainee mean score for the statement regarding the NIAAA low-risk drinking guidelines was low in comparison with other elements in the PRS-provider assessment. The training module instructs the learner about several different types of alcohol screening instruments, one of which is the NIAAA low-risk drinking guidelines. However, the alcohol use guide that the student trainees were instructed to use for the simulated live encounter with the standardized patient used the AUDIT-C (alcohol use disorder identification test consumption) for the instruction on what were low- versus high-risk drinking levels. Although the low-risk drinking guidelines used in the AUDIT were the same as the NIAAA guidelines, the student trainees would most likely not have remembered this in responding this statement on the PRS-provider. This outcome would suggest that this particular question would need to be modified for any future assessments.

In this study, we believed that the development of a Web-based course dedicated to teaching health care practitioners how to hold a conversation about alcohol with a patient/client needed to be engaging and easy to use. We were pleased with the significant difference in change over time for trainee knowledge and skills relevant to conducting an alcohol SBI encounter. The 3 statements that did not achieve significance were, in fact, all pertaining to trainee attitude, which suggests that for this population of physician assistant students, attitude about the importance of discussing alcohol use and screening was already at a high level.

### Simulation and Standardized Patient Encounters

Encountering challenges with deploying and utilizing standardized patient training methods on the Web are not new [11,19]. However, with the advancement of technology-based approaches to address education needs of health care professionals, it is almost an essential tool to meet these needs. In this study, we found that virtual standardized patient encounters did not work well, overall. This finding contends with the larger literature base [10,16]. In theory, moving face-to-face encounters to a virtual environment should be more convenient to use because it minimizes barriers such as cost, access, security, scalability, and flexibility; however, we find that there are several obstacles with transitioning from theory to practice. Research suggests that some of the most pertinent factors to consider when designing/implementing a standardized patient–centered curriculum are location, availability, and cost [20]. Although these factors were accounted for in this study, challenges persisted around (1) standardized patient knowledge of the content matter, (2) standardized patient and student utilization of technology, and (3) coordination of standardized patient encounters. Anecdotal feedback from student participants suggested that the mechanism of the virtual environment was successful. However, navigating through scheduling standardized patient encounters, training, and educating both standardized patients and simulation center instructors was challenging.

The coordination of operating an independent website and employing an established simulation center presented several practical challenges that were difficult to overcome. First, connecting the 2 LMS platforms proved to be problematic and was ultimately abandoned in favor of incorporating all scheduling and video conference aspects into Catalyst Learning Center [18]. Second, scheduling live encounters that worked for the study team, simulation center, and student cohort was complicated, and the arrangement required substantial manual organization. In addition, the challenge to adequately and consistently train a variable pool of standardized patients in a complex behavior change approach was demanding.

The study team provided dedicated instruction to the standardized patients; however, the standardized patients were not alcohol SBI specialists, and the students reported that the standardized patient feedback was often inconsistent with the training content. Even after several modifications based on feedback from the students, study team, and simulation center staff, the standardized patient live-encounter process was challenging to arrange, difficult to manage, and required unsustainable effort to control for human error at various stages. Students generally had positive responses to the live

standardized patient encounter and reported that they it beneficial for the training. There is room for improvement in delivering behavior change instruction to standardized patients, and integrating alternate technology will improve the process of accessing standardized patients remotely.

### Program Management Challenges

Coordination among the website developers, simulation center, and research teams required considerable oversight.

#### *Individual Schools*

Three schools were subcontractors of the grant and were committed from the onset to participation and implementation of the program. Some of the challenges we encountered included getting administrator buy-in, administrator attitudes, and their perception of the importance of the study. In one school, added after the grant commenced, was a new program with only its first cohort of physician assistant students, and creating a structured curriculum for the students and trying to initiate a new training curriculum at the same time was met with resistance. The presence of advocates and/or program champions who could speak about the importance of an alcohol SBI training/curriculum helped facilitate the navigation of the administrative maze. Along the lines of having program advocates within the administration, the literature supports the inclusion of independent faculty development resources to better align desired health care professionals' training outcomes with training resources [21].

#### *Technical Teams*

As this was a pilot in which changes were made incrementally to incorporate end-user feedback, the website required constant maintenance and updating to accommodate trainee and researcher expectations. Unanticipated needs and issues resulted in the need for sophisticated updates to the site that were both costly and time intensive for the site developers. As with any Web-based application, Catalyst Learning Center [18] was exposed to security risks. Despite several levels of encryption, security vulnerabilities enabled suspicious activity from outside entities and made it difficult for the users to access the site at times. It is important to note that this is a risk, and there is an increased need to protect Web-based programs of this nature.

#### *Learning Management System Communication*

Significant challenges arose in communication between the university's simulation center and the Catalyst website [18]. In the process of addressing *ease of using the site*, we wanted to have the Catalyst site include the ability to schedule the simulation center live standardized patient encounters, where the individual student would view the available standardized patient encounter timeslots and match a standardized patient encounter to when the student had availability. This proved to be beyond the current capacity of both the simulation center and the Catalyst website [18], thus all scheduling for the live standardized patient encounters was done manually.

### Limitations

As this was a pilot program dedicated to the design, development, implementation, and evaluation of a Web-based alcohol SBI training module for physician assistants within an academic program, our primary limitation was the lack of control over how the final training module was implemented within each academic setting. As noted in Table 1, each University or College program implemented the training module in a unique manner, one that was well-suited for their specific academic program. Although this is what we wanted to take place in terms of long-term sustainability of the Web-based training module, this made it challenging for comparability across academic setting. Thus, our results are presented in the aggregate across all academic programs as opposed to a comparison between academic programs.

A second limitation is the ability to generalize our results to other physician assistant programs in the country, again because of unique implementation of the training within each of our participant settings, either University or College. However, although this is seen as a limitation, the sensitivity analysis would suggest that the alcohol SBI training can be implemented in a variety of different physician assistant courses and settings and can be successful in each.

We had some loss of survey response at the 30-day satisfaction survey follow-up period because of an attrition rate of 26.9% (130/482). This again was because of the lack of control over how each faculty member encouraged students to complete the full set of evaluation surveys, although we sent out multiple emails to the students directing them to the Catalyst Learning Center [18] to complete the follow-up satisfaction survey. However, we still retained a 73% completion rate for the satisfaction survey with an overall satisfaction mean score of 4.23, indicating a general satisfaction with the training they received. We conducted an analysis to determine potential differences between those who completed the training and those who did not and found no significant difference in terms of the effectiveness of the outcomes.

### Conclusions

The benefits of employing technology-enhanced learning techniques in health professional training has become widely acknowledged. Utilizing these training methods are not without challenges. We find that employing a combined didactic alcohol SBI training model with virtual standardized patient encounters presented unique challenges in the implementation phase. However, such an approach on the Web is relatively innovative and beneficial for student learning. As placing the training on the Web is a relatively new venture, especially the virtual standardized patient, future studies may explore whether a condensed alcohol SBI training on the Web is beneficial and what, if any, content needs to be expanded, highlighted, or completed in person. Furthermore, we note that as more researchers explore creative ways to educate health care professionals about alcohol SBI techniques, our study provides some insight on how to implement technology-based studies and what pitfalls to avoid.

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## Authors' Contributions

LTL is the principal investigator and author of the original idea for the study. She prepared, edited, and reviewed the final submission of this paper. TC, GDR, and KE were faculty members, and they reviewed and edited the final version of the paper. CL and LO were project coordinators and were directly involved in the development and implementation of the project along with the review and editing of the final paper. AE was the project data manager and conducted all data analyses and prepared the final tables for the Results section. DS was the author of the attitudes, knowledge, and skills scale used for this study and provided background on previous SBIRT models.

## Conflicts of Interest

None declared.

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## Abbreviations

**ANOVA:** analysis of variance
**AUDIT:** alcohol use disorders identification test
**e-learning:** electronic learning
**LMS:** learning management system
**MSU:** Missouri State University
**NIAAA:** National Institute on Alcohol Abuse and Alcoholism
**PCP:** primary care provider
**PRS:** Proficiency Rating Scale
**SAMHSA:** Substance Abuse and Mental Health Services Administration
**SBI:** screening and brief intervention
**SBIRT:** screening, brief intervention, and referral to treatment
**SC-Columbia:** Stephens College, Columbia, Missouri
**SC-Knoxville:** South College, Knoxville, Tennessee
**SLU:** Saint Louis University
**UMKC:** University of Missouri–Kansas City

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Viewpoint

# E-Clinical High Risk for Psychosis: Viewpoint on Potential of Digital Innovations for Preventive Psychiatry

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## Abstract

E-mental health is an emerging area of research that has the potential to overcome some of the current barriers to progress in working with people at clinical high risk for psychosis (CHR-P). This article provides an overview of how e-mental health could be used in the detection, prediction, and treatment in the CHR-P population. Specifically, we evaluate e-detection, e-prediction, and e-therapeutics for this clinical population. E-mental health holds great promise to improve current management of CHR-P individuals.

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**KEYWORDS**

psychotic disorders; schizophrenia; prognosis; treatment; clinical high risk; digital; e-health; internet; smartphone; mobile phone

## Introduction

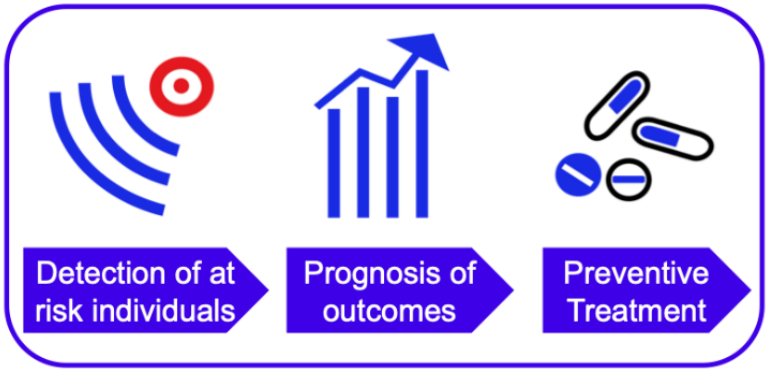
The identification of people at clinical high risk for psychosis (CHR-P) [1] offers a unique opportunity to alter the illness course of psychotic disorders [2]. These individuals often have several risk factors for psychosis [3] and typically present with attenuated psychotic symptoms in the context of a recent decline in functioning [4]. They display symptoms and functional impairments that are qualitatively similar to those observed in established mental disorders [5]. The risk of transition to psychosis within 2 years in these individuals is approximately 20% [6]. This risk is not the same across the different CHR-P subgroups. In particular, individuals meeting criteria for short-lived psychotic episode show a distinctive and very high risk of developing persistent psychotic disorders that cumulates to about 50% at 2 years [7]. CHR-P individuals presenting with a short-lived psychotic episode that is spontaneously remitting but characterized by disorganized behavior have an even higher risk of developing a persistent psychotic disorder, cumulating at 89% at 5 years [8]. These individuals also have unmet clinical needs not typically addressed by the current configuration of mental health services [9,10]. Overall, the risk for the development of psychosis from a CHR-P stage has declined from 29% [11] to 20% [6] in recent years, although not across all sites [12]. This variable transition risk is due to different sampling strategies being adopted to recruit these individuals [13]. Emerging evidence indicates that the method of recruitment prior to a CHR-P assessment is fundamental in enriching their actual level of risk for psychosis [13].

Although the CHR-P paradigm has been adopted in various countries worldwide [14-17], a number of challenges have arisen, hindering its penetrance into mainstream clinical practice. The real-world success of the CHR-P paradigm rests on three core components: an efficient detection of at risk cases, accurate prediction of their outcomes, and effective preventative treatments to alter the course of these outcomes Figure 1.

There are currently barriers to the implementation of each component. First, well-established CHR-P services [17] detect as low as 5% of first episode psychosis (FEP) patients before illness onset [18]. Even within national youth mental health services, the proportion of FEP cases detected at their CHR-P stage is only 12% [19]. Second, although the prognostic performance of the current CHR-P psychometric tools is excellent [20], it is highly dependent on the way CHR-P individuals are recruited [21]. Furthermore, prognostic outcomes in this population are mostly based on group-level predictions, and it is not yet possible to forecast the onset of psychosis at the individual-subject level [22]. This is a substantial limitation given that the CHR-P group is highly heterogenous and includes different subpopulations with differing outcomes [7]. Third, no specific preventive treatment appears to be more effective than others in preventing onset of psychosis [23], treating attenuated positive symptoms [24,25], treating attenuated negative symptoms [26], treating depressive symptoms [27], reducing distress [28], or improving social functioning [29]. Again, the lack of evidence may partially reflect the fact that one-size-fits-all approaches for this population do not work and individualized treatments should be offered instead.

E-Mental health is a new approach that may be uniquely suited to overcome some of these barriers. Individuals at CHR-P have a young age range (most criteria are set at 14 to 35 years) and as such tend to be highly engaged with the digital world [30]. Although previous reviews have highlighted the emerging potential for e-mental health in psychosis [31-34], there is currently no overview focusing on the potential and prospects specifically in CHR-P. In this article, we provide an overview how e-mental health can be applied to the detection, prediction, and treatment of CHR-P. Studies included in this overview are summarized in Table 1. Although this is not a systematic review and there is no assumption that the literature surveyed is comprehensive, we provide our search strategy and inclusion criteria in Multimedia Appendix 1.

**Figure 1.** Core clinical and research components for effective prevention of psychosis, from Fusar-Poli et al [35].




## E-Detection

Detecting individuals at risk prior to the onset of psychosis has been a key research priority over the past two decades since the Personal Assessment and Crisis Evaluation study first developed the concept of the CHR-P [16]. Typical inclusion in the CHR-P group is based on attenuated psychotic symptoms, brief episodes of psychosis, or functional deterioration in those with genetic vulnerability for psychosis [35,36]. A distinct approach to the identification of CHR-P individuals is the basic symptom concept proposed by Huber and colleagues [37]. Basic symptoms involve self-experienced perceptual and cognitive anomalies that are thought to represent the earliest manifestation of psychosis risk [38]. More recent studies have shown that the combined presence of both basic symptom and CHR-P criteria increases the predictive power significantly [39]. However, it should also be noted that CHR-P participants who do not make the transition to psychosis are characterized by extensive psychiatric comorbidity and reduced occupational and social functioning [40]. Accordingly, these two domains are also potentially important for targets for e-mental health applications, in terms of both prediction and preventive treatments.

Recruitment strategies have a significant impact on subsequent transition rates of CHR-P cohorts, with self-referrals, assertive community outreach, and population screening associated with lower rates of transition to psychosis [41]. Despite the expansion of CHR-P services, only a small proportion of FEP patients are detected [42]. It is thus a key priority for CHR-P to improve detection of individuals prior to the FEP while not diluting the sample's baseline risk of psychosis. As the majority of FEP patients actively seek information regarding mental health issues online as their symptoms first develop [43], early identification of CHR-P individuals may be possible through digital detection strategies. These could include online screening as well as use of social media information. Recent evidence, for example, suggests that references to sadness, loneliness, hostility, rumination, and increased self-reference on Facebook predict later onset of depression [44]. A similar approach may be useful in CHR-P as the development of psychosis is characterized by linguistic anomalies that can be detect by automated speech analysis [45,46].

Online screening has the potential to reach a greater number of individuals compared with traditional routes of referral to CHR-P services. McDonald et al [47] used a website for detection of CHR-P in the community. Potential participants were invited via email, flyers, and posters to a website [48] and then asked to complete the 16-item version of the prodromal questionnaire (PQ-16) and 9-item questionnaire of perceptual and cognitive aberrations (PCA) for basic symptoms. This allowed screening of a large number of individuals, 52.3% (1202/2296) of whom met PQ-16 cutoff criteria and 73.6% (1691/2296) of whom met PCA cutoff criteria. Of those meeting screening cutoff criteria who then attended a clinic interview, 31.2% (101/324) met clinical CHR-P criteria. Importantly, a subset of 8 individuals (2.5%) also met criteria for FEP. Receiver operating characteristic curve analysis revealed good to moderate sensitivity and specificity for predicting CHR-P status based on the online results [47]. A machine-learning approach that selected all 25 items from both the PQ-16 and the PCA in addition to demographic variables lead to an improved specificity of 57% while only marginally affecting sensitivity (81%), compared with the original online screening tool.

This study suggests that online screening of community samples for emerging psychosis is possible, potentially identifying a large number of people meeting CHR-P criteria. However, it is currently unclear how many of these participants meeting CHR-P criteria will actually develop psychosis. Accordingly, 2-year transition rates are needed to validate whether the sample detected are truly at risk of developing a psychotic disorder or whether they are false positives. A similar approach to McDonald et al [47] has been implemented using the 32-item self-screen prodrome questionnaire [49], although, again, long-term transition rates are not known. Furthermore, the validity of self-screening questionnaires, particularly when conducted in nonclinical populations, has been questioned [50] due to poor prognostic performance in predicting subsequent psychosis.

More targeted screening of populations accessing secondary mental health services that use electronic health records is also possible through online screening. Our group developed a psychosis risk calculator for patients already accessing secondary mental health services [18]. This tool uses routine clinical data including *International Classification of Diseases, Tenth Revision* (ICD-10), spectra diagnoses to predict future risk of developing a psychotic disorder and has been externally validated twice in different National Health Service (NHS) Trusts [51] showing an acceptable prognostic performance (Harrell C of 0.73). Patients who have accessed secondary mental health services have a 5-fold increased risk compared with the general population [18], suggesting this may be an efficient way of detecting new cases of psychosis while not diluting the level of risk in the sample. As it uses routine clinical data, the calculator could be used to automatically screen electronic health records for those at increased risk of future psychosis. However, it does rely on the assessment of health professionals to provide ICD-10 diagnoses, and therefore it cannot be used universally for self-screening. The calculator is one of the few eHealth tools in the CHR-P population that is being implemented into clinical routine practice [52].

The North American Prodrome Longitudinal Study has produced an online risk calculator for individuals meeting CHR-P criteria [53]. It showed an overall accuracy of 72% in predicting psychosis when validated in an independent external data set [54]. However, it requires input in the form of a structured interview to confirm CHR-P status and neuropsychological testing, limiting its applicability to wider clinical populations.

E-Mental health offers the opportunity for efficient, scalable screening of those at risk of psychosis across populations that are currently not reached by conventional recruitment, potentially allowing better detection of individuals prior to their FEP. Preliminary evidence suggests that it is indeed feasible. The next step is determining whether these tools can be implemented in practice to identify individuals at increased risk of psychosis while not diluting the overall risk of the sample with false positives.

## E-Prognosis

The risk of transition to psychosis from CHR-P is maximal within the first 2 years [55]. This period is therefore a crucial time for predicting onset of psychosis. Traditionally, this has been achieved through regular clinical monitoring from CHR-P services to assess for transition to psychosis, but advances in mobile phone technology offer the opportunity for a far greater temporal resolution in monitoring changes in mental state that may occur on a daily or even momentary basis.

The experience sampling method (ESM) uses mobile phones to measure self-rated changes in mental state on a daily basis [56]. It has excellent ecological validity and allows close monitoring of mental state, particularly in regard to predictors of transition to psychosis. ESM techniques in CHR-P were initially rudimentary, requiring participants to fill out responses in a paper diary when prompted by a wristwatch alarm [57,58]. Palmier et al [59] demonstrated that it is feasible to monitor symptoms through a mobile phone app in a small sample (n=12) of CHR-P individuals, paving the way for further cross-sectional ESM studies. Klippel et al [60] showed in 46 CHR-P individuals that momentary stress increased psychotic experiences via affective disturbance using the PsyMate app. Reininghaus et al [61] used ESM to link threat perception to psychotic experiences in 44 CHR-P individuals and in another study [62] to show an association with sensitivity to outsider status and aberrantly salient experiences with psychotic experiences. Van der Steen et al [63] used ESM to demonstrate an association between affective and psychotic experiences in response to stress in CHR-P individuals, showing an association between stress and psychotic experiences. ESM has shown potential utility in monitoring fine-grained changes in psychopathology during the development of psychosis; however, longitudinal studies are needed to determine its significance for predicting the onset of psychosis. To date, one longitudinal study has been registered: Booij et al [64] plan to predict outcome in various stages of psychosis using mobile phone diary measures of symptoms, stress, emotions, and functioning.

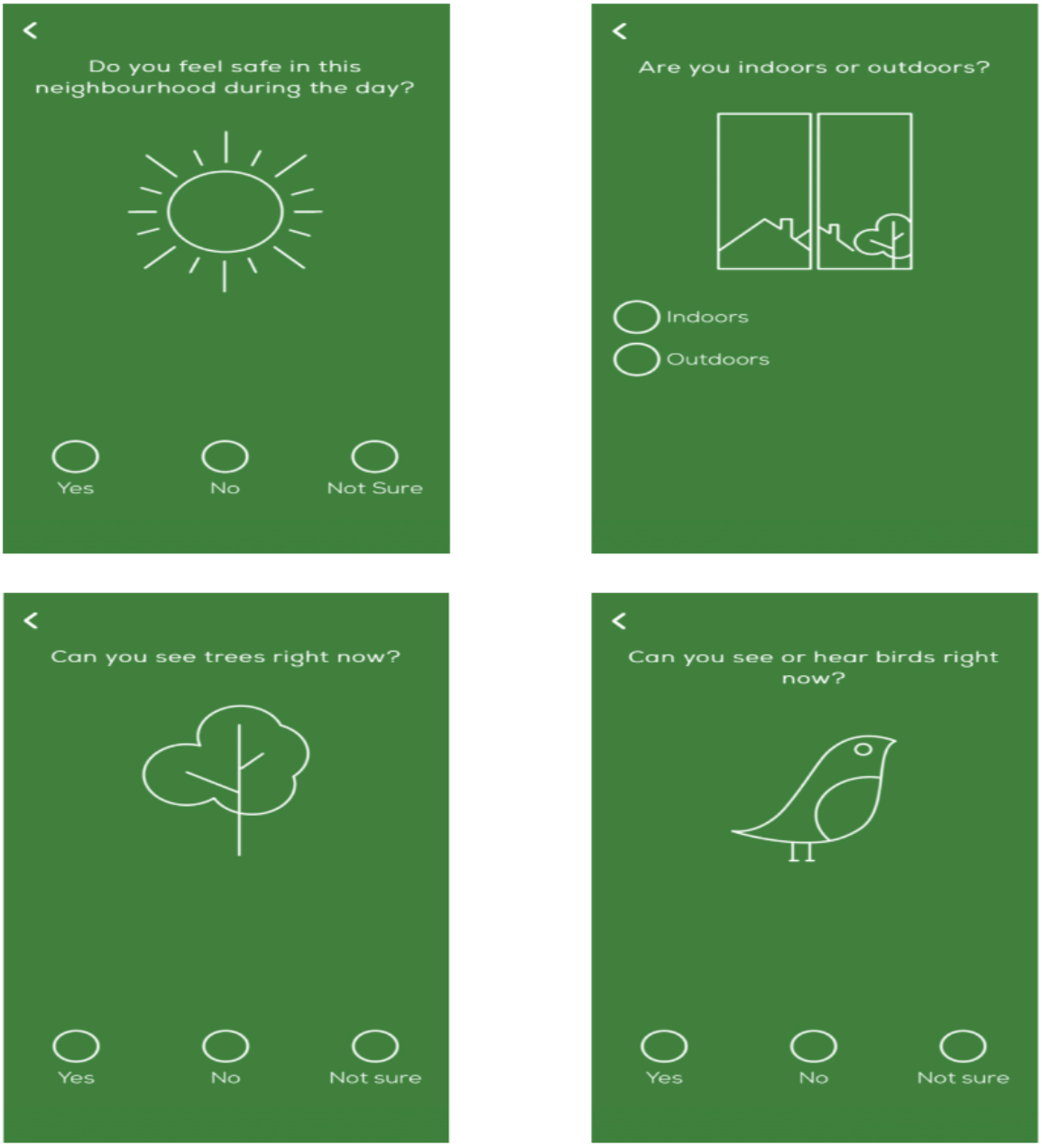
Digital phenotyping, also known as personal sensing, is a novel investigational technique whereby passive measures of mobile phone activity are recorded in real-time [65], which has been postulated to provide a digital phenotype of psychiatric disorders [66]. These measures may include the participant's interaction with their phone (eg, call logs, number of messages, keyboard use) as well as measures of their activity and movement (eg, through accelerometers or Global Positioning System tracking). Passive data provide a continuous readout every day and require no active role by the participant, thus providing significant advantages over traditional, episodic cross-sectional data. Passive data are also potentially more ecologically valid than symptom ratings elicited by standard questionnaires or interviews, and there is reduced risk of subject attrition.

However, the use of passive mobile phone measures warrants some important ethical considerations [65]. As with any investigation, informed consent, data security, and anonymization are crucial. Additionally, in those with psychotic disorders, care must be taken not to exacerbate paranoia when using participants' personal devices. Passive measures therefore may be particularly suited to CHR-P individuals, who retain insight, particularly for the prediction of psychosis onset. Unlike ESM, they do not require continual user input and may therefore be less burdensome to participants. A pilot study suggests digital phenotyping could predict relapse in schizophrenia based on anomalies in patient behavior [67]; further studies in CHR-P populations are underway, for example, using the MindStrong app [68].

ESM and digital phenotypes have complementary strengths. ESM provides explicit information about a patient's state of mind and as such is key to understanding their motivations and behaviors, whereas digital phenotyping has the important advantage of placing minimal burden on the patient apart from keeping their mobile phone charged and as such is ideal for clinical translation. Initial studies suggest that it might be possible to use passive data generated via digital phenotyping as a proxy for active data collected via ESM [69]; in the context of CHR-P, this could enable the background monitoring of risk of transition to psychosis with minimal interference on the day-to-day life of patients.

In addition to informing diagnosis, prognosis, and treatment, e-tools could be used to gain greater understanding of the mechanisms that underlie transition to psychosis. For example, our research team is currently using the Urban Mind app [70] to investigate the impact of the surrounding social and physical environment on risk of transition to psychosis in individuals at CHR-P (see Figure 2 for user interface).

**Figure 2.** Urban Mind app user interfaces.




These studies suggest that e-mental health has potential value in identifying risk factors for subsequent transition to psychosis and predicting the onset of psychosis. In addition, these approaches may also be applied toward prognosis for outcomes other than transition to psychosis, such as functional outcomes and development of nonpsychotic disorders. ESM and digital phenotyping are two appealing methodologies with great promise and are ideally suited to longitudinal designs to examine the development of clinical trajectories in CHR-P populations.

## E-Treatment

One criticism of CHR construct is that there is no treatment conclusively shown to prevent the onset of psychosis [71]. However, there are several promising therapeutic strategies currently under investigation that could significantly reduce psychosis risk and address important additional areas of impairment—in particular, cognitive deficits and social and occupational functioning.

Since individuals at CHR-P do not have a mental disorder as such, any treatment has to be well tolerated and acceptable. Moreover, by definition these individuals retain a degree of insight into their symptoms [72], offering a significant therapeutic window of opportunity prior to the onset of psychosis. Guidelines currently suggest psychological therapy and recommend not treating with antipsychotic medication [73]. As various psychological therapies can be delivered online, e-mental health has the potential to enhance access to treatments and reduce costs. A systematic review and meta-analysis suggested that guided online cognitive behavioral therapy (CBT) for various psychiatric disorders had equivalent effect sizes compared with face-to-face interventions [74], highlighting the potential utility of administering CBT through digital modalities.

Other psychological interventions such as mindfulness, which has shown some efficacy for psychosis [75], may also be effective when provided online [76]. Alvarez-Jiminez et al [77] conducted a novel strengths and mindfulness-based online social therapy for individuals at CHR-P. Participants found the intervention acceptable and showed an improvement in social functioning and subjective well-being, warranting further study.

Digital interventions showing promise in established psychosis, relevant to CHR-P, include avatar therapy [78], online CBT skills program for hallucinations [79], mobile phone apps delivering therapeutic interventions [80-82], and online peer-to-to peer support networks, reported to increase feelings of social connectedness [83]. Indeed, Rice et al [84] have developed an e-mental health service providing clinician-delivered Web chat counseling, a moderated peer-to-peer social network, and user directed online therapy. This enhanced moderated online social therapy is seeded in eheadspace, part of headspace, a flagship Australian youth mental health program with an integrated early intervention in psychosis component [85].

An important aspect of the clinical presentation of CHR-P is cognitive deficits across a range of domains associated with transition to psychosis [86,87]. One way of targeting cognitive deficits in CHR participants could be cognitive remediation (CR)–based treatments [88] that can be administered via computerized training procedures [89]. These approaches improve neural circuits underlying cognitive deficits with significant impact on social functioning [90], especially if administered in the early stages of schizophrenia [91]. There is emerging evidence that CR treatments may be effective in targeting cognitive dysfunctions in CHR participants. Loewy et al [92] examined the effects of CR administered through laptop and home computers on verbal learning and memory. CR significantly improved verbal memory (effect size = 0.61) as well as positive symptoms. Hooker et al [93] presented a pilot uncontrolled study of cognitive training delivered online for CHR-P, showing this intervention is feasible and appears to provide improvements in the global cognition in response to training.

Digital interventions could also be extended to address functional impairments in CHR-P individuals. In a recent study, Schlosser et al [82] examined a mobile-based digital health intervention designed to improve motivation and quality of life in young people with schizophrenia. Compared to the control group, the active treatment arm demonstrated significant improvements in levels of depression, defeatist beliefs, and self-efficacy as well as a trend for improved negative symptoms. These improvements were maintained 3 months after the end of trial. Accordingly, these data suggest that mobile-based interventions could be useful for addressing important domains of functioning in CHR-P populations.

Virtual reality (VR) is an emerging tool for the treatment of a wide range of mental disorders that involves interactive computer-generated worlds in which therapeutic strategies can be implemented and tested [94]. In established schizophrenia, VR approaches have shown preliminary efficacy in targeting positive symptoms, such as delusions [95] and hallucinations [96], as well as increasing social participation [97]. VR has also shown potential as a treatment adjunct in psychosis in modalities such as cognitive remediation and social skills training [98], showing preliminary promising results.

Following successful pilot research demonstrating the safety of VR in the CHR-P population [99], this technique has been used to investigate the effect of various simulated social environments on psychopathology. A simulation of the London underground transport system has been used to investigate paranoid ideation [100,101] and perceived ethnic discrimination [102], while café [103] and bar simulations [104] have been used to investigate the effect of social stress on interpersonal distance and paranoid ideation, respectively. These studies show the possibilities of using VR to study psychopathology in a simulated environment. Arguably, VR may be better suited as a treatment modality in CHR-P compared with more established stages of psychosis.

**Table 1.** Summary of included studies of e-mental health in clinical high risk for psychosis.

| Study and type | Summary | Results |
|---|---|---|
| **E-Detection** | | |
| McDonald et al 2018 [47] | Web-based community screening for CHR-P[a]. | Good to moderate sensitivity and specificity for predicting CHR status based on online screening. |
| Fusar-Poli et al 2017 [18] | Risk calculator based on routine clinical data of patients accessing secondary health services. | Acceptable predictive performance; Harrell C of 0.80 (0.79-0.82). |
| Fusar-Poli et al 2018 [51] | External validation of the above study in a second NHS[b] trust. | Acceptable predictive performance; Harrell C of 0.73. |
| Fusar-Poli et al 2019 [52] | Protocol for implementation study of the above into routine clinical care. | N/A. |
| Cannon et al 2016 [53] | Risk calculator based on specialized clinical assessment. | Acceptable predictive performance; Harrell C of 0.71. |
| Carrión et al 2016 [54] | External valiation of the above study in a second cohort. | Good discrimination area under the curve of 0.790 (0.644-0.937). |
| **E-Prognosis** | | |
| Palmier-Claus et al 2012 [59] | Feasibility of smartphone self-report of symptoms using the ClinTouch app. | A total of 82% (36/42) of participants were compliant with the smartphone measures. |
| Klippel et al 2017 [60] | ESM[c] study of stress and psychotic symptoms using the PsyMate app. | Effects of stress on psychotic experiences were mediated through affective disturbance. |
| Reininghaus et al 2016 [61] | ESM study of threat perception and psychotic experiences using PsyMate app. | Outsider status and threat anticipation were associated with more intensive psychotic experiences in those who experienced sexual abuse compared with those exposed to low levels of sexual abuse. |
| Reininghaus et al 2016 [62] | ESM study of sensitivity to outsider status, salient experiences, and psychotic experiences using the PsyMate app. | Elevated stress sensitivity, aberrant salience, and enhanced threat anticipation were associated with increased intensity of psychotic experiences. |
| van der Steen et al 2017 [63] | ESM study of affective and psychotic experiences in response to stress using a digital wrist watch to instruct participants to enter written self-report at random time points. | Greater associations between negative affect and stress compared with psychotic patients ($P$=.008) and controls ($P$<.001). |
| **E-Treatment** | | |
| Alvarez-Jimenez et al 2018 [77] | Pilot study of the online social therapy intervention, Momentum. | Of the 70% actively engaged during the study, all reported positive experiences, considered it safe, and would recommend it to others; 93% reported it to be helpful. Large improvements in social functioning ($d$=1.83, $P$<.001) and subjective well-being ($d$=0.75, $P$=.03). |
| Rice et al 2018 [84] | Study protocol for enhanced moderated online social therapy (MOST). | N/A. |
| Loewy et al 2019 [92] | Randomized trial investigating the effectiveness of auditory-processing exercises administered through laptops in CHR-participants compared to the effects of computer games (CG) training. | Targeted cognitive training showed a significant improvement in verbal memory compared to CG participants (effect size = 0.61). Positive and total symptoms improved in both groups over time. |
| Hooker et al 2014 [93] | Pilot uncontrolled study of online cognitive training. | Significant improvements in processing speed ($P$=.01, $d$=0.63) and nonsignificant improvements in visual learning and memory ($P$=.06, $d$=0.54) and global cognition ($P$=.06, $d$=0.45). |
| Valmaggia et al 2007 [99] | Study of the feasibility and safety of VR[e] environments. | No adverse events; no increase in mean anxiety score ($P$=.29). |
| Valmaggia et al 2015 [101] | VR study assessing childhood bullying and paranoid ideation in a simulation of the London underground. | More paranoid appraisals of VR simulations compared with controls ($P$<.001). |

| Study and type | Summary | Results |
|---|---|---|
| Valmaggia et al 2015 [100] | VR study assessing social defeat and paranoid appraisals in a simulation of the London underground. | More paranoid ideation during VR simulation compared with controls $\chi 2(1)=21.06$, ($P<.001$). |
| Shaikh et al 2016 [102] | VR study assessing ethnic discrimination and persecutory paranoia in a simulation of the London underground. | Higher levels of perceived ethnic discrimination correlated with greater paranoid persecutory ideation in VR environment r=0.25, $P=.009$. |
| Geraets et al 2018 [103] | VR study assessing interpersonal distance regulation in a simulated café. | Interpersonal distance increased when social stressors were present in the environment F=3.02, $P=.02$. |
| Veling et al 2016 [104] | VR study assessing paranoia in a simulated bar environment. | Increased paranoia compared with controls, regression coefficient 3.80 (95%CI 0.24–7.37) $P=.04$. |

[a]CHR-P: clinical high risk of psychosis.

[b]NHS: National Health Service.

[c]ESM: experience sampling method.

[d]VR: virtual reality.

## Conclusion

Digital technologies are at present underused as a research or clinical tool for CHR-P and may be ideally placed to address the current challenges of the field. These include detecting those at risk of psychosis outside specialized CHR-P clinics, monitoring to predict future development of psychosis, identifying digital biomarkers for psychosis and other clinical outcomes, and delivering novel treatment modalities. Furthermore, individuals at CHR-P, by definition young and help-seeking, are ideally suited to digital interventions. However, longitudinal studies of digital technologies are required to assess which measures are useful for predicting risk of psychosis in individuals identified by online screening. Future research is required to rigorously test whether digital interventions have a place in the detection or management in people at CHR-P. In addition, we need greater understanding of the relationship between the different types of measures (eg, active and passive data collected via ESM and digital phenotyping, respectively) in order to develop and validate e-tools that provide maximal information while minimizing burden on the patient.

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### Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy and inclusion criteria.
[PDF File (Adobe PDF File), 128 KB - mental_v6i10e14581_app1.pdf ]

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## Abbreviations

**CBT:** cognitive behavioral therapy
**CHR-P:** clinical high risk for psychosis
**CR:** cognitive remediation
**ESM:** experience sampling method
**FEP:** first episode psychosis
**ICD-10:** International Classification of Diseases, Tenth Revision
**NHS:** National Health Service

**NIHR:** National Institute for Health Research
**PCA:** 9-item perceptive and cognitive aberrations questionnaire
**PQ-16:** 16-item prodromal questionnaire
**VR:** virtual reality

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Review

# Conversational Agents in the Treatment of Mental Health Problems: Mixed-Method Systematic Review

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## Abstract

**Background:** The use of conversational agent interventions (including chatbots and robots) in mental health is growing at a fast pace. Recent existing reviews have focused exclusively on a subset of embodied conversational agent interventions despite other modalities aiming to achieve the common goal of improved mental health.

**Objective:** This study aimed to review the use of conversational agent interventions in the treatment of mental health problems.

**Methods:** We performed a systematic search using relevant databases (MEDLINE, EMBASE, PsycINFO, Web of Science, and Cochrane library). Studies that reported on an autonomous conversational agent that simulated conversation and reported on a mental health outcome were included.

**Results:** A total of 13 studies were included in the review. Among them, 4 full-scale randomized controlled trials (RCTs) were included. The rest were feasibility, pilot RCTs and quasi-experimental studies. Interventions were diverse in design and targeted a range of mental health problems using a wide variety of therapeutic orientations. All included studies reported reductions in psychological distress postintervention. Furthermore, 5 controlled studies demonstrated significant reductions in psychological distress compared with inactive control groups. In addition, 3 controlled studies comparing interventions with active control groups failed to demonstrate superior effects. Broader utility in promoting well-being in nonclinical populations was unclear.

**Conclusions:** The efficacy and acceptability of conversational agent interventions for mental health problems are promising. However, a more robust experimental design is required to demonstrate efficacy and efficiency. A focus on streamlining interventions, demonstrating equivalence to other treatment modalities, and elucidating mechanisms of action has the potential to increase acceptance by users and clinicians and maximize reach.

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**KEYWORDS**

artificial intelligence; mental health; stress, pychological; psychiatry; therapy, computer-assisted; conversational agent; chatbot; digital health

## Introduction

### Rationale

Conversational agents are software programs that use artificial intelligence to simulate a conversation with a user through written text or voice. Recent everyday examples include digital assistants such as Siri (Apple), Cortana (Microsoft), Google Now, and Alexa (Amazon) [1]. The first conversational agent of this kind was ELIZA [2], which was programmed to mimic conversation with a Rogerian psychotherapist using typed text. In the 50 years since ELIZA, interest in conversational agents and artificial intelligence has waxed and waned, and this is reflected in publication rates over time [3]. However, significant advances in technology over the past 2 decades have facilitated the design of conversational agents that can undertake evermore

complex tasks [4]. This has resulted in an explosion of publications in this area, particularly since 2009 [3].

Evidence has begun to accumulate around the potential benefits of conversational agents in diverse fields [5] within health and medical care [6] and specifically in mental health [7-11]. Increased access to information through the internet and mobile phones has highlighted the potential for conversational agents to provide autonomous, interactive, and crucially accessible mental health support. Existing digital therapies have suffered from low adherence and concerns about their efficiency without continued human support [12,13]. Existing digital therapy formats tend to focus on psychoeducation and a modular style of fixed content and duration that is inflexible for users. Conversational agents hold particular promise compared with other digital mental health interventions as they can provide greater interactivity that emulates therapeutic conversation and provides choice and control over session content and intensity. Research has demonstrated that users respond and connect to conversational agents in social ways, and they can encourage honest disclosure [14,15]. They also have potential for greater scalability compared with other therapy modalities such as human therapists, *Wizard of Oz* programs (where a therapist responds via a computer), or digital interventions that require ongoing support from a clinician to produce favorable outcomes.

The application of conversational agents in mental health is varied and includes diagnostic tools, symptom monitoring, and treatment or intervention [16]. Existing systematic and scoping reviews of conversational agent interventions in the mental health field have focused on a subset of conversational agents with a visual character (embodied) [8-10] or are now outdated [7]. As far as we are aware, this is the first comprehensive systematic review of conversational agents in the treatment of mental health problems.

### Objectives

We conducted a systematic review and synthesis of conversational agents in the treatment of mental health problems. Conversational agents are diverse in design [1] and include, for example, chatbots (eg, casual conversation delivered verbally or through text), embodied conversational agents (ECAs; a virtual visual character that simulates human style, face-to-face conversation with gestures, and nonverbal behavior), conversational agents with a physical presence (eg, robots), and conversational agents within virtual reality (VR). For this systematic review, studies that included an automated conversational agent that simulated a 2-way, real-time conversation, with text or verbal based input (either fixed response options or free text) and an independent (not supported by a human) stand-alone system were included. Studies that used *Wizard of Oz* methods, where a person or therapist responds through the computer or programs that required the ongoing support from a therapist or similar, were excluded. We followed the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols guidelines [17,18]. The protocol was registered prospectively at PROSPERO (registration number: CRD42018106652).

## Methods

### Literature Search

A systematic search of the literature was performed in September 2018 and updated in January 2019 using MEDLINE (1946 to August week 5, 2018), EMBASE (1974 to September 2018), PsycINFO (1806 to September 2018), Web of Science (1900 to September 2018), and the Cochrane library (All to September 2018). The search was not restricted by publication year or language. Overall, 3 categories of search terms were included: (1) relational agent, (2) mental health, and (3) intervention. The Boolean operator AND was used to bring together separate categories and OR was used to combine terms within categories. Keywords were collated from the existing literature, academics in the field of conversational agents, and the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [19]. The search strategy included keyword truncations and mappings to subject heading (medical subject heading) that were adapted appropriately for each database. The reference lists of all included studies were handsearched to identify all relevant references. Gray literature, including conference abstracts or proceedings, and dissertations or theses identified through the database searches were also included for screening.

### Eligibility Criteria

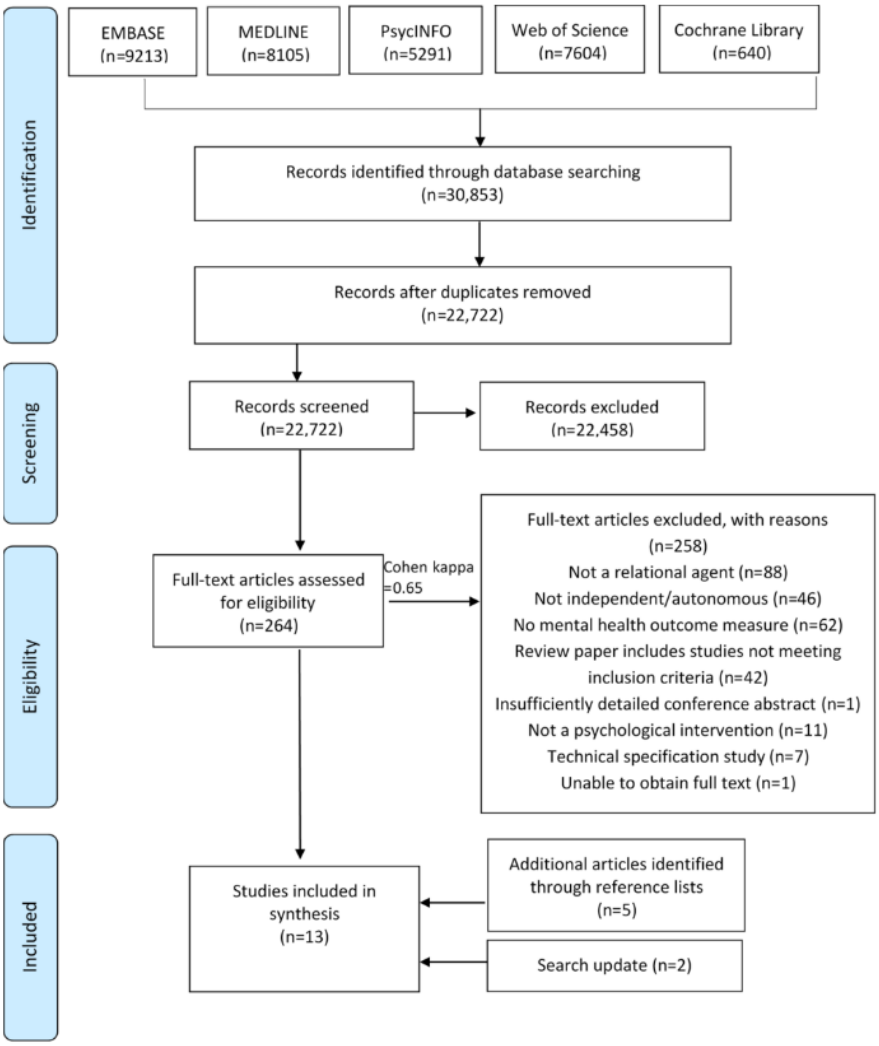
Studies were included if they reported on a conversational agent intervention for mental health; the agent was autonomous and could be used independently without support from a human; they simulated conversation; they relied on a turn-taking process with the user; and they reported on a mental health outcome. Review papers were included if all studies that were included met the inclusion criteria for this review. Studies were excluded if the output from the conversational agent was solely predetermined, for example, psychoeducation and not generated in response to user input; they used asynchronous communication, for example, email; they relied on a human user to generate responses (eg, *Wizard of Oz* methods); they required support from a person to operate, for example, a therapist or similar; they were limited to adherence to medication or physical health behaviors, for example, smoking cessation; they focused solely on the technical function, development or programming of the agent; and they lacked sufficient detail to determine eligibility (eg, short conference abstracts). Studies not written in English were translated as required. The review included a diverse range of study designs such as randomized controlled trials (RCTs), quasi-experimental designs, feasibility studies, and mixed method studies.

### Screening

Studies identified through the database searches were exported to reference management software (Mendeley), and duplicates were deleted. Study selection was conducted by the first author (HG). Screening procedures were piloted before beginning the screening process. Abstracts and titles were initially screened, and articles not meeting the inclusion and exclusion criteria were removed. The first author (HG) then screened full texts and selected the articles for inclusion. Any lack of clarity over the eligibly of the studies was resolved through a discussion with a second author (WM). A random, 9.8% (26/264) sample

of studies identified for full-text screening were also independently screened by a second reviewer. Cohen kappa was used to measure interrater agreement. Finally, reference lists of all included papers were screened for additional studies and the inclusion and exclusion criteria applied. See Figure 1 for a detailed breakdown of the flow of the included studies.

**Figure 1.** Flow diagram of included studies. Search updates were conducted until January 2019, with 2 new papers being identified.




## Data Extraction

Data from the included studies were extracted into a prespecified form, which included author, year of publication, study design, mental health domain, conversational agent name and description (including embodiment, access, theoretical approach, and input and output style), number and characteristics of participants (including age, gender, presence, and type of diagnosis or psychological problem), intervention description (including length and structure of intervention), control group description (if applicable), mental health outcome measures, user experience measures, attrition, and primary findings (primary mental health outcome and user experiences). Owing to the diversity in study designs, outcomes measured, intervention modalities, and durations and the varied use of active and inactive control groups, a meta-analysis would not have led to meaningful conclusions and was thus not undertaken. Instead, extracted data were narratively synthesized in line with guidance on the conduct of narrative synthesis in systematic reviews [20].

## Risk-of-Bias Assessment

Risk-of-bias assessment of each study was conducted to ascertain the validity and reliability of the methods and findings to inform the narrative synthesis of the studies. The validated 16-item quality assessment tool for studies with diverse designs (QATSDD [21]) was deemed appropriate for this review to assess study quality as it includes quantitative (14 items), qualitative (14 items), and mixed-methods (16 items) items. Each of the 16 items is rated from 0 (not at all) to 3 (complete). Specifically, the tool assesses the clarity of the theoretical framework, study aims, study settings, the representativeness of the sample, rationale for data collection procedure, the appropriateness and reliability of data analysis, and the study's strengths and limitations. For each included study, the scores for each item were summed and a percentage of the total possible score was calculated. If a study did not provide enough details to rate an item, the item was scored 0. The quality of each included study was assessed by the first author (HG).

# Results

## Study Selection

The search identified 30,853 articles (see Figure 1) using the predefined search strategy outlined above. Duplicates were removed (8131), and articles not meeting the inclusion and exclusion criteria based on the title and abstract (22,388) were excluded. Handsearching through references resulted in an additional 5 studies being eligible for inclusion. The search was updated in January 2019, and 2 additional eligible studies were identified and included. Lack of clarity over the eligibility of articles (n=13) was resolved through a discussion with the second author (WM). Owing to the large number of articles identified from the initial search and limited researcher resource, interrater reliability was not assessed at the title and abstract stage. However, interrater reliability was assessed at full-text eligibility stage. A random sample of 26 studies (10% of the 264 studies identified for full-text screening) were independently screened by a second reviewer. The percentage agreement between first author (HG) and the independent rater was 96% (25/26 in agreement). Cohen kappa was 0.65, indicating substantial interrater agreement. Any differences in ratings were discussed, and an agreement was reached. A total of 13 articles were included in the review evaluating 11 different conversational agents.

## Risk of Bias

The methodological quality of the included studies varied (see Table 1). Using the QATSDD [21] assessment tool, methodological quality ranged from the lowest score of 35% [22] to the highest score of 88% [23]. The average quality score was 59%. All of the included studies with percentage scores above 70% were RCTs [23-26].

All included studies received the maximum score of 3 for the criterion *statement of aims or objectives in main body of report*. All included studies scored a 2 or 3 for *fit between research question and method of analysis* and *fit between stated research question and method of data collection*. Most studies provided adequate *descriptions of procedure for data collection* and *detailed recruitment data*. Most studies (n=10) provided discussions of the key strengths and limitations of the study (scoring 2), and 3 studies gave thorough, complete discussions of strengths and limitations, obtaining a maximum score of 3. The lowest average scores were found for *representative sample of target group of a reasonable size*, *good justification for analytic method selected*, *assessment of reliability of analytic process (qualitative only)*, and *evidence of user involvement in design*. See Table 1 for mean scores on each criterion across studies.

**Table 1.** List of criteria used to assess methodological quality and average score across studies.

| Item | Criteria | Mean[a] |
|---|---|---|
| 1 | Explicit theoretical framework | 1.5 |
| 2 | Statement of aims/objectives in main body of report | 3.0 |
| 3 | Clear description of research setting | 2.1 |
| 4 | Evidence of sample size considered in terms of analysis | 1.5 |
| 5 | Representative sample of target group of a reasonable size | 1.3 |
| 6 | Description of procedure for data collection | 2.2 |
| 7 | Rationale for choice of data collection tool(s) | 1.8 |
| 8 | Detailed recruitment data | 2.2 |
| 9 | Statistical assessment of reliability and validity of measurement tool(s) (quantitative only) | 1.5 |
| 10 | Fit between stated research question and method of data collection (quantitative only) | 2.5 |
| 11 | Fit between stated research question and format and content of data collection tool, for example, interview schedule (qualitative only) | 1.9 |
| 12 | Fit between research question and method of analysis (quantitative only) | 2.5 |
| 13 | Good justification for analytic method selected | 1.2 |
| 14 | Assessment of reliability of analytic process (qualitative only) | 0 |
| 15 | Evidence of user involvement in design | 0.4 |
| 16 | Strengths and limitations critically discussed | 2.2 |

[a]Scores can range from 0 (not at all) to 3 (complete).

## Study Characteristics

The characteristics of the included studies are summarized in Multimedia Appendix 1. The 13 studies identified were conducted between 2013 and 2018 in 4 countries. Among them, 5 studies were conducted in the United Kingdom [23,24,27-29], 6 studies in the United States [22,25,26,30-32], 1 study in Sweden [33], and 1 study in Japan [34]. Across the studies, there was considerable heterogeneity in study design, intervention design, and outcome measures used. The majority of the included studies focused on interventions for common mental health problems, including depression [28-31] and/or anxiety [25,26], specific phobia (heights) [23], loneliness [22],

and psychological distress [24,27]. Three studies focused on improving mental well-being [32-34]. A large proportion of studies (n=7) were preliminary and included feasibility [30], pilot RCTs [27,28,31-33], or nonrandomized trials [34]. In addition, 2 studies used quasi-experimental designs [22,29], and 4 studies were full-scale RCTs [23-26].

Most studies (n=8) used mixed methods [22,25,26,28-30,32,33], and the majority (n=9) of them reported on both mental health outcomes and user experiences [22,23,25,26,28-30,32,33].

Over half of the included studies (n=7) used specifically designed control groups, including screen or online psychoeducation [25,26,30,31], paper and CD-/MPEG-1 standard (MP3)-based psychoeducation [32] or an active control condition utilizing another conversational agent ELIZA [2,24,27]. Two studies used treatment as usual (TAU), which consisted of treatment for depression with a clinician [28] or corresponded to no treatment [23]. One study used a waitlist control group [33], and 1 study used a nonrandomized control group of participants who had expressed interest in taking part in the study but could not complete the intervention at that time [34]. Finally, 2 quasi-experimental studies did not use a control group [22,29]. However, Ring et al [22] compared groups that used 2 different versions (proactive and passive) of the conversational agent intervention.

## Participants

Only 1 study, a pilot RCT, recruited participants from clinician caseloads or registers [28]. The remaining studies recruited self-selected participants from the community through outpatient clinics [32], universities [24-27,30,31,33], online advertisements [22,33,34], and radio advertisements [23] and by downloading the intervention app through the app store [29].

The included studies reported results from a total of 1200 participants. Study sample sizes ranged from 14 [22] to 454 [34]. Study participants ranged between 16 and 75 years old, and gender prevalence was 70.3% (692/985) female from studies that reported this data (12/13). One study with 129 participants [29] did not collect data on age or gender, and 1 study recruited only women [32]. Participants varied widely in severity of psychological distress from minimal psychological symptoms [22] to formal clinical diagnoses such as major depressive disorder [28] and acrophobia [23]. In addition, 5 of the 13 included studies recruited participants who self-reported symptoms of psychological distress to varying degrees.

## Conversational Agent Interventions

Overall, 6 of the conversational agents were embodied (7 studies) [22,23,28,30-32,34]. Conversational agents used different technologies, with 3 conversational agents accessed on an app [25,29,33], 4 online (5 studies) [24,26,27,32,34], 3 using an offline computer program (4 studies) [22,28,30,31], and 1 VR program utilizing a VR headset [23].

The majority (8 out of 11 agents, evaluated in 9 studies) of the conversational agents included took natural language input either written [24-27,29,33,34] or spoken [23,28]. The remaining 3 agents took responses from participants using fixed onscreen response options (4 studies) [22,30-32]. The output mainly consisted of questions or written text (6 out of 11 agents, evaluated in 7 studies) [24-27,29,33,34]. Furthermore, 4 agents used spoken output [22,23,28,32]. In addition, 2 studies (1 conversational agent) [31] did not specify whether the conversational agent output was written or spoken.

The conversational agents provided interventions aimed at reducing symptoms [22-29], increasing well-being [32-34], or improving self-management [30,31]. Across the set of conversational agents, a range of therapeutic orientations were used, including cognitive behavioral therapy [23,25,28,34], method of levels (MOL) [24,27], mindfulness-based stress reduction [32], structured communication enhancement strategy [30,31], and eclectic interventions drawing on a wide variety of approaches [22,26,29,33]. Over half of the conversational agents (7 out of 11) focused on providing psychoeducation and self-management strategies [25,26,28,29,32-34], 1 agent (evaluated in 2 studies) utilized the principles of MOL therapy in a question-and-answer format [24,27], 1 agent offered social companionship [22], and 1 agent (evaluated in 2 studies) facilitated practice of effective communication with human health care professionals around psychological symptoms [30,31].

Conversational agent interventions varied widely in frequency and duration (see Table 2). From short interventions of 1 session (participant-determined length [24] up to 20 min [27]), 3 sessions (unspecified duration [31], 15-20 min each [30]), and 6 sessions (30 min each [23] through to daily usage over 2 weeks [25,26,33], 4 weeks [26,28], or a month [32]). One study only used data from participants who had engaged with the intervention at least every other day (>15 times) over a month [34]. Finally, 1 study installed 1 of 2 versions (*passive*, activated at will, and *proactive*, activated by a motion sensor) of the same conversational agent into participants' homes for 1 week. One study enabled participants to continue TAU for depression with a clinician alongside the conversational agent intervention [28]. The majority of studies (n=9) set no upper limits on usage during the defined study period [22,24-26,28,29,32-34].

**Table 2.** Intervention engagement.

| Study | Total intervention length | Frequency of use, mean (SD) or median (IQR) | Intervention duration (min), mean (SD) or median (IQR) |
|---|---|---|---|
| Freeman et al, 2018 [23] | 6 × 30-min sessions over 2 weeks | 4.66 (SD 1.27) | 124.4 (SD 34.2) |
| Bird et al, 2018 [24] | 1 session | Not applicable | 13 (SD NR[a]) |
| Fulmer et al, 2018 [26] | Unlimited access for 2 weeks or 4 weeks | 192 interactions (SD NR) | NR |
| Fitzpatrick et al, 2017 [25] | Daily intervention for 2 weeks | 12.1 (SD 2.23) | NR |
| Ly et al, 2017 [33] | Daily intervention for 2 weeks | 17.71 | NR |
| Gaffney et al, 2014 [27] | 1 session | Not applicable | 19.23 (SD 0.002) |
| Inkster et al, 2018 [29] | Unlimited access for 2 weeks | 83% (90/108) of high-usage users (at least one use) used the app for more than 4 days | NR |
| Gardiner et al, 2017 [32] | Unlimited access for 30 days | NR | 52 (IQR 101.4) |
| Pinto et al, 2016 [30] | 3 × 15-20-min sessions (baseline, 4 weeks, and 8 weeks) | 12 of 25 participants completed all sessions | NR |
| Burton et al, 2016 [28] | Daily intervention over 4 weeks | 10.5 (IQR NR) | 134 (IQR NR) |
| Suganuma et al, 2018 [34] | At least 15 times over 1 month | 45% (191/427) completed >15 days of intervention | NR |
| Pinto et al, 2013 [31] | 3 sessions (baseline, 4 weeks, and 8 weeks) | NR | NR |
| Ring et al, 2015 [22] | Unlimited access over 1 week | 15.9 (SD 8.1) interactions | 2.3 (SD 0.038) each |

[a]NR: not reported.

## Feasibility and Engagement

One study reported low uptake as they aimed to recruit 52 participants but closed the study at 28 participants [28]. Attrition rates between pre- and postmeasures were reported in 11 studies and varied widely from no attrition [23,24,33] to 74.1% (1978/2668) of participants [34]. Reasons reported for dropout included difficulties attending the university to take part because of financial difficulties [30], technical problems [22,27], and mental illness [22]. One study with a high attrition rate (74.1%, 1978/2668) [34] did not report any reasons; however, it should be noted that the majority of the dropouts were from the control condition (1846/2109, 88.3%) compared with 23.6% (132/559) in the intervention condition.

Studies reported differing metrics for engagement, and reporting was inconsistent (see Table 2). Engagement with the conversational agent interventions was highly variable from a short period of interaction in 1 session (eg, a mean of 13 min; [24]) to a median interaction total of 134 min [28] or exchanging a mean of 192 messages during intervention [26]. In the study by Suganuma et al [34], 236 out of 427 (55.2%) of intervention participants did not complete 15 or more days of the intervention and were excluded from the analysis. In addition, 3 people (6%) in the study by Freeman et al [23] found the intervention sessions too difficult and did not complete the intervention. However, 44 out of 49 (90%) participants completed the intervention, with a mean total intervention time of 124 min. One study [31] did not report any measures of engagement.

## Psychological Outcomes

Primary outcome measures were all validated but varied (see Multimedia Appendix 1 for details); therefore, the term psychological distress will be used to facilitate a summary. Of the 13 studies included, 5 controlled studies reported significant posttreatment improvements in psychological distress in the intervention group compared with a no treatment or information control group [23,25,26,31,34]. Significant improvements were observed on measures of depression [25,26,31], psychological distress [34], anxiety [26], fear of heights [23] and positive affect [26,34]. Effects ranged from small ($d$=−0.24 [34]) to very large ($d$=2.0 [23]). In addition, 2 pilot trials with active control groups found significantly higher ratings of problem resolution in the intervention group compared with the control group [24,27].

Furthermore, 4 controlled studies reported no significant posttreatment differences on measures of psychological distress between the intervention and control groups [24,27,32,33] with both intervention and control conditions demonstrating reduced distress [24,27,33] or increased uptake of stress management techniques [32]. Despite significant reductions in depression observed in the intervention group compared with the control group in the intention-to-treat analysis by Fitzpatrick et al [25], no significant posttreatment differences in anxiety were observed between groups.

Finally, the 2 uncontrolled studies included in the review [22,29] and 2 studies that did not test for between-group effects [28,30] reported reductions in depression [28-30] and loneliness [22] postintervention. Generally, greater engagement with the conversational agent resulted in greater reductions in psychological distress [22,26,28,29,33]. Only 3 studies included a follow-up period [23,24,27].

### User Experience Outcomes

Generally, from studies that reported user experience outcomes (n=11), participants reported being satisfied with the conversational agent interventions offered [22,23,25,26,29,30,32]. In addition, 3 studies reported that participants found the conversational agent interventions available and accessible [26,32,33]. Participants reported that they found the agent empathic [26], that they liked the interactivity [30], the agent's personality [22,25], the agent's ability to form a relationship [28,33], and the agent's ability to learn from input [26]. Participants reported that they liked the ability to customize the gender and appearance of ECAs [28] and the option to tailor the session length to their own needs [28]. Participants in the study by Fitzpatrick et al [25] reported that they liked the daily check-ins and information provided. Furthermore, 2 studies reported that participants indicated that they would recommend the conversational agent intervention to other people [18,24] (the proactive version).

The predominant challenges to intervention with a conversational agent included repetitive content [22,25,26,28,29,33], limitations in the agents ability to understand or respond appropriately [22,25,26,29], a shallow or superficial relationship [28,33], the sound and quality of the agents voice [32], and specific intervention tools or content [25,29]. Some participants in the study by Pinto et al [30] reported that they would like more frequent, longer intervention sessions, and greater freedom to tailor content and responses to their needs.

## Discussion

### Principal Findings

The use of conversational agents for treating mental health problems appears to be limited but is growing quickly, with 5 of the included studies published in 2018 alone [23,24,26,29,34]. Furthermore, despite the heterogeneity in evaluation methods, there is an increasing emphasis on fully powered RCTs testing efficacy. Included interventions were generally brief, allowed participants to control the intensity of intervention, and drew from a wide variety of psychological approaches. All included studies reported reduced psychological distress postintervention with a conversational agent. In addition, 5 controlled studies demonstrated significant reductions in psychological distress compared with an information or no treatment control group with small-to-large effects. This provides some support for the utility of conversational agents in treating mild-to-moderate psychological distress in adults [23,25,26,31,34]. However, their broader utility in promoting positive well-being in nonclinical populations appears uncertain [32,33]. Controlled studies with active control conditions (eg, another conversational agent or human psychological therapy) failed to demonstrate superior effects [24,27,28]. However, it is important to highlight that these studies assessed relative rather than absolute treatment efficacy, and thus, we cannot conclude an absolute lack of treatment efficacy [35].

Studies managed to recruit participants through several different methods. Remarkably, the only study that reported difficulties in recruiting participants relied on clinicians to refer patients to the study [28]. Studies that used more flexible recruitment routes such as online adverts [34] and app stores [29] recruited greater numbers of participants. It is possible that clinician apprehension about digital treatment for mental health problems affected recruitment rates. This is supported by research indicating that clinicians are perhaps more reluctant to recommend digital interventions without clinician input or support [36,37]. Our findings illustrate that conversational agents are generally an acceptable format of intervention for participants. Interestingly, participants valued aspects of agents usually seen as unique to therapy with a human, such as empathic responses, *personality*, the ability to build a relationship, and an interactive, conversational approach. This is consistent with research demonstrating that people relate to conversational agents as if they were human despite knowing that they are computer programs [38]. Participants also valued the ability of the agent to learn from their input, perhaps emulating the learning of a human therapist over time. Participants found intervention with conversational agents difficult or frustrating when the agent did not understand, became confused, or was repetitive. This perhaps mirrors expectations around core relationship factors such as feeling understood. Control was also important for participants especially regarding tailoring session length and content to their own needs and engaging with interventions in their own words (eg, free-text rather than fixed response options). The accessibility of the interventions was a key strength for many participants and where accessibility was limited, participants highlighted this and suggested ways to improve accessibility (eg, online access [30]).

### Limitations of Included Studies

The studies described have several limitations. The methodological quality of the included studies varied, and sample sizes were mainly small and self-selected, which reduces the ability to draw firm conclusions about the reliability and validity of the findings. Furthermore, because of short or absent follow-up, conclusions about the sustainability of treatment gains cannot be made. Psychological comorbidity was not assessed in any of the studies despite comorbidities being prevalent in individuals with common mental health problems [39]. Safety was only explicitly evaluated and reported in 1 study [30]. Safety is a vital consideration in mental health interventions that use free-text, natural language input either written [24-27,29,33,34] or spoken [23,28]. Studies have demonstrated that these types of conversational agents are often not able to respond appropriately to risk information such as suicidal ideation [40,41] and have the potential to result in harm. Furthermore, users can expect a level of understanding beyond what is currently technologically possible [41]. Engagement with interventions was not reported consistently and appeared highly variable, and the reasons for this remain unexplored. Furthermore, the impact of the design or features of the conversational agents (eg, embodiment and speech or text based) on engagement or outcomes was not explicitly assessed or compared; therefore, conclusions cannot be drawn as to the most effective or acceptable modality. No studies evaluated therapeutic equivalence or superiority to other treatment modalities such as face-to-face therapy. Finally, a large proportion of agents were eclectic interventions comprising a

variety of strategies and psychoeducation drawing on a range of therapeutic orientations [22,26,29,33]. Therefore, it is difficult to ascertain what the *active* ingredients of the interventions are.

### Strengths and Limitations

Owing to the lack of standardized terminology in this area, we conducted a comprehensive search that prioritized sensitivity over specificity. We also reviewed reference lists for additional papers not identified through the database searches. Published abstracts commonly presented in technology conferences were also included as they typically provide enough detail for decisions to be made about inclusion. The review was also registered on PROSPERO before commencing. We also included a broad range of formats for conversational agents, including VR and embodied and/or text and speech input. Cohen kappa showed substantial agreement in full-text screening, and there was a high percentage of agreement overall. This is despite inconsistencies in the reporting of interventions which made the process of eligibility assessment more complicated and reflected the heterogeneity and complexity in the field. Owing to the heterogeneity of the included studies, a meta-analysis was not undertaken. Furthermore, some potentially relevant conversational agents developed for the treatment of mental health problems were excluded from this review because of not reporting a mental health outcome measure (eg, ELIZA [2,42-44]).

### Future Directions

Continued growth in the use of conversational agents in mental health treatment is expected. Considering the findings, several priority areas for further research are apparent. First, addressing technical deficits such as repetition and confusion, which were reported in half of the included studies [22,25,26,28,29,33], may help to overcome barriers to engagement. Increased interdisciplinary working between computer science and mental health may facilitate this and help to drive innovations forward. Given that only 1 included study explicitly reported on safety [30], demonstrating safety will also be key to developing patient and public trust [40]. Furthermore, given the range of differing modalities of conversational agents and lack of direct comparisons between them found in this review, it will be important to compare modalities, for example, embodied or nonembodied or speech or text or offer increased choice to individuals. This would enable further insight into what works and for whom. Our review found that a large proportion of conversational agents use an eclectic mix of psychological interventions with often limited theoretical basis [22]. Only 1 included study reported on the process of psychological change [27] with conversational agent Manage Your Life Online (MYLO). Identifying and demonstrating the key mechanisms of action of conversational agent interventions has the potential to increase treatment efficiency, reduce unnecessary burden on users, and increase transparency. Given the diversity of mental health problems (eg, depression, anxiety, and phobias) appearing potentially amenable to treatment with conversational agent interventions, consideration of transdiagnostic approaches to intervention would further increase applicability and reach (eg, to people with comorbidities or difficulties that do not easily fit into prespecified diagnostic categories). Finally, in line with guidance on research priorities for digital interventions [45], it will be important to demonstrate efficacy and/or superiority compared with alternative conversational agent interventions and other treatment modalities such as face-to-face therapy to develop patient and clinician confidence in this type of intervention.

## Conclusions

This systematic review provides an assessment of conversational agent interventions used for the treatment of mental health problems. On the basis of the current evidence, the efficacy and acceptability of conversational agent interventions appears promising compared with no treatment or information control. However, studies failed to demonstrate superiority when compared with other active, conversational interventions, and their broader utility in promoting well-being in nonclinical populations is unclear.

Therefore, whether conversational agent interventions are an adequate substitute to other therapy modalities remains unclear. Future studies should strive to demonstrate efficacy, equivalence (or superiority), and cost-effectiveness through RCTs with comparisons with other forms of treatment. Studies that can demonstrate exactly how interventions achieve psychological change and for whom will be important in streamlining bloated interventions to increase acceptability. Finally, transdiagnostic approaches to treatment may provide further opportunity to maximize the reach and simplicity of conversational agent interventions.

## Conflicts of Interest

None declared.

Multimedia Appendix 1
Characteristics of included studies.
[PDF File (Adobe PDF File), 319 KB - mental_v6i10e14166_app1.pdf ]

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## Abbreviations

**ECA:** embodied conversational agent
**MOL:** method of levels
**QATSDD:** quality assessment tool for studies with diverse designs
**RCT:** randomized controlled trial
**TAU:** treatment as usual
**VR:** virtual reality

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Review

# Curation of Mental Health Recovery Narrative Collections: Systematic Review and Qualitative Synthesis

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## Abstract

**Background:** Mental health recovery narratives are first-person lived experience accounts of recovery from mental health problems, which refer to events or actions over a period. They are readily available either individually or in collections of recovery narratives published in books, health service booklets, or on the Web. Collections of recovery narratives have been used in a range of mental health interventions, and organizations or individuals who curate collections can therefore influence how mental health problems are seen and understood. No systematic review has been conducted of research into curatorial decision making.

**Objective:** This study aimed to produce a conceptual framework identifying and categorizing decisions made in the curation of mental health recovery narrative collections.

**Methods:** A conceptual framework was produced through a systematic review and qualitative evidence synthesis. Research articles were identified through searching bibliographic databases (n=13), indexes of specific journals (n=3), and gray literature repositories (n=4). Informal documents presenting knowledge about curation were identified from editorial chapters of electronically available books (n=50), public documents provided by Web-based collections (n=50), and prefaces of health service booklets identified through expert consultation (n=3). Narrative summaries of included research articles were produced. A qualitative evidence synthesis was conducted on all included documents through an inductive thematic analysis. Subgroup analyses were conducted to identify differences in curatorial concerns between Web-based and printed collections.

**Results:** A total of 5410 documents were screened, and 23 documents were included. These comprised 1 research publication and 22 informal documents. Moreover, 9 higher level themes were identified, which considered: the intended purpose and audience of the collection; how to support safety of narrators, recipients, and third parties; the processes of collecting, selecting, organizing, and presenting recovery narratives; ethical and legal issues around collections; and the societal positioning of the collection. Web-based collections placed more emphasis on providing benefits for narrators and providing safety for recipients. Printed collections placed more emphasis on the ordering of narrative within printed material and the political context.

**Conclusions:** Only 1 research article was identified despite extensive searches, and hence this review has revealed a lack of peer-reviewed empirical research regarding the curation of recovery narrative collections. The conceptual framework can be used as a preliminary version of reporting guidelines for use when reporting on health care interventions that make use of narrative collections. It provides a theory base to inform the development of new narrative collections for use in complex mental health interventions. Collections can serve as a mechanism for supporting collective rather than individual discourses around mental health.

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**KEYWORDS**

mental health recovery; narrative medicine; culturally appropriate technology

## Introduction

### Background

Recovery has become a guiding ethos for mental health research, policy, and service development [1]. Recovery is defined by the individual [2] and has been described as "a way of living a satisfying, hopeful and contributing life whether or not the limitations of illness continue" [3]. A focus on recovery extends the traditional clinical priority of symptom amelioration to a more holistic perspective on mental health [4,5]. The development of an associated recovery movement has centered on the experience of the individual [6] and emphasizes the importance of including knowledge from experts by experience in understanding mental health problems [7]. This orientation places an increased emphasis on first-person knowledge and encourages provision of care to be tailored to the individual [8].

An emphasis on mental health recovery can lead to an increased use of recovery narratives. For the purposes of this paper, a recovery narrative is defined as a first-person lived experience account of recovery from mental health problems, which refers to events or actions over a period [9] and which can be given live or in a recorded form [10]. Live recovery narratives are shared in the context of an in-person or Web-based relationship and involve some form of mutual exchange, whereas recorded recovery narratives are presented in an invariant form, frequently as text, audio, or video but occasionally in formats such as visual artworks [11]. Access to both categories of narrative is increasing [10], and a recent systematic review has identified both helpful and harmful impacts that they can have on recipients [10].

Recovery narratives are regularly used as a resource in health care practice [12]. At the level of public health, recovery narratives have been used as an effective resource in antistigma campaigns [13,14], where they can act as a form of social contact between people with experience of mental health problems and others [15]. Written recovery narratives are a useful resource in psychotherapy sessions [16,17], and a US national survey has shown that the sharing of live recovery narratives is a key feature of the work of peer specialists [18]. The sharing of live recovery narratives is also a feature of recovery education approaches such as recovery colleges [19], where they might be developed through *Telling My Story* courses, which can provide benefits to both the narrators and recipients [20]. More broadly, the relevance of narratives to mental health is well established; there is a consensus that their creation and consumption can be helpful both to the individual sharing their story and to the intended recipients [21]. Indeed, traditional talking therapies have been likened to a process of joint narrative creation [22], and case histories have long been used to educate health care professionals [23].

When recovery narratives are presented in a recorded form, they can be grouped into collections, and the emergence of a wide range of publicly available collections of recovery narratives is a notable phenomenon of at least the last 20 years. Early examples of collections were published in books, often grouping together narratives sharing a common diagnosis or symptomatology [24,25], sometimes explicitly motivated by intentions such as presenting a positive outlook for people experiencing mental health problems or for carers [25]. Collections of written recovery narratives have also been presented in health service booklets, which are intended to make real stories of recovery available to other service users [26], and in regular series of personal accounts in academic journals such as *Psychosis* [27] and *Psychiatric Services* [28]. Collections of recorded recovery narratives are also widely available on the Web, sometimes presented in bespoke websites, where they might be explicitly motivated by their value as a stigma reduction tool [29] or as a reference resource for people experiencing mental health problems [30]. Other forms of Web-based collection include series of video or audio blogs hosted by charities [31,32], providing a moderated route for people to share their recovery experiences.

Creating and disseminating collections of recovery narratives require individual or collective effort in addition to the effort of producing the individual narratives included in a collection. Examples might include locating potential contributors or selecting and organizing submissions. In this paper, the work done to enable a collection is referred to as *curation*, and the people who do it are referred to as *curators*. Our usage of this term draws on existing usage within the discipline of museum studies, where the work of curators has been studied and taught for several centuries [33] and is understood as both a purposeful and political act, with curators often engaging with artifacts or collections that are sensitive and challenging [34]. The study and teaching of curation focus on reflective practice as a mechanism for understanding how to negotiate sensitivities and to bring meaning to the artifacts being curated [35]. Recently, digital curation has adopted as a term to cover the long-term management of digital data [36] and has also emerged as a research topic in its own right [37].

There are a range of specific sensitivities around recovery narratives, and we might expect the work of curating recovery narrative collections to be sufficiently different from that of curating a museum exhibit that it is worthy of study. Recovery narratives can contain sensitive and personal information such as experiences of distress and criticisms of interactions with health services. They can identify the narrator as well as third parties, which is important given the ongoing existence of stigma in relation to mental illness [38]. Similar to other forms of health material, engaging with the content presented in a recovery narrative may cause emotional distress on the part of recipients [39] and have adverse effects on people accessing the narratives [40], particularly given the known risks around receiving Web-based material and self-harm [41]. Curators shape and influence the material that is presented and, hence, what is

available for usage by others, and this is particularly relevant given the contested nature of recovery as a concept [42] and the status of recovery narratives as tools of resistance, opposition, collective action, and social change [43].

In building collections, curators are likely to have developed specific knowledge and practices to address these issues, and given an increasing use of recovery narratives in health care practice, developing a systematic understanding of decisions made by curators might provide benefits to their future health services usage. It might also provide a greater understanding of the characteristics of recovery narrative collections used in health service practice, such as biases in the composition of these collections affecting the types of narrative included.

### Aims of the Study

No previous systematic review on the curation of mental health recovery narratives has been conducted. The aim of this study was to produce a conceptual framework identifying and categorizing decisions made in the curation of mental health recovery narrative collections.

## Methods

### Design

A systematic review was conducted to identify and synthesize documentary information on curatorial decision making for collections of mental health recovery narratives. The systematic review followed guidance provided in the PReferred Reporing Items for Systematic reviews and Meta-Analyses (PRISMA) statement [44]. A protocol for the search and synthesis process was published in advance through PROSPERO [45]. Pilot searches of bibliographic databases identified minimal peer-reviewed empirical research evidence on this topic and hinted at a gap in research knowledge, and hence, the review was designed to enable the creation of a preliminary conceptual framework to inform the design of future research work. To produce an informative framework, searches were designed to systematically locate all available peer-reviewed research articles and to locate a selection of nonresearch documents produced by curators, providing direct evidence on curatorial decision making.

A qualitative evidence synthesis was conducted of all sources while retaining a clear audit trail of concepts derived from included peer-reviewed research articles. Documents were included in the synthesis if (1) they related to a collection containing at least three recovery narratives about mental health (any diagnosis or mix of diagnoses, excluding solely substance abuse), (2) the document contained researcher- or curator-derived information about decision making around the curation of the collection, (3) the document was published in English, (4) the publication date was before July 31, 2018, and (5) the collection was publicly available (on the Web or in print).

### Data Sources

#### *Publications in Bibliographic Databases*

Research on recovery narratives is interdisciplinary [12], and hence, a broad range of bibliographic databases were searched to identify peer-reviewed publications. The selection of these databases was informed by database selections in 2 parallel systematic reviews on the characteristics [12] and impact of recovery narratives, augmented by scoping searches and expert consultation. A total of 13 bibliographic databases were searched from inception to July 31, 2018: Applied and Complimentary Medicine Database, Applied Social Science Index and Abstracts, Cochrane Library, CINAHL, EMBASE, JSTOR, MEDLINE, PsycARTICLES, PsycINFO, Scopus, Social Science Research Network, Web of Science, and ACM digital library. The search was designed as shown in Textbox 1 and was specialized to each of the relevant databases as needed. Scoping searches were used to select a range of synonyms for use within each clause.

**Textbox 1.** Bibliographic database search.

(Curat* OR Manag* OR creat* OR oversee* OR assembl* OR collect* OR present*)

AND

(psych* health OR psych* illness OR psych* problem* OR psych* disorder OR mental distress OR emotional distress OR recover* OR trauma OR Mental* OR psych* OR mad OR madness OR emotional distress OR trauma)

AND

(narrative* OR stories OR account* OR experience* OR tale* OR lived experience OR personal experience OR testimon*)

AND

(repositor* OR collection* OR compendi* OR antholog* OR forum OR blog OR vlog)

Searches were conducted by RM and AR, and the resulting papers were collated by RM, who removed duplicates. RM and AR screened the titles and abstracts of the remaining papers according to the inclusion criteria to identify those that were potentially eligible. RM and AR independently rated 1 in 5 of the other's screening for consistency, achieving complete concordance. The full-text versions of the remaining papers were screened for eligibility by RM. AR independently rated 1 in 5 for consistency, achieving complete concordance.

#### *Specific Journals*

Overall, 3 journals (*Schizophrenia Bulletin*, *Psychosis*, and *Psychiatric Services*) were identified as regular publishers of recovery narratives. Journal indexes were hand searched from inception for peer-reviewed publications, and journal websites were hand searched for nonresearch documents.

#### *Gray Literature Databases*

Variants of the search terms outlined above were used to search the gray literature for peer-reviewed publications and

nonresearch documents using dissertation database searches, Google Scholar, BASE, and OpenGrey.

### *Forward and Backward Citation Tracking*

Forward citation tracking of included peer-reviewed publications was conducted using Google Scholar. The reference lists of included peer-reviewed publications were hand searched.

### *Digitally Accessible Books*

Scoping searches had shown that printed books presenting collections of recovery narratives sometimes began with an editorial chapter providing information about how the book had been curated. A sample of books was identified using Google Books, a large Web-based repository of digitized texts estimated to index more than 30 million books [46]. Google Books offers a relatively restricted searching interface. Guided by scoping searches, the synonymous search term "mental health recovery stories" was used to search Google Books. The 50 books that came up in the first 5 search pages of search results were accessed and hand searched for the presence of an editorial chapter. If present, this chapter was treated as a candidate documentary source and was assessed against the inclusion criteria.

### *Web-Based Collections*

Web-based collections identified using the search term "mental health recovery stories" in the Google search engine were hand searched for nonresearch documents. Collections identified in the first 5 search pages were hand searched.

### *Health Service Booklets*

Scoping searches demonstrated that health service booklets can contain editorial sections presenting information on curation, but they also identified that these booklets are frequently not available on the Web or in publication databases. Health service experts (n=7) were consulted for recommendations of specific health service booklets that included information about the process of curating the booklets. Editorial sections of recommendations were treated as a candidate documentary source and were assessed against the inclusion criteria.

## Quality Assessment

A quality assessment of all included peer-reviewed qualitative research publications was conducted using the Critical Appraisal Skills Programme (CASP) qualitative checklist [47], using an established scoring system and thresholds for high-, moderate-, and low-rated quality (high: 9-10, moderate: 7.5-8.5, and low: 0-7) [48]. The rated quality did not determine inclusion. No quantitative research publications were included.

## Data Extraction and Synthesis

Short narrative summaries were produced of included qualitative research publications and are included in the Results section. These summarize the methods, rated quality, and curatorial issues identified in the publication.

Owing to a lack of previous frameworks on the curation of mental health recovery narratives, a qualitative synthesis [49] of all included documents was conducted using inductive thematic analysis. In stage 1, text present in 1 research article [50] and 2 contrasting documents relating to Web-based collections [51,52] was analyzed by RM and SRE to identify preliminary curatorial themes that are presented in Multimedia Appendix 1. In stage 2, a thematic analysis of all the included documents was conducted. The included documents and preliminary themes were transferred into NVivo version 11 (QSR International) for data handling and analysis by RM and SRE. The relevant material in documents was coded, and initial themes were extended and restructured into hierarchies through constant comparison [53]. In stage 3, this framework was refined into a conceptual framework by a broader analysis team that included experts in recovery research, digital curation, and health sociology and an experienced curator of a recovery narrative collection. The names of themes included in the framework were refined, and some included subthemes mere merged. Contributions from text fragments coded in the included research publications were tracked so that the contribution to the conceptual framework of research publication could be highlighted in the Results section.

Once the final conceptual framework had been established, planned subgroup analyses were conducted on (1) documents relating to Web-based collections and (2) documents relating to printed collections. These were used to compare and contrast the relative strengths of conceptual framework themes in these 2 subgroups.

# Results

## Flow Diagram

The PRISMA flow diagram for the systematic review is shown in Figure 1.

## Summary of Included Documents

The 23 documents included in the qualitative evidence synthesis are summarized in Table 1. Each has been assigned unique identifiers (UIDs). These UIDs are listed in Table 1, and are referred to in the samples of coded text presented in Multimedia Appendices 1 and 2. Table 1 also includes references to all included documents, to enable replication, and to provide researchers with a corpus of publicly available documents with insights into curation.

One peer-reviewed article was included [50]. The other 22 documents comprised documents providing descriptions of how curation had been structured for specific Web-based collections (n=4), Web-based documents written to provide guidance for narrators wishing to submit material to specific collections (n=11), editorial book chapters (n=4), and forewords to health service booklets of mental health recovery narratives (n=3). For 2 of the Web-based collections, hand searching of websites identified 2 includable documents each, and hence, both were included in the synthesis. None of the included booklets were indexed in publication databases or search engines.

**Figure 1.** Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for documents included in qualitative synthesis.

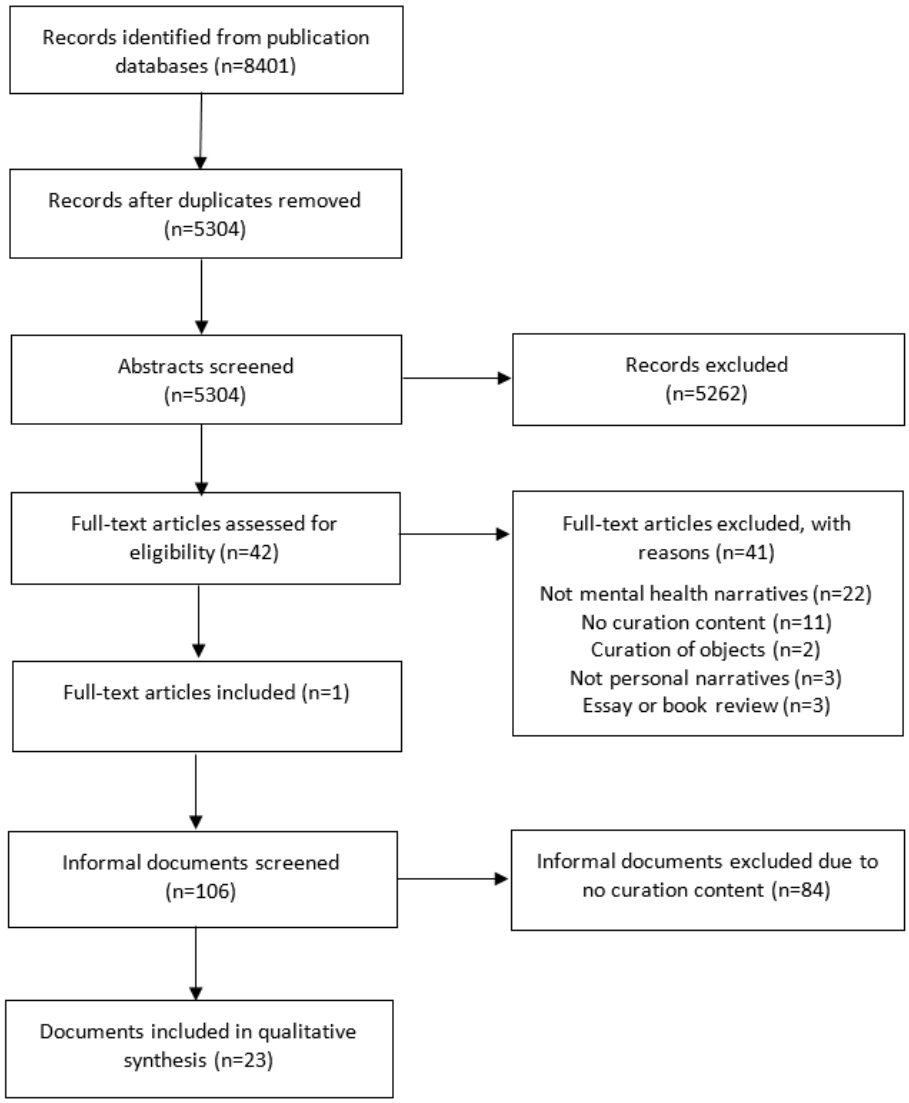

**Table 1.** Summary of documents subject to inductive thematic analysis.

| UID[a] | Reference | Categorization | Collection(s) referred to | Country of collection | Narrative format |
|---|---|---|---|---|---|
| 1 | Crossley and Crossley [50] | Journal article | Two books: The Plea for the Silent [54] and Speaking our Minds [55] | England | Text |
| 2 | Health Talk [51] | Description of curation | HealthTalk: Web-based collection of health narratives | England | Audio, text, and video |
| 3 | Bradstreet [56] | Description of curation | Multiple collections of mental health recovery narratives curated by the Scottish Recovery Network | Scotland | Audio, text, and video |
| 4 | Write to Recovery [57] | Description of curation | The "Write to Recovery" Web-based recovery narrative collection | Scotland | Text |
| 5 | Time to Change [52] | Guidelines for narrators: Web-based collection | Time to Change collection of mental health blogs | England | Text |
| 6 | Mind, the Mental Health Charity [58] | Guidelines for narrators: Web-based collection | Mind collection of blogs and vlogs | England | Text and video |
| 7 | NAMI California [59] | Guidelines for narrators: Web-based collection | National Alliance on Mental Illness collection of "Share your story" blogs | United States | Text |
| 8 | NAMI - You are Not Alone [60] | Guidelines for narrators: Web-based collection | National Alliance on Mental Illness collection of "Share your story" blogs | United States | Text |
| 9 | Empower Idaho [61] | Guidelines for narrators: Web-based collection | Empower Idaho collection of recovery stories | United States | Video |
| 10 | Crowe [62] | Description of curation | Australian Government National Mental Health Commission collection of "Personal stories" | Australia | Text |
| 11 | Resources to Recover [63] | Guidelines for narrators: Web-based collection | Resources to Recovery collection of "Stories of hope and recovery" | United States | Text |
| 12 | Boll [64] | Guidelines for narrators: Web-based collection | Resources to Recovery collection of "Stories of hope and recovery" | United States | Text |
| 13 | Substance Abuse and Mental Health Services Administration [65] | Guidelines for narrators: Web-based collection | Various collections curated by the Substance Abuse and Mental Health Services Association | United States | Text |
| 14 | Mental Health Stories [66] | Guidelines for narrators: Web-based collection | Mental Health Stories collection of recovery stories | England | Text |
| 15 | LeCroy and Holschuh [67] | Editorial chapter of a book | Book with title "First-person accounts of mental illness and recovery" | United States | Text |
| 16 | Gilbert [68] | Editorial chapter of a book | Book with title "Beating Depression: Inspirational Stories of Hope and Recovery" | England | Text |
| 17 | Basset and Stickley [69] | Editorial chapter | Book with title "Voices of Experience: Narratives of Mental Health Survivors" | England | Text |
| 18 | Gray [70] | Editorial chapter | Book with title "The Madness of Our Lives: Experiences of Mental Breakdown and Recovery " | United States | Text |
| 19 | International Mental Health Collaborating Network [71] | Foreword to booklet | Booklet with title "Recovery Stories: Cornish Journeys of Hope" | England | Text |
| 20 | CMHT Institute of Mental Health [72] | Foreword to booklet | Booklet with title "Journey to Recovery" | Singapore | Text |
| 21 | South London and Maudsley NHS Foundation Trust [26] | Foreword to booklet | Booklet with title "Moving Forward: Stories of Recovery" | England | Text |

| UID[a] | Reference | Categorization | Collection(s) referred to | Country of collection | Narrative format |
|---|---|---|---|---|---|
| 22 | Oxford University Press: Schizophrenia Bulletin [73] | Guidelines for narrators: academic journal | Schizophrenia Bulletin: Collection of "first person accounts" | United States | Text |
| 23 | Psychiatry Online [74] | Guidelines for narrators: academic journal | Psychiatric Services: Collection of "personal accounts" | United States | Text |

[a]UID: unique identifier.

## Narrative Summaries of Findings in Included Peer-Reviewed Articles

The single included peer-reviewed paper [50] presented a comparative analysis of 2 books presenting collections of narrative identifiable as recovery narratives within the definition adopted for this review. This paper was rated to be of moderate quality using CASP.

The 2 books considered in this paper were *The Plea for the Silent* [54] and *Speaking our Minds* [55], published in 1957 and 1996, respectively. Through this analysis, key curatorial considerations were identified as (1) intended societal influence of the collection, (2) approach to narrator safety, and (3) approach to establishing authenticity of included narratives. The paper explains that *The Plea for the Silent* was published in a society with high levels of legal and social discrimination against people with experience of mental health problems, with an explicit purpose of enacting change but also a need to protect contributors. To support influence on society, curators chose to justify the authenticity of narratives with reference to formal health records and the perceived societal status of the narrators (eg, by stating that narrators were civil servants or teachers). They chose to anonymize the narrators to protect them from stigma or legal difficulties. *Speaking our Minds* was published into a society with higher levels of activism around the rights of people experiencing mental health problems. The included narrators were all activists. The curators chose to name narrators so as not to deny them a personal voice and to justify authenticity in relation to activism activities.

## Conceptual Framework on the Curation of Mental Health Recovery Narratives

The conceptual framework derived through inductive thematic analysis is presented in Table 2. It identifies 9 higher level curatorial issues present in included documents, each of which is accompanied by subthemes identifying more specific curatorial issues. Each subtheme is illustrated with short textual descriptions of specific choices adopted by curators. Choices were included if they were identified in 1 or more source documents. Choices identified through the included peer-reviewed article [50] are highlighted in italics, and all other choices have been identified from informal documents. For the latter, illustrative text coded against that choice is provided in Multimedia Appendix 2.

In some cases, the range of choices structured within a theme highlights contentious issues where a curator has to pick from a range of competing possibilities. One example is anonymization as a route to narrator safety, where 3 alternatives are present (anonymize narrators to protect identity, clearly identify narrators to give them a voice, and provide guidance on choices around revealing narrator identity).

## Strength of Theme Analysis: Curation in Web-Based and Printed Collections

The conceptual framework integrates curatorial issues and choices across Web-based and printed collections, where printed collections were composed of published books and health service booklets. Subgroup analyses were used to identify issues or choices which were more relevant to either (1) Web-based or (2) printed collections.

Providing benefits for narrators as well as recipients was more of a concern for Web-based collections. This was because of the open-ended and interactive nature of Web-based collections relative to published books, meaning that they often encouraged recipients to submit their own stories and, hence, become narrators themselves. Audience interaction was also more relevant to Web-based collections.

Societal positioning as a superordinate category was commonly found in printed books where it appeared in explicit editorial reflections on the context in which the book was published, provided to offer explanation and justification for the stance taken in curating the material presented in the book.

A theme that emerged as important across all collections was safety of the narrator, recipient, and third parties mentioned in narratives. Recipient safety was discussed more frequently in relation to Web-based collections, presumably because of the instantly accessible nature of Web-based material, making it more likely to be accessed by people experiencing severe distress.

Online calls for submission were much more common for Web-based collections and typically led to direct submission of narratives rather than the construction of narratives through interviewing. The process of selecting narratives was not discussed in any depth in any included documents.

How to edit material emerged as an important issue for curators of all collections (eg, it was discussed in many documents). It was split into editing to support narrator and third-party safety and editing for clarity of presentation. No mention was made of the legal implications of editing and, hence, becoming potentially responsible for content.

Ordering of narratives was more relevant to printed material, presumably because of its inherently linear presentation. Allowing a diversity of formats was more relevant to collections presented on the Web, reflecting the greater freedom of online presentation.

**Table 2.** Conceptual framework of curatorial issues and choices.

| Curatorial issues and specific choices[a] | UID[b] |
|---|---|
| **Purpose** | |
| **Narrator benefits** | |
| To support narrators' recovery | 13 |
| To empower narrators | 13,17 |
| **Recipient benefits** | |
| To help recipients understand mental health problems | 15 |
| To help recipients talk about mental health problems | 15 |
| To help recipients understand when to seek help | 12 |
| **Societal influence** | |
| To reduce stigma about mental health | 12 |
| *To provide access to unheard voices* | 1 |
| **Audience** | |
| **Identification** | |
| Target people with an interest in mental health | 20 |
| **Interaction** | |
| Allow commenting on narratives | 6 |
| **Safety** | |
| **Narrator safety** | |
| *Anonymize narrators to protect identity* | 1 |
| *Clearly identify narrators to given them a voice* | 1 |
| Provide guidance on choices around revealing narrator identity | 8,3 |
| Develop a supportive relationship with a narrator | 2 |
| Provide guidance on the emotional impact of creating narratives | 13 |
| Provide guidance on how sharing might impact relationships | 3 |
| Signpost narrators to resources that can help if distressed | 8 |
| Continue to support a narrator after a narrative is public | 3 |
| **Recipient safety** | |
| Provide guidance to narrators on how to create narratives that exclude features known to trigger harmful behaviors | 6 |
| Moderate comments in narratives shared on the Web | 6 |
| **Third-party safety** | |
| Provide guidance on protection of others identifiable in narratives | 3 |
| **Collection of narratives** | |
| **Recruiting narrators** | |
| Targeted requests (through health services, support groups, targeted advertising) | 2,22 |
| Online calls for submission (on organizational websites) | 7,8 |
| **Creation of narratives** | |
| Interviews with narrators | 2 |
| Direct submission by narrators | 7,8,12 |
| **Selection of narratives** | |
| **Narrative selection** | |
| Review submitted material | 8 |
| **Narrative diversity** | |

| Curatorial issues and specific choices[a] | UID[b] |
|---|---|
| Seek a diverse range of narratives | 3 |
| **Editing of narratives** | |
| **Editing for clarity** | |
| Shorten, enhance flow, and remove repetition | 18 |
| **Editing for safety** | |
| Destroy identifying information | 21 |
| **Presentation of narratives** | |
| **Ordering** | |
| Order narratives by clinical diagnosis | 3 |
| Order narratives to highlight mutual connections | 18 |
| **Format** | |
| Allow a diversity of formats | 3 |
| Present narratives that conform to a specific format | 11 |
| **Authenticity** | |
| *Established through references to formal health records* | 1 |
| *Established through reference to societal status of narrator* | 1 |
| *Established through reference to narrator activism* | 1 |
| **Ethics and legality** | |
| **Consent** | |
| Establish clear consent for use (written or verbal) | 3 |
| **Ownership** | |
| Establish through formal written agreements | 7 |
| **Societal positioning** | |
| Position relative to public policy | 17 |
| Position relative to clinical language | 3 |

[a]Italicized text indicates a choice identified from a peer-reviewed article.

[b]UID: unique identifier.

# Discussion

## Principal Findings

This review revealed a lack of empirical research into the curation of collections of mental health recovery narratives, with only 1 peer-reviewed paper located from the extensive database search. This is a significant result, given the ongoing public health usage of such collections (eg, in antistigma campaigns) and the influence that curators will have on the content and presentation of collections and, hence, potentially, on how mental health issues are perceived by recipients of narratives presented in collections.

The review demonstrates that documentary information about the curation of mental health recovery narrative collections does exist, mostly presented alongside the collections themselves, with relevant information sometimes distributed across multiple documents. This observation enables further work drawing on such documents as an evidence source, for example, to provide further insights into considerations unique to a specific type of collection such as a health service leaflet.

A conceptual framework of 9 major curatorial issues was identified from publicly available documents: purpose, audience, safety, collection of narratives, selection of narratives, editing of narratives, presentation of narratives, ethics and legality, and societal positioning. This provides an evidence-based foundation for future research to establish good practice guidelines for the curation of collections as they increase in number and reach. It could serve as an interim guide to issues that curators of new or existing collections should consider when deciding how to structure their work. It could be used as a preliminary version of reporting guidelines for health care interventions that make use of narrative collections.

Curation in museums studies has been introduced as both a *purposeful* and a *political* act [34], and this was reflected in specific knowledge about the curation of mental health recovery narratives developed through this review. Some collections had clearly been created for a specific purpose. Identified purposes

were recognizably specific to mental health, focusing on either supporting or enhancing the mental health of individuals (narrators and recipients) or creating a healthier society. Political issues considered by curators included the relationship of the collection to public policy positions at the time of curation and clinical language as a contentious issue, especially in relation to its use to present and order narratives.

The review highlighted safety (of narrators, recipients, and third parties) as an important curatorial issue. It revealed a lack of consensus around anonymization as a route to safety, which was reflected in a tension between an approach of obscuring identity and hence protecting a narrator or third party from damaging responses such as stigma and empowering narrators by allowing them to be identifiable and hence giving them a recognizable voice. A middle way, of supporting choice by providing narrators with guidance on how to make choices about their identity, was present. A lack of consensus around issues of safety may indicate that there is no *best* curatorial approach to this issue. Rather, curators may benefit from awareness of a range of strategies to select from.

The processes of selection and presentation of narratives were identified as places in which the emergent properties of groups of narratives were actively considered by curators. In some cases, curators of collections were explicitly interested in assembling a diverse set of experiences, while still respecting the individual rights of contributors [75]. This suggests the value of using collections of narratives, rather than individual narratives, in health care practice.

### Limitations

The review only included publicly available documents. Their accuracy in reflecting decisions made around curation cannot be verified, and they may not provide complete information about all curatorial decisions made as curators may not discuss some decisions publicly. In-depth interviews with curators of collections might augment the conceptual framework developed for this review.

Although the breadth of database searches means that all available research evidence has been included, for feasibility, the review placed limitations on the number of search engine pages used to identify informal documents. Therefore, the presented framework does not draw on all available nonresearch documents. The conceptual framework might be extended by a review that considered evidence presented in all printed works or in all Web-based collections. Such a review may need to consider thousands of collections.

### Comparison With Previous Work

If some curators are explicitly interested in the use of collections of recovery narratives to present a more holistic view of mental health problems, then the work of a curator might be seen as intersecting with the emerging discipline of Mad Studies [76], which has an interest in how to general collective discourses about experiences of mental ill health and its relationship to unhealthy aspects of society is. Curating collections might be seen as loosely analogous to the Mad Studies concept of "centralizing of experiential knowledge," described by Sweeney [77]. Curators of mental health recovery narratives might then be seen as activists, and this view is certainly present in museums studies where curatorship has been positioned as a form of social practice [78] and where approaches to the curation of culturally sensitive material, such as indigenous remains [79], homophobia [80], or damaging working conditions in sweatshops [81], have been selected to draw attention to societal problems. Contributing a narrative to a collection may also be seen as a form of activism, and digital research into affinity spaces highlights the social capital that an individual may develop through contributing a narrative [82]. The latter provides further insights into the dangers of anonymizing narrators (in that enforced anonymization precludes the use of a narrative by its narrator to develop social capital).

The safety of narrators, recipients, and third parties emerged as an important topic for curators. As such, choices identified in the review might be seen as part of a wider body of research around the safe usage of online health material, which might in turn inform curatorial practices. A realist review [40] has documented the exposure to contradictory or misleading health material as a route to harm, and this might be seen as a rationale for curatorial work to establish the authenticity of contributors A literature review has documented mechanisms by which online health material can trigger self-harm or suicide, and how to handle this kind of material might be thought of as a key consideration in recipient safety [41]. Our review has located choices around audience participation as a part of the curatorial process and the use of moderation of potential comments by curators as a possible tactic. The use of moderation has been considered in a previous review about online peer support, where the majority of interventions that were reviewed included some form of moderation by health care professionals, researchers, or service users [83]. In some cases, interaction without moderation can have harmful consequences for both people who are sharing and those who are receiving the material [84]. However, mental health issues such as stigma are regularly discussed in nonmoderated Web-based interfaces such as Twitter [85].

From an ethical perspective, recovery narrative collections have the potential to both benefit and harm others, so the biomedical ethical principles of beneficence and nonmaleficence are relevant [86]. Future research to investigate the types and mechanisms of impact is needed, and evaluations of the use of recovery narratives should specifically consider potential harms [87].

## Conclusions

This review has presented a conceptual framework identifying issues that curators of mental health recovery narrative collections attend to, drawing on available research publications and other public documents. This framework might be used to inform good practice guidelines for narrative curation and as a preliminary version of reporting guidelines for use when reporting on health care interventions that make use of narrative collections. Our study has highlighted the role of curators in shaping the material that they present and, hence, in shaping an understanding of mental health issues in recipients. Further work might extend this conceptual framework through interviews with curators so as to access details about decision

making that are not available in public documents. It might also examine the impact of curatorial decisions on recipients of narrative collections.

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## Conflicts of Interest

None declared.

Multimedia Appendix 1
Curatorial issues emerging from initial joint analysis of a sub-sample of 3 (13%) of 23 included documents.
[PDF File (Adobe PDF File), 51 KB - mental_v6i10e14233_app1.pdf ]

Multimedia Appendix 2
Samples of text coded against items in the conceptual framework in included informal documents.
[PDF File (Adobe PDF File), 89 KB - mental_v6i10e14233_app2.pdf ]

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## Abbreviations

**CASP:** Critical Appraisal Skills Programme
**NIHR:** National Institute for Health Research
**PRISMA:** PReferred Reporing Items for Systematic reviews and Meta-Analyses
**UID:** unique identifier


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Original Paper

# Analysis of the Recomposition of Norms and Representations in the Field of Psychiatry and Mental Health in the Age of Electronic Mental Health: Qualitative Study

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## Abstract

**Background:** For the World Health Organization, electronic health (eHealth) is seen as an effective way to improve therapeutic practices and disease prevention in health. Digital tools lead to major changes in the field of mental medicine, but specific analyses are required to understand and accompany these changes.

**Objective:** Our objective was to highlight the positions of the different stakeholders of the mental health care system on eHealth services and tools, as well as to establish professional and user group profiles of these positions and the uses of these services.

**Methods:** In order to acquire the opinions and expectations of different categories of people, we carried out a qualitative study based on 10 focus groups (n=70, from 3-12 people per group) composed of: general practitioners, psychiatrists, psychologists, social workers, occupational therapists, nurses, caregivers, mental health services users, user representatives, and the general public. The analyses of focus group discussions were performed independently by four investigators through a common analysis grid. The constant comparative method was adopted within this framework.

**Results:** The interviewees expressed different problems that new technologies engender in the field of mental health. What was previously strictly under the jurisdiction of physicians now tends to be fragmented and distributed over different groups and locations. New technologies reposition care in the field of domestic, rather than therapeutic, activities, and thus the conception of care as an autonomous activity in the subject's life is questioned. The ideal of social autonomy through technology is part of the new logic of health democracy and empowerment, which is linked to a strong, contemporary aspiration to perform. Participants emphasized that there was the potential risk of a decrease in autonomy for the digitally engaged patient, while personal empowerment could become a set of obligations.

**Conclusions:** This qualitative research highlights the heterogeneity of opinions among the groups and within each group. It suggests that opinions on electronic mental health devices are still far from being stabilized, and that a change management process should be set up to both regulate the development and facilitate the use of these tools.

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**KEYWORDS**

ehealth; mental health; psychiatry; social representations; focus group; users; caregivers; qualitative analysis; digital tools.

## Introduction

The field of electronic mental health (e-mental health) is particularly active and produces new tools at an extremely rapid pace [1-3], forcing people to position themselves in relation to these now unavoidable innovations that lead to major recompositions of thought [4]. Far from being a side effect or a passing fad, the development of connected objects in the mental health field is epistemologically like new approaches in psychiatry, which are based on contextually situated networks. In our opinion, this represents a fundamental trend that will nourish, and be nourished by, the already observed changes in nosographic and therapeutic categories in the field [5].

The importance of this trend is illustrated by the considerable interest in new technologies among members of the mental health field. For example, many references in the scientific literature are interested in the important potential of electronic health (eHealth) technologies for transforming and improving therapeutic and preventative health practices [6]. Not only are they likely to improve the effectiveness of care, they could also change its very nature [7]. They would thus be likely to disrupt the current methods of care, to majorly modify what we know or believe about psychiatric disorders [8], and to participate in P4 (predictive, preventive, personalized and participatory) medicine. Thus, while eHealth technologies could make it possible to improve patient-physician interactions and treatment compliance [9], they could also modify the patient-physician relationship by making it less hierarchical. At the level of the health care system, eHealth strategies could optimize the accessibility and efficiency of care, thus improving the effectiveness of treatment and reducing the cost of interventions.

The European E-men project was set up to develop an e-mental health innovation and transnational implementation platform in Northwest Europe. The project is promoting better and more accessible mental health care through the increased use of e-mental health interventions in a six-country European Union partnership. Funded by the Interreg North-West Europe Programme, the project aims to support the development and testing of electronic interventions in the different partner countries and to increase awareness about the potential of e-mental health through seminars, publications, and the development of policy recommendations. Furthermore, a cooperation platform has also been set up to address e-mental health implementation challenges in the long-term. Developing a better understanding of e-mental health acceptance is an important part of the E-men project, as it works to provide guidance on how to increase broader and more responsible implementation. Several actions have been undertaken in the E-men project to achieve such an understanding. In this paper, we will focus specifically on one of these actions, namely the analyses of the representations and declared practices of members of the field of psychiatry and mental health in the context of rapid and disruptive technological developments. We will address this question on the basis of the results of an empirical survey (the Qualitative study of m-Health expectations and uses by all stakeholders [EQUME]) conducted by the World Health Organization (WHO) Collaborating Centre of Lille (France), in the framework of its involvement in the E-men project.

## Methods

### Overview

We set up the EQUME qualitative study to collect information from the main groups of actors involved in the field of e-mental health: general practitioners (GPs), psychiatrists, mental health services users, users' representatives (those people who are members of an association of services users or on the board of this sort of association), the public, caregivers, social workers, psychologists, occupational therapists and nurses. These groups are referred to as stakeholders throughout this paper, as they each have some connection to the e-mental health field. 10 focus groups were formed from these main groups, with a total of 70 individuals involved (Table 1). We chose the term actor because it refers to the Actor-Network Theory [10], which considers the system comprising human and nonhuman actors, including technologies.

Focus group methodology was used to collect material on topics of interest through group exchanges. The exchanges were moderated by a moderator and an assistant moderator and were the subject of audio and video recordings. It should be noted that the EQUME study was the subject of a declaration of compliance with reference methodology at the Commission nationale de l'informatique et des libertés (CNIL) (N°2040798 v 0, March 3, 2017). All participants signed a consent form to be filmed.

The focus groups were conducted in accordance with the classic criteria of this methodology, namely: (1) Six to twelve participants [11,12]; (2) meetings lasted between one-two hours [13,14]; and (3) groups were ideally led by a moderator (MM) and an assistant moderator (DS or BDR) [15]. The moderator organized the conversation by asking questions to focus the topic of conversation and by encouraging everyone to participate. To do this, a semidirective interview grid was used. The assistant was responsible for making the video recordings and creating an environment conducive to discussion.

The semidirective focus group animation grid was developed by a pluridisciplinary team (two researchers in social sciences, a psychologist, a psychiatrist, and a services user) after prior analysis of the scientific literature, based in particular on the acceptability model for eHealth devices (acceptability, usability, utility, reliability, risk) [16].

**Table 1.** Participants of the focus groups.

| Categories of actors | Participants | | | Age of participants, n (IQR) | Knowledge of electronic mental health tools, n (IQR) |
|---|---|---|---|---|---|
| | Men | Women | Total | | |
| GPs[a] | 4 | 1 | 5 | 48.4 (40-59) | 4.5 (3-5) |
| Psychiatrists | 3 | 2 | 5 | 43.6 (25-62) | 3.2 (0-8.5) |
| Users' representatives | 2 | 1 | 3 | 54.3 (29-77) | 3.3 (1-6) |
| The public | 0 | 6 | 6 | 38.5 (29-53) | 3.2 (1-7) |
| Family caregivers | 6 | 3 | 9 | 62.2 (48-74) | 1.8 (0-4) |
| Social workers | 0 | 5 | 5 | 43.2 (29-57) | 1.6 (0-5) |
| Psychologist | 1 | 6 | 7 | 35.7 (25-59) | 1.7 (0-5) |
| Services users | 11 | 1 | 12 | 42 (30-59) | 3.7 (0-9) |
| Occupational therapist | 2 | 7 | 9 | 38.4 (24-56) | 1.1 (0-4) |
| Nurses | 4 | 5 | 9 | 36.7 (25-48) | 2.6 (0-6) |
| Total/Average | 33 | 37 | 70 | 44.3 (24-77) | 2.2 (0-9) |

[a]GPs: General Practitioners

### Data Analysis

To analyze the exchanges of the 10 focus groups, a thematic analysis grid was developed. From the first video recorded, the pluridisciplinary team of researchers independently created a list of the mentioned topics and categorized them. These initial categorizations were then pooled to form the analysis grid that was then applied to all groups. Each focus group was the subject of two independent analyses by two researchers, and then information was pooled during harmonization meetings. Disagreements on categorization were settled by a discussion using the description associated with each category. This method produced five major themes: (1) relationship patterns and tensions between psychiatry and mental health; (2) distribution of skills or methods of collaboration between Information and Communications Technology (ICT) and health professionals; (3) impact of eHealth on the caregiver and patient relationship; (4) process of autonomization; and (5) regulation of the sociotechnological ecosystem. Within these five major themes, the different positions of the actors in each group were recorded, with most participants involved in the discussions. We used a constant comparison analyses methodology, such as proposed by Glaser [17], a methodology that is well suited to analyze multiple focus groups [12].

## Results

### Overview

We have identified 5 main themes, divided into 19 subthemes. The first theme was related to "Relationship Patterns and Tensions Between Psychiatry and Mental Health," which was divided into 4 subthemes: (1) psychiatry versus mental health; (2) psychiatry and mental health: a hierarchical reversal; (3) from psychiatry to mental health: no paradigm shift; and (4) from mental health to mental disability: a shift from a curative to a rehabilitative approach.

The second one was related to "Distribution of Skills or Methods of Collaboration Between Information and Communications Technology and Health Professionals," which contained 4 subthemes: (1) the impossibility of replacing human actors with technology; (2) the possibility of replacing human actors with technology; (3) collaboration between ICT and health professionals; and (4) technology finely integrated into everyday life.

The third main theme was associated with the "Impact of Electronic Health on the Caregiver and Patient Relationship," and had three themes: (1) technology as an agent of change and improving connections; (2) electronic mental health is a barrier to the health care relationship; and (3) electronic mental health only brings about changes without a paradigm shift.

The 4th theme, relating to the "Process of Autonomization," was divided into 5 subthemes: (1) technology participates in processes of expertise and empowerment; (2) in favor of maintaining the caregivers' monopoly; (3) developing technological habits marked by hyperreflexivity and dependence; (4) contemporary aspiration for individualism and to perform; and (5) social injunction to autonomy.

Finally, the last main theme that emerged from the analysis was the "Regulation of the Sociotechnological Ecosystem," dealing specifically with regulation under the authority of the health system, the lack of a therapeutic framework leading to an extension from the private to the public domain, and self-regulation of the electronic health ecosystem.

### Relationship Patterns and Tensions Between Psychiatry and Mental Health

#### *Summary*

The field of mental health is marked by numerous conceptual, organizational, and legislative developments, including developments in e-mental health that question and often upset the relationship between health and mental health in terms of normal, pathological, individual, and systemic mental health, and in terms of the limits of the field of psychiatry. Four main

positions about the field stand out among the groups interviewed.

### *Psychiatry Versus Mental Health*

For GPs, social workers, users' representatives and the public, mental health cannot be superimposed on psychiatry. For GPs, the severity of the disorders set up the boundaries and territories of expertise and power of two types of professionals: psychiatrists and psychologists. Thus, severe disorders were under the jurisdiction of physicians and fell within psychiatry, while mild disorders were under the jurisdiction of psychologists and fell within the field of mental health. The users' representatives expressed that same idea and specified that the bounds of the field of psychiatry lie in public intervention, while those of mental health lie in private care. They added that the mental health and psychiatry dyad is usually viewed positively on the mental health side while the psychiatric side has negative connotations and is often associated with confinement.

For the public, mental health would be the social, mental, and subjective topic while psychiatry would be the natural, cerebral, and scientific subject. Philosophers and anthropologists described a movement that began in the 1980s to value naturalistic explanatory models (the cerebral etiology of the disease), which is associated with the advent of neuroscience [18]. While the first model focuses on the enhancement of the individual's life and addresses a socialized subject, the second, biological and cognitivist perspective addresses a natural or cerebral subject [19]. In this naturalistic model, the symptoms of the disorder or disease are emptied of their personal and moral contents, and all that is left is the biological and cerebral science. This depsychologization strategy is classically considered guilt-free [20], which could explain its prevalence in the public, but it must be handled with caution. For example, it is not necessarily preferable in society to be have a brain injury than to have been diagnosed with a psychological disorder. The hope is that the advent of ICT could potentially update the debates linked to the renaturalization of disorders and their related stigmatization issues by basing their management around technology designed specifically for that purpose.

Social workers and the public stated that, "mental health is (psychic) well-being." They also added that wellbeing was not a subdomain of health. According to the public, it was up to the legislator to define the contours of what is considered or not to be health:

> *Health issues are not treated in the same way as wellness issues.*
>
> *Legislation exists.*
>
> *It is up to the High Authority for Health (HAS) to say what is health and what is not.*

Social workers and the public did not seem to support the process of extending the pathology of a disease to symptoms that were not originally covered by it. This distinction may appear in contradiction with the general dynamics of recognition of health as a medical problem, and the tendency of medicine to include wellbeing in its field, as noted by Ehrenberg. Referring to the notion of mental health, the sociologist specifies that:

> *Taking charge of schizophrenia or improving its performance and psychological balance, in work, sexuality or relationships with children fall under the same label. Mixing frankly pathological problems with concerns for well-being, the notion is so broad that it is indeterminate [21].*

### *Psychiatry and Mental Health: A Hierarchical Reversal*

Psychologists, psychiatrists, some of the services users, and some of the occupational therapists interviewed considered mental health to be a broader field that includes psychiatry. For occupational therapists, the term mental health was more generic, inclusive, and extensive and was focused on prevention in public health, while psychiatry was synonymous with illness and pathology. Psychiatrists argued that they must not bear sole responsibility for the field of mental health. For psychologists and certain users:

> *mental health concerns the individual, the person, it contains the individual's lifestyle, well-being and social relations.*

This is illustrated by Ehrenberg's theory of a hierarchical reversal:

> *mental illness is now an aspect of mental health. The madman to be locked up is only one element in a larger whole which has encompassed him, that of the citizen in difficulty who must be supported (but also repressed, contained differently than in the past) and who must be the actor of his disease [21].*

This process questions the continuum between the patient and those who are healthy, as well as the concept of them and us, which is part of an evolution of representations and practices that has occurred over decades. This evolution went from a paternalistic view of care in the 1950s, to a patient-centered view in the 1990s, to a collaborative and partnership-based system of care beginning in the 2010s, leading to the normativity of full inclusion [22].

### *From Psychiatry to Mental Health: No Paradigm Shift*

For nurses, some of the services users and some of the occupational therapists interviewed, mental health and psychiatry were synonymous terms, as "it's just a matter of words." The only development reported concerns communication and image. One nurse said:

> *Mental health is less scary than psychiatry, but I don't see a paradigm shift with the name change: it's just sweeter to hear.*

One occupational therapist also said that mental health is "the new buzzword" to make psychiatry less stigmatizing. Mental health would therefore strictly cover the field of psychiatry, but the use of the term mental health could potentially reduce stigmatic representations associated with psychiatry.

### *From Mental Health to Mental Disability: A Shift From a Curative to a Rehabilitative Approach*

Caregivers were categorical, stating that health is "when it goes well." No caregiver appreciates or uses the term mental health and they instead use the idiom "psychic disability." This logic

of "disabling situations" [23] is no longer only interested in the causes but also in the consequences of health problems in a given environment [24]. This new logic of disability not only inserts mental pathology into a broader frame of reference than illness, but also changes its meaning [25]. Morgiève et al state that:

> *In the shift from the patient with a psychiatric-neurological illness to the 'person with a disability,' the medical objective of reducing or eliminating symptoms loses its centrality. It becomes one of the elements of a system aimed at reducing the impact of these symptoms on daily life in order to improve the quality of life [26].*

A shift thus takes place from a curative logic inscribed in a health model (eg, the problem is only individual, is based on an anomaly, is a matter for specialists) to a rehabilitative logic inscribed in a social model (eg, the problem is also in the social structure, is based on differences, is a public question) [23].

## Distribution of Skills or Methods of Collaboration Between Information and Communications Technology and Health Professionals

### *Summary*

The introduction of ICT in the field of mental health brings the question of the distribution of skills, the fields of jurisdiction, and the methods of collaboration between ICT and health professionals. Four means of collaboration were proposed by the different groups.

### *Impossibility of Replacing Human Actors with Technology*

For most participants, technology could not replace health professionals. Different representations are associated with this impossibility. Some GPs legitimized and defended their field of work by reaffirming their influence while discrediting the ICT field:

> *When I hear e-health, I still think it's about health at discount prices and fashionable gimmicks, something commercial; I don't feel like we're talking about medicine, medicine is about serious stuff you use.*

User representatives agreed that "it's just a gadget." According to this group, mental health would be the territory of medicine and under the authority of the doctor who guarantees its seriousness, so technology for managing it would be reduced to an accessory status. Psychologists wished to confine the role of eHealth to that of a therapeutic adjuvant because they feared "that someone will steal know-how that could be duplicated by the machine." Nurses, who recognized a possible superiority of technology, feared that this could have consequences on the employment of health professionals. This fear was more generally found among respondents of a survey conducted by the European Commission. Its results showed that respondents were pessimistic about the impact of robots and artificial intelligence on jobs, and more than 7/10 thought they steal jobs and cause more job loss than job creation [27].

For services users, caregivers, and the public, technology could not replace the health professional but could be complementary. All insisted on the need for it to be placed under medical authority:

> *removing the human is complicated; digital tools must just accompany doctors, patients, not replace medicine, especially in mental health.*

Nurses stressed the centrality of the human and narrative dimensions in care, which they felt could not be supported by ICT:

> *it is not desirable that an e-mental health tool replace a professional in diagnosis because a patient is also his history.*

For occupational therapists, tools like ICT sped up time "when you have to take it in psychiatry." GPs and users' representatives placed emphasis on the importance of communication. The first group asserted that psychiatry is care through communication and "therefore incompatible with e-health," and the second said that eHealth "is not real health, the one where we talk with patients because health without a third party is not health," while patients who used it "believe that they can heal themselves with their mobile phone." One user representative concluded that "it's discounted health." Psychologists also mentioned the impossibility for ICT to replace social interaction, but more specifically the transfer that remains strictly under their jurisdiction. They nevertheless thought that these new tools would redefine their roles.

### *Possibility of Replacing Humans with Technology*

For social workers, the process of replacing the health professional with technology "is in progress," while for some psychiatrists it was still only a "high probability," and for nurses "the technology is able to do instead and do better." Some psychiatrists spoke about the possibility of a future superiority of ICT over humans, which is associated with fears of dehumanization and of the impossibility for physicians to regulate the use of technological devices.

### *Collaboration Between Information and Communication Technology and Health Professionals*

Some participants from the public envisaged that in the future, "if knowledge grows, we can have devices as capable as a doctor." Some psychiatrists spoke about the future superiority of the human and machine pairing over the human alone. In these two configurations there is no opposition between these sociotechnological groups but rather a collaboration between human and machine.

### *Technology Finely Integrated Into Everyday Life*

GPs considered that wanting to make eHealth its own, distinct field was nonsense. According to these doctors, there would be no tension related to the use of these tools that they described as already being a part of everyday life. This inclusion of ICT in normal activity seems to extend from therapeutic activities to domestic activities, blurring the boundaries that once separated them. The conception of care as an autonomous activity in the subject's life was thus questioned in the public

group, with an example of "Is the jogging tracker a mental health tool?"

## Impact of Electronic Health on the Caregiver and Patient Relationship

### *Summary*

The introduction of ICT into the therapeutic health care relationship modifies previously established regulatory procedures, thus forcing patients and physicians to renegotiate the rules they would normally follow. The impact on the patient and caregiver relationship caused by eHealth is organized along three axes.

### *Technology as an Agent of Change and Improving Connections*

For most participants, e-mental health made it possible to find a therapeutic relationship and was a means of connecting to others. Participants from the public stated that "we think that it tends to distance us" whereas "just the fact of making the effort to send a message, the link is stronger." The public nevertheless considered this potential improvement in connection with others to be based on the acceptability of the technology by users. Caregivers emphasized the reciprocity and bidirectionality of these tools, which are a way for the patient to come into contact with professionals for the first time but also a way for health professionals to come into contact with patients through tools they use on a daily basis. Psychiatrists mentioned situations where patients "come to show their applications on smartphones." New technological tools chosen by the patient thus intervene in the therapeutic relationship, leading to a redistribution of the roles of each of the actors. Psychologists believed that eHealth gave a new social place to patients who "re-enter in the society." These tools make it possible to imagine new projects whose concrete implementation makes it possible to "change the team's view of the patient." Psychologists also noticed the equal spread of these tools, thanks to which "everyone will have their little coach in their pocket," and their capacity for catering to each individual because each one will have "his application according to the situation."

One psychologist said that, "you will call your psychiatrist into your living room." This scene illustrates a strong shift in the paradigm, as the patient becomes the one who brings the doctor to them and into their home. Thus, ICT seems to reconfigure hierarchical relationships and locate care not only in the therapeutic field but also in the private sphere. If there were no longer any boundaries delineating the field of health from the rest of life, psychologists questioned the therapeutic dimension of this continuum:

> *but can we intervene in the patient's life all the time, is it therapeutic?*

Caregivers were interested in the possibility of patients questioning the medical profession:

> *I will be happy when health professionals will be afraid of the note their patients will put on the internet.*

Users also evoked a possible extension of their power generated by the use of e-mental health devices:

> *It allows for discussion with the doctor, without being superior but being better informed. The relationship is better.*

### *Electronic Mental Health is a Barrier to the Health Care Relationship*

For occupational therapists, e-mental health devices could be a barrier to access to care. They said that they fear that these tools discouraged people from consulting professionals, or even lead them to self-diagnosis. According to them, ICT lead to a damaging lack of "communication and interpersonal relationships" and it would even be a means for physicians to "get rid of their patients." For some GPs, eHealth could hinder the therapeutic relationship. A nurse reported his patients saying, "I stopped my treatment because on the internet..." and he then concluded that eHealth "serves to make people sicker."

### *Electronic Mental Health Only Brings About Changes Without a Paradigm Shift*

For most nurses and user representatives, and some GPs, eHealth tools were only new ways to practice old techniques and did not create a new paradigm for patient management. One doctor specified:

> *the maniac depressed [outdated term] he uses paper, the bipolar [current term] he uses his computer.*

One user representative illustrated the lack of relational change by saying:

> *You can't be friends on Facebook with your psychiatrist.*

According to them, the technological space did not entail any modification in the health care relationship.

## Process of Autonomization

### *Summary*

The participants' positions on the roles of new technologies in terms of individual empowerment and empowerment processes can fit into five categories.

### *Technology Participates in Processes of Expertise and Empowerment*

For the public, social workers, services users, and nurses, eHealth was changing the role of the patient and making them a more active and autonomous actor. Mental health services users explained that the new technologies allowed them to access more information and that "the fact of having information makes us independent of a doctor." According to nurses, e-mental health allowed for "shared responsibility between caregiver and patient" and thus that "we leave the paternalistic model" behind. GPs emphasized the disruptive dimension of ICT in mental health that allowed "a new paradigm, a new system, a new use impossible to do otherwise." According to a general practitioner, this process could even bring legitimacy and competence to patients in a field that would no longer be exclusively, or even at all, that of doctors.

### *In Favor of Maintaining the Caregivers' Monopoly*

Some psychologists and caregivers saw the potential for eHealth to help or empower patients. However, they made it an essential condition "that it passes through the human," that the tools were used as a secondary accessory, and that it was validated by health professionals and not by patients. For all occupational therapists, eHealth reduced individual empowerment because the patient did not know what was good for them or what they should do with the information they found. In the discourse of these three groups, patients seemed to be considered passive targets who were supposed to comply with the prescriptions of health professionals who possessed the legitimate knowledge of their condition and the best way to treat it [28-30].

### *Developing Technological Habits Marked by Hyperreflexivity and Dependence*

For some psychologists, occupational therapists, and social workers, the patient became dependent on a machine:

> *I don't think it gives autonomy, it organizes rather dependence on the device.*

Psychologists described these tools as invasive and that they needed to be used less often. ICT in mental health can help one develop some level of scientific expertise and a critical awareness of one's activities, but it also develops inward-looking attitudes and hyperreflexivity. For caregivers and nurses, ICT did not increase the reflexivity of patients who, because of their pathology, would have already developed a propensity for too much self-observation:

> *it is in the normal process of illness to seek to rationalize, to focus, to question, to talk about oneself in the end.*

### *Contemporary Aspiration for Individualism and to Perform*

For some psychologists:

> *the omnipresence of a health medium permanently in one's pocket is likely to develop a personal emulation to do better, to want better, and to be healthier.*

Users described eHealth as individualistic, as "it's every man for him." Electronic health seems to correspond to a strong contemporary aspiration to perform as well as to an ideology of individualism and taking control of one's life. Taking responsibility for one's life as an individual, rational actor is thus privileged and promoted in contemporary industrial societies [31].

### *Social Injunction to Autonomy*

User representatives were critical:

> *Empowerment with technology is a complete fake.*
>
> *Empowerment / ICT / Mental health = bad stuff they want to impose on us. The philosophy of regaining power over one's life is good but it is quoted in all government reports, it seems confusing.*

Patient engagement in health care is at the forefront of research policy and practice and is now widely recognized as an essential ingredient of a high-quality health system. However, the discourses of the digitalized and digitally engaged patient are seen as part of a left-wing policy orientation in care. These discourses position patients as ready to actively engage in their own health care and promote their own health, which may be seen as an attempt to shift the burden of responsibility from the State to the individual [28]. In the discourse of the digitally engaged patient, individual empowerment becomes a set of obligations that they need to take care of themselves [29]. There is then a paradigm shift from "my health is my doctor's responsibility" to "my health is my responsibility and I have the tools to manage it" [32].

## Regulation of the Sociotechnological Ecosystem

### *Summary*

Because of the way digital data is created, stored, and used, both personal and private practices are quickly interwoven within networks and economies [33]. The means of regulating the mechanisms of this new sociotechnological ecosystem are therefore essential, since private practices are caught up in a collective system in which different actors compete for control of the field [34]. For this theme, three types of views emerged from the focus groups.

### *Regulation Under the Authority of the Health System*

Some GPs, social workers, and nurses affirmed the need for regulation to guarantee the reliability, security, and confidentiality of computerized health data. However, a GP explained that technological devices could guarantee more data security than some "archaic" tools. For users' representatives, the use of ICT "enters a health system and a health system has its rules." Psychologists specified that validation of tools must be done by health professionals and not by patients, while psychiatrists were concerned about the inability of their professional group to regulate their use. Users mentioned the Ministry of Justice, the Ministry of Health, researchers, doctors, professionals who represent patients (ie, families and peer-helpers), as legitimate bodies and actors who could regulate the field of eHealth. Some GPs and nurses were also concerned about the extension of their legal liability. They expressed fear of being watched and judged, and of potential legal risks. A general practitioner thus pleaded for a "presumption of benevolence" towards the medical profession.

### *Lack of a Therapeutic Framework Leading to an Extension From the Private to the Public Domain*

Occupational therapists and some participants from the public, as well as some caregivers and some users' representatives, described a current lack of a therapeutic framework in eHealth that seems dangerous to them as, "we risk being passively invaded." Some caregivers pointed to the need for standards and regulatory systems. The public also raised the question of the confidence that can be placed in the technological tool. To guarantee the safety of users, it seemed essential to them to be able to identify three types of groups: those who hide behind the development of the tools, those who have a financial interest, and the people "behind the computer from whom medical advice is sought." These participants were aware of the complexity and multitude of human and nonhuman actors working together to configure these devices and the need to understand how users,

designers, developers, and funders were able to construct, interpret. and negotiate the generated data.

One user representative worried:

> *mental health is in your head, new technologies are open so you open your head open.*

Another user representative stated that eHealth could not contribute to individual empowerment because the implementation of technological tools required very complex settings and that "it therefore becomes a collective affair."

These comments echoed various analyses that say that the human network is contributing to a transformation, initiated over the last thirty years, in which individual subjectivity has become a collective issue [25]. The agency of each individual now seems to be at the center of social life:

> *the more the individual is considered as an autonomous whole, which must be able to decide and act by himself, the more the question of his interiority becomes a public concern [21].*

### *Self-Regulation of the Electronic Health Ecosystem*

Some caregivers, users' representatives and members of the public believed that the eHealth ecosystem is self-regulating. According to one user representative, users of technological devices were "health actors" and he saw "no risk of capture." The use of eHealth would thus result from free will, where "everyone sets his limits." Participants from the public insisted on the concept of ethical and legal acceptability of these new technologies, which according to them continued to prevail.

These results are all summarized in Table 2.

**Table 2.** Synthesis of the results.

| Discussion themes and opinions of stakeholders | GPs[a] | Psychiatrists | Service users' representatives | The public | Caregivers | Social workers | Psychologists | Services users | Occupational therapists | Nurses |
|---|---|---|---|---|---|---|---|---|---|---|
| **Relationship patterns and tensions between psychiatry and mental health** | | | | | | | | | | |
| Psychiatry versus mental health | ✓ | | ✓ | ✓ | | ✓ | | | | |
| Psychiatry and mental health: a hierarchical reversal | | ✓ | | | | | ✓ | ✓ | | |
| From psychiatry to mental health: no paradigm shift | | | | | | | | ✓ | ✓ | ✓ |
| From mental health to mental disability: a shift from a curative to a rehabilitative approach | | | | | ✓ | | | | | |
| **Distribution of skills or methods of collaboration between information and communications technology and health professionals** | | | | | | | | | | |
| Impossibility of replacing human professionals with technology | ✓ | | ✓ | ✓ | ✓ | | ✓ | ✓ | ✓ | |
| Possibility of replacing humans with technology | | ✓ | | | | ✓ | | | | ✓ |
| Collaboration between information and communication technology and health professionals | | ✓ | | ✓ | | | | | | |
| Technology finely integrated into everyday life | ✓ | | | | | | | | | |
| **Impact of electronic health on the caregiver and patient relationship** | | | | | | | | | | |
| Technology as an agent of change and improving connections | ✓ | ✓ | | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |
| Electronic mental health is a barrier to the health care relationship | ✓ | | | | | | | | ✓ | ✓ |
| Electronic mental health only brings about changes without a paradigm shift | ✓ | | ✓ | | | | | | | ✓ |
| **Process of autonomization** | | | | | | | | | | |
| Technology participates in processes of expertise and empowerment | ✓ | ✓ | | ✓ | | ✓ | | ✓ | | ✓ |
| In favor of maintaining the caregivers' monopoly | | ✓ | | | ✓ | | ✓ | | ✓ | |
| Developing technological habits marked by hyperreflexivity and dependence | | | | | | ✓ | ✓ | | ✓ | |
| Contemporary aspiration for individualism and to perform | | | ✓ | | | | ✓ | | | |
| Social injunction to autonomy | | | ✓ | | | | | | | |
| **Regulation of the sociotechnological ecosystem** | | | | | | | | | | |
| Regulation under the authority of the health system | ✓ | ✓ | ✓ | | | ✓ | ✓ | ✓ | | ✓ |

| Discussion themes and opinions of stakeholders | GPs[a] | Psychiatrists | Service users' representatives | The public | Caregivers | Social workers | Psychologists | Services users | Occupational therapists | Nurses |
|---|---|---|---|---|---|---|---|---|---|---|
| Lack of a therapeutic framework leading to an extension from the private to the public domain | | | ✓ | ✓ | ✓ | | | | ✓ | |
| Self-regulation of the electronic health ecosystem | | | ✓ | ✓ | ✓ | | | | | |

[a]GPs: general practitioners

## Discussion

### Primary Findings

The interviewees expressed different problems that new technologies engender in the field of mental health. What was previously strictly under the jurisdiction of physicians now tends to be fragmented and distributed over different groups and locations. New technologies reposition care in the field of domestic, rather than therapeutic, activities, and thus the conception of care as an autonomous activity in the subject's life is questioned. The ideal of social autonomy through technology is part of the new logic of health democracy and empowerment, which is linked to a strong, contemporary aspiration to perform. Participants emphasized that there was the potential risk of a decrease in autonomy for the digitally engaged patient, while personal empowerment could become a set of obligations.

This qualitative research highlights the heterogeneity of opinions among the groups and within each group. It suggests that opinions on electronic mental health devices are still far from being stabilized, and that a change management process should be set up to both regulate the development and facilitate the use of these tools.

### Limitations

The aim of this study was to understand some of the existing representations and concerns of the main groups affected by the use of e-mental health tools. The study did not claim to be exhaustive or even representative of such groups, and data obtained are essentially representative of two major, urban, French cities. Moreover, two specific problems must be mentioned. First, four people among the users' representatives group did not show up or cancelled their participation in the focus group too late to be replaced, so users' representatives are thus underrepresented in the results. Second, the system users' group is composed of an unexpectedly high proportion of men and the potential reasons for this bias are unknown.

### Conclusion

The data we have presented highlights an important inter- and intragroup, and even intraindividual, fragmentation of points of view on eHealth, with participants making statements that may appear contradictory with each other. This suggests that positions on these new technological devices are still far from being stabilized and may evolve even during a focus group. Indeed, these devices themselves are a very recent innovation, are little known, and evolve very rapidly and unpredictably.

Another apparent result is that, far from allowing the cooperation between actors that they are supposed to promote, the emergence of these apparently diverse reactive mechanisms, classical defensive tensions, and positioning within psychiatry and medicine in France have generated groups of actors who want to defend their categorical interests and their social or socio-professional identity. The existence of these reactions leads to the hypothesis that there is concern among participants about observable and imaginable changes generated by the development of ICT in the health field, and also suggests that a specific change support process must be put in place to allow good ownership and optimal use by stakeholders. The specificity of these new tools is that they enable the overcoming of the traditional boundaries and modes of regulation and communication, which has allowed the move towards the fluid and evolving functioning of individuals in a network.

This study must be seen as a first step toward a more detailed understanding of the current representations in e-mental health. A quantitative study concerning services users is already ongoing in the framework of the EQUME study. Studies about actual health care practices in the field are also needed to complement this first study on representations, as well as more organizational studies concerning change management support for the French e-mental health ecosystem.

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## Conflicts of Interest

None declared.

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## Abbreviations

**CNIL:** Commission Nationale de l'Informatique et des Libertés
**eHealth:** electronic health
**e-mental health:** electronic mental health
**EQUME:** Qualitative study of m-Health expectations and uses by all stakeholders
**GCS:** Groupement de coopération sanitaire
**GP:** general practitioner
**ICT:** Information and Communications Technology
**UNAFAM:** Union nationale de familles et amis de personnes malades ou handicapées psychiques
**WHO:** World Health Organization

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Original Paper

# Young People's Response to Six Smartphone Apps for Anxiety and Depression: Focus Group Study

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## Abstract

**Background:** Suicide is one of the most frequent causes of death in young people worldwide. Depression lies at the root of this issue, a condition that has a significant negative impact on the lives of those who experience it and on society more generally. However, 80% of affected young people do not obtain professional help for depression and other mental health issues. Therefore, a key challenge is to find innovative and appealing ways to engage young people in learning to manage their mental health. Research suggests that young people prefer to access anonymous Web-based programs rather than get face-to-face help, which has led to the development of numerous smartphone apps. However, the evidence indicates that not all of these apps are effective in engaging the interest of young people who are most in need of help.

**Objective:** The study aimed to investigate young people's response to six currently available smartphone apps for mental health and to identify features that young people like and dislike in such apps.

**Methods:** Focus groups were conducted with 23 young people aged 13 to 25 years in which they viewed and used six smartphone apps for mental health. A general inductive approach following a realist paradigm guided data analysis.

**Results:** The results revealed that young people value autonomy and the opportunity to personalize experiences with these apps above other things. Finding a balance between simplicity and informativeness is also an important factor.

**Conclusions:** App developers need to consider using participant-design frameworks to ensure that smartphone apps are providing what young people want in a mental health app. Solutions to the need for personalization and increasing user engagement are also crucially needed.

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**KEYWORDS**

depression; adolescent; smartphone; mobile phone; mental health

# Introduction

## Background

Depression lies at the heart of what is now the second most prevalent cause of death among young people aged 15 to 29 years across the globe: suicide [1]. The reported incidence rates of major depressive disorder among young people are as high as 8% in Australia [2] and 11% in the United States [3]. However, many more young people remain undiagnosed or experience depression at subclinical levels, suggesting that the number affected is actually much higher [4].

Early intervention can reduce the duration and impact of depression, as well as reducing the chances that it will become a lifelong disability [5]. Despite this, only around 20% of affected youths obtain professional help [2]. This likely occurs for several reasons including the lack of motivation that often accompanies depression [6], a lack of understanding and knowledge about depression [7], and the stigma associated with mental illness [8]. There is thus a crucial need to find ways to engage young people with professional mental health services and in learning about mental health.

Multiple studies have demonstrated that young people prefer to access the relative anonymity of Web-based mental health resources rather than obtain face-to-face help [9,10]. The internet is one of the top sources of help that young people report seeking for mental health issues [11]. Smartphone apps are increasingly of interest in health contexts because they have the potential to provide both anonymity and accessibility, given the widespread usage of mobile phones by young people [12], with several systematic reviews reporting positive effects of usage on mental health across age groups [13,14].

Nevertheless, a recent systematic review [15] demonstrated that trial attrition rates in studies investigating the effectiveness of digital mental health interventions in young people such as smartphone apps can be as high as 70%. Even trial participants who complete the studies frequently engage minimally with the intervention throughout the duration of the study, particularly where the programs are completed unsupervised in the participant's own time. These high dropout rates suggest that while these interventions may be *effective* in reducing symptoms of depression, they often fail to *engage* young people. In particular, the review demonstrated that the numerous digital interventions that rely on educational modules to communicate about mental health are unappealing to young users. Participants in some of the reviewed studies described such learning modules as "tiring" [16] or "tedious" [17]. Another study of apps for various health conditions including participants from multiple age groups similarly demonstrated that approximately 26% are discarded after a single use [18].

It is thus important to identify the features of mobile apps for mental health that young people find most appealing to inform future intervention design. Research across a broad range of ages suggest that features such as privacy and security of personal information are often of concern to users of mental health apps [19]. In apps relating to general health management, young people report that the *look and feel* are important factors in usage [20]. Studies have demonstrated that young people appreciate design features in mental health apps that are engaging and easy-to-use and are more motivated to use apps that fit these criteria [21]. One study explored the response of young people to a range of health-related apps in focus groups, identifying other important design criteria [22]. However, few studies have taken a similar approach in relation to mental health apps by directly investigating the response of young people to currently available apps, with a view to determining the appeal of various features to this specific population. The aim of this study, therefore, was to explore young people's perspectives about the usability of six currently available smartphone apps for mental health to determine features that will increase appeal and engagement with future interventions.

## Research Questions

The following two research questions were asked:

1. What opinions do young people express about the usability and appeal of six currently available mental health smartphone apps?
2. Which features of these apps are most appealing or unappealing to young people and why?

# Methods

## Overview

The research question lent itself to a general inductive approach as described by Thomas [23]. This approach is commonly found in health and social sciences research and evaluation and allows detailed readings of the data to inform analysis rather than be shaped by previous hypotheses or focused on theory generation as in other inductive approaches such as grounded theory [24]. This approach was considered desirable in this context because the authors wanted the findings to be generated from the data itself rather than a priori knowledge but did not intend to develop a theory.

A general inductive approach follows a realist paradigm which takes a middle ground between constructivism and positivism, taking the view that *reality* is something that can be measured and defined independently of how we perceive it, while valuing the varying perspectives of participants [25]. Such an approach was thought to be appropriate in this study owing to the need to explore the diversity of responses to the topic under consideration, while developing an idea of the overall *reality* of user response that app developers must consider.

Focus groups were selected as the method of data collection because of the potential for interactive discussions to generate valuable details about shared experiences and diverse perspectives [26]. Focus groups are a method of data collection that have been commonly used in studies evaluating electronic health (eHealth) tools [27,28].

## Participants

The sample consisted of 24 young people aged 13 to 25 years. Participants were recruited from high schools and a university in Western Sydney, Australia, and included 15 females and 8 males. The only inclusion criterion was that participants had to be between 13 and 25 years of age. Participants were excluded

if they had both scores on the Depression Anxiety Stress Scale depression subscale [29] greater than 15 (indicating severe depression; range of possible scores=0-21), and current suicidal thoughts, as there was an ethical risk associated with including high-risk participants. One participant was excluded on the basis of these criteria leaving a total sample size of 23. The excluded participant was referred to local mental health services and followed up by a clinical psychologist who was a member of the research team. Participants who were university students were provided with course credit and participants who were high school students were provided with a $50 gift voucher for study involvement.

Participants were assigned to 1 of 4 groups on the basis of their preferred attendance location, but with a view to balancing genders across the groups; 2 groups consisted of youths aged 18 to 25 years who were university students, the third group contained slightly younger participants aged 14 to 19 years including both university students and high school students, and a final group consisted of a younger age range from 13 to 15 years who were high school students (see Table 1). Participants' depression scores ranged from no depression to severe depression, with mean scores suggesting moderate levels of depression on average across the sample.

**Table 1.** Characteristics of group participants.

| Group | Total (N=23) | Female (n=15) | Male (n=8) | Age range (years) | Mean age (years) | University/high school students | Depression[a,b] |
|---|---|---|---|---|---|---|---|
| 1 | 7 | 5 | 2 | 18-25 | 20 | University | 1-15 |
| 2 | 7 | 5 | 2 | 18-25 | 20 | University | 1-8 |
| 3 | 6 | 4 | 2 | 14-19 | 16 | 2 university, 4 high school | 2-10 |
| 4 | 3 | 1 | 2 | 13-15 | 14 | High school | 2-9 |

[a]Range of scores on Depression Anxiety Stress Scale depression subscale.

[b]Total range is 1-15 with a mean of 8.

## Procedures

Ethics approval was obtained from the institutional ethics board. Notices recruiting participants for a study about music, mood, and well-being were posted around the university and in high schools. Potential participants contacted the researchers to indicate interest and were screened for eligibility in a brief phone interview by a clinical member of the research team. One participant was excluded after consultation between 2 clinical members of the research team. Eligible participants were then emailed an information sheet explaining the nature and possible consequences of the study. All participants provided written consent to participate and those under the age of 16 years also provided written consent from a parent. Each group attended 2 sessions of approximately 1.5 to 2 hours each with the sessions 1 week apart. Groups were conducted on 3 different campuses of a university in Western Sydney, Australia, in a private room. Some of the participants in the focus groups were known to each other, and 2 of the participants were known to the group-moderator. However, all participants were reminded that they were free to withdraw from the study at any stage and the moderator made a deliberate effort to allow discussions to be largely group directed so as to encourage open expression from all participants.

## Materials

Participants were questioned about their use of technology in general and then were presented with information about six different apps. The six apps presented to participants had different points of focus (Table 2), but all were concerned with mood management or management of mood disturbances, specifically depression and anxiety. All had been commercially released and were available for download on the Apple App Store. Several websites making recommendations about mental health apps were reviewed and apps that were frequently mentioned were shortlisted. The final group of six apps were selected to reflect a diverse range of approaches to mental health and a variety of features and characteristics. The selected apps were: Mood Mission, Music eScape, Pacifica, Mindshift, Headspace, and What's Up

Mood Mission is an app developed by psychologists and researchers at Monash University, in which users rate their mood and are provided with a tailored list of tasks or missions that they can undertake to improve their mood. Music eScape was designed by researchers from the Queensland University of Technology. Users swipe their finger across the screen of their device to draw a path from the mood they are currently in to the mood they would like to get to. The app then builds a playlist from the music stored on their device designed to take them to their desired mood. Pacifica is based on principles from cognitive behavioral therapy (CBT) and mindfulness and was developed by a commercial company with a team of clinical advisors. The app allows users to track their moods, set daily challenges, access peer support communities, and explore techniques for improving mental health. Mindshift is an app for anxiety developed based on principles of CBT. It allows users to record their levels of anxiety and find ways to change the thinking patterns behind their anxiety and provides guided meditations. Headspace was designed by researchers at New York University and the University of Southern California to teach meditation and mindfulness as a stress reduction technique.What's Up? is an app by a private developer and is based on CBT principles. It includes educational modules about challenging dysfunctional thoughts and beliefs, space for diarizing thoughts and feelings, and open forums for discussion with other people.

Participants downloaded the apps to their personal devices during the focus group or were able to use it on an iPad provided by the researchers. Discussions were guided by a topic outline, but were allowed to flow naturally as participants responded,

with the moderator taking particular care to draw out diverse viewpoints from the groups. Discussions in the first session considered questions relating to app usability and appeal broadly, while the second session considered participant opinions about individual app features one-by-one in more detail (see Multimedia Appendix 1).

**Table 2.** Mental health apps assessed in focus groups.

| App name | Mental health focus | Developer | Tools |
|---|---|---|---|
| Mood Mission | Depression and anxiety | Monash University | Variety of personalized behavioral strategies |
| Music eScape | Stress/distress | Queensland University of Technology | Develops music playlists to shift from one mood to another |
| Pacifica | Stress and anxiety | Commercial company with clinical advisors | CBT[a] based mood tracking; personalized behavioral strategies; psychoeducation; links to therapists; peer support |
| Mind Shift | Anxiety | Anxiety Disorders Association of British Columbia | CBT approach; mood tracking; psychoeducation |
| Headspace | Stress | New York University and University of Southern California | Mindfulness and meditation |
| What's Up? | Depression | Private developer | CBT approach; psychoeducation; social forums; diary |

[a]CBT: cognitive behavioral therapy.

### Data Analysis

Focus group content was transcribed verbatim and thematic analysis performed to identify the broad explicit and implicit themes within the data using an inductive analysis style [30]. Initially, open coding was used to assign 258 segments of data to 55 codes by the first author. Once open coding had been completed, this was checked and a second wave of analysis using axial coding was conducted in a collaborative process between several authors to derive a refined set of codes. Axial coding, as described by Charmaz [31], is used to discern connections between data categories and codes. Data were clustered into six higher order latent themes with subthemes, which reflected app features that appealed or did not appeal to participants, including two crosscutting themes which applied across all other themes.

Memos were also taken throughout coding to note impressions about the influence of group dynamics, as recommended by Smithson [32], particularly as groups consisted of individuals with varying degrees of experience of depression who may have different viewpoints. Memos were based on the strategies developed by Stevens [33], including looking for statements that evoked conflict and contradictions in the discussion as well as shared experiences expressed by the participants. Notes taken by the group moderator during the sessions were also referred to in analysis.

## Results

### Overview

Across discussions of different apps, six higher order themes were identified: accessibility, motivation, social connection, credibility, personalization, and simplicity (see Table 3). As depicted in Figure 1, the 2 crosscutting themes of simplicity and personalization permeated the discussions across all other themes. The figure shows the number of data segments allocated to each theme and the overlap with the crosscutting themes of personalization and simplicity, demonstrating that while these 2 themes were discussed in isolation to the other themes (No interaction), they also formed a part of the discussions relating to accessibility, motivation, social connection, and credibility. Simplicity held greater weight in the discussion than personalization, and motivation was the theme that had the most data segments allocated to it overall apart from the crosscutting themes. The themes and their subthemes will be discussed individually below.

### Personalization and Simplicity

As will be seen throughout discussion of other themes, many app features were perceived by participants as having both negative and positive aspects. A primary solution advocated by participants to overcome this was personalization: the ability to opt-in or opt-out of features such as the use of missions, social features, or notifications, or to tailor content and appearance to one's own preferences and circumstances.

For example, some argued that the content itself should be customizable. For example, 1 participant said the following:

> *I think putting information and expecting it to work for everyone is a bad idea. Personalised is always best because what works for this person may definitely not work for this person as well.* [Female, Group 1]

It was suggested that:

> *When you first start to use the app it could give you a bunch of stuff and be like, "Okay, how do you feel about this? How do you feel about that?" and then personalize your experience based on that.* [Female, Group 2]

Apps that did not do that were perceived as less helpful. For example, 1 participant said in relation to Mind Shift:

> *The actual structure of it doesn't assess where you're at and then provide information on that. It's more like here are a hundred different things and then you can try and hunt through that to find something.* [Male, Group 1]

**Table 3.** Higher order themes and subthemes.

| Major theme | Subtheme level 1 | Subtheme level 2 |
|---|---|---|
| Personalization | Opt-in, opt-out | —[a] |
| | Personalized content | — |
| | Customizable appearance | — |
| | Set preferences | — |
| Simplicity | Minimize number of features | — |
| | Easy to navigate and find information quickly | — |
| | Information that is easy to absorb | — |
| | Minimalist design | — |
| Accessibility | Access from home | — |
| | Compatibility | — |
| | Cost | — |
| Motivation | Missions, rewards, objectives | Sense of achievement; requires energy |
| | Tracking mood | Identify patterns; discouraging if little progress |
| | Notifications | Useful reminders; annoying, increases guilt or anxiety |
| | Statistics | Understanding prevalence |
| Social connection | No substitute for face-to-face help | — |
| | Peer communication settings | Potential for inaccuracies; good to know others share your feelings; existing platforms have more content and faster response |
| | Anonymity | Encourages openness; a license for misuse |
| | Links to professional help | Live chats, hotline calls, or referrals; off-putting to some |
| Credibility | Original material | — |
| | Not dumbed down | — |
| | Not telling people what to do | — |
| | Knowing the source | — |

[a]Not applicable.

Others said that having a customizable appearance, with changeable skins or color schemes would make the app feel more personal.

Simplicity was another crosscutting theme that appeared in multiple discussions. Participants across the groups were in consensus about the fact that the apps needed to be easy to access and navigate. As 1 participant said:

> *If it's too difficult to use an app, I would just uninstall it. There's just so many apps now that if it's too difficult I'll just find another one.* [Male, Group 4]

Others agreed that apps should be targeted in their focus and should not have too many features. One participant said the following:

> *If you have a mental health app that is also playing music, that is also telling you to exercise, there's like a very small amount of people who will want all those three things in one app.* [Female, Group 1]

*What's Up?* was one app which participants agreed contained too much information. The dominant perspective in Group 1, for example, was the following:

> *I wouldn't recommend someone who's worried to look at this app. It's just too much information bombarded at them.* [Female, Group 1]

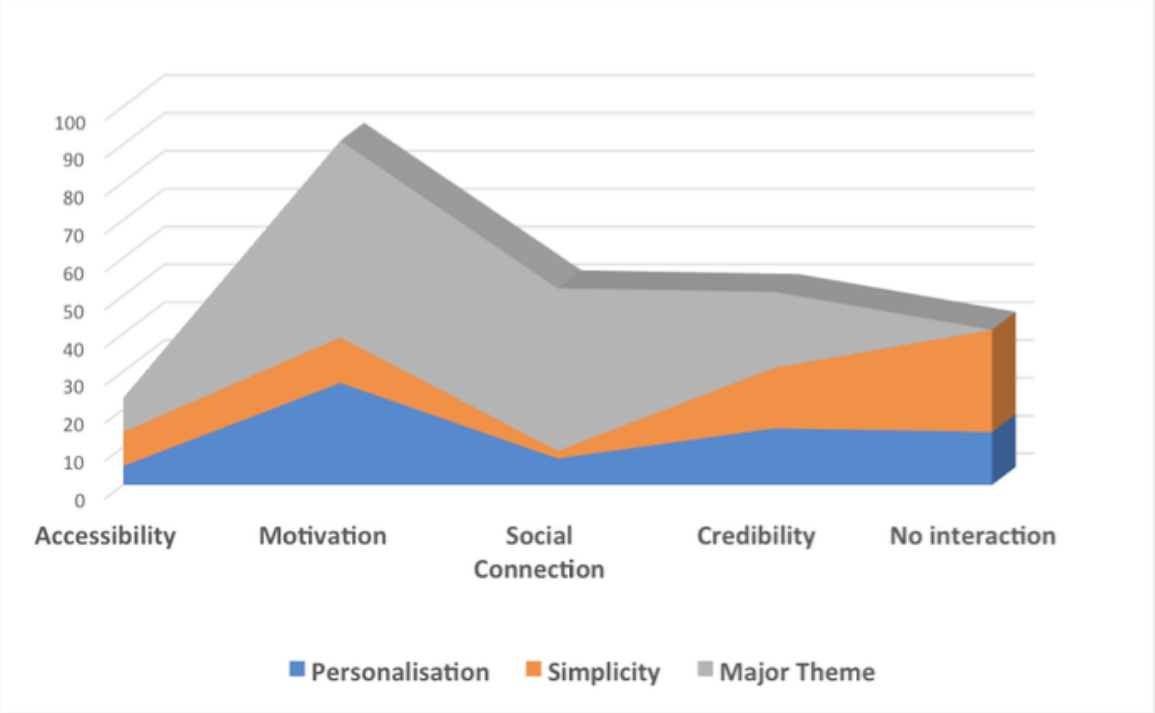
Another agreed, saying the following:

> *You wouldn't want to read the whole thing because it's just too much.* [Female, Group 1]

Similarly, others felt that it was important that people be able to find quick fixes easily:

> *When it's very clear how to do things, that's what's best. Anything that requires extra thought, like if the buttons are too small so you have to squint to read them or zoom in or something or there's way too many buttons or something. Usually that's the stuff that's most annoying.* [Male, Group 3]

**Figure 1.** Distribution of data segments across major themes and interaction with crosscutting themes of simplicity and personalization.




Others pointed out the importance of the content being easy to absorb. As 1 participant said:

> *I think it's nice to have apps that don't require you spending a lot of time on them in one go. You can just dip in and out of them for two or three minutes at a time.* [Female, Group 4]

Apps that contained a lot of information or reading received a negative response from participants. For example, 1 participant said the following about Mood Mission:

> *If I was to download this and all of this came up, I'd be like, 'Oh my god' and then – because as I'm looking at it right now it's giving me a headache.* [Female, Group 1]

Similarly, 1 participant said the following in relation to *Mindshift*:

> *There's too much information. I feel like it tells you 'Do this, do this, do this, do this', but it's not giving you suggestions on how to get to that.* [Female, Group 2]

Aesthetically, simplicity was important to users as well. In relation to *Music eScape*, a participant said the following:

> *I like that it's very minimal as well. It's colourful but it's still simple* [Female, Group 1]

*Headspace* was another app which garnered positive comments about the design across the groups. As a participant said in relation to *Headspace*:

> *There's a very specific aesthetic that I enjoy and it's that very clean, simplistic, almost IKEA-ish look.* [Female, Group 3]

This opinion prompted other participants in the group to agree on the need for clarity and simplicity in both the esthetic and the content. In fact, as stated by another participant in that group, an overly complex design could add to a user's sense of anxiety:

> *Some apps that can be really busy can be really anxious. Especially a mental health app, being really clean cut it's just calming and good to look at it and it just pleases you. It kind of clears you. It's like, "Everything's in order and it's great."* [Female, Group 3]

## Accessibility

One perceived advantage to the use of apps was the ability to access it from home or any other place. Participants commented on how people who feel depressed find it difficult to leave the house or to speak to people in person about their problems. One participant stated as follows:

> *A lot of times people who are really depressed just don't want to leave the house. They can't be bothered filling up their Opal card [a public transport ticket used in Australia], or catching a bus is too much effort, or they panic. So, there should be a way to access those things within your home.* [Female, Group 3]

Compatibility was another aspect that influenced how accessible users found the apps considered in this study. It was also important to participants that apps be accessible across a wide range of devices including phones, computers, and iPads, and that they be compatible with both Android and Apple operating systems. Participants also pointed to some issues relating to accessibility with *Music eScape*. In Group 1, despite a high level of enthusiasm for the overall concept and the design, there was agreement that the app's reliance on music stored on one's

device limited its usefulness. Consensus within the group on this issue was evidenced by the way the participants finished each other's sentences, indicating their shared viewpoints. Several participants said that they would only use the app if it was compatible with music streaming platforms such as Spotify, but on exploring the app, the groups found that it was not and expressed the opinion that this would render it unusable for them. Participants in Group 2 similarly reached consensus about this limitation, as expressed by 1 participant:

> *I don't save music to my phone.* [Female, Group 2]

Another prohibitive aspect of some apps that related to accessibility was cost. For example, in Group 2, participants began discussions about *Pacifica* by agreeing that they would not want to pay for a mental health app:

> *What's the point when there's other apps that could do the same thing it does but they could do it, let's say, for no charge.* [Female, Group 2]

However, 1 participant disagreed with the others, stating the following:

> *When it comes to anyone feeling better, whether it's going to the gym or things like that, people will pay because they're wanting to feel better within themselves.* [Female, Group 2]

This led the group to agree that there might be situations in which they would be willing to pay for a mental health app, such as if it was highly reputable and if the cost was a one-off, low payment. Nevertheless, this emerged as a negative point in relation to other apps as well, such as this comment in relation to *Headspace:*

> *It annoyed me a bit because it's got a lot of stuff that sounds cool but then when you click on it, it tries to make you sign up for a subscription.* [Female, Group 2]

## Motivation

Motivation was a theme that emerged from discussions about features found in several apps. The features under discussion were typically interactive features that required the user to engage in particular activities, such as missions, objectives and rewards, and mood tracking. Participants across the groups held varying viewpoints about whether these features would be motivating or demotivating to users and whether they would encourage them to engage more or less with the app or with activities that could benefit their mental health. The effect of notifications and statistics about other users on user motivation was also discussed. Participants argued that they could be both motivating and discouraging or could require more energy than a depressed user would have. For example, in relation to Mood Mission, several participants like the ideas of missions or objectives, stating:

> *I feel like achievements would be good if it was there because it kind of motivates you.* [Female, Group 2]

However, others stated:

> *It could be helpful but at the same time you wouldn't want it to remind you constantly that you have to do this or that. What if there are days where you just can't be bothered?* [Female, Group 1]

This opinion was echoed by several participants who argued that when a user is lacking in motivation and energy because of depression, the concept of missions could be overwhelming. Thus, it was suggested that it would be best to make the use of missions or objectives

> *Optional so that if you want it you can use it. If you don't want to, no problem.* [Male, Group 1]

Similarly, in relation to mood tracking features such as in *Pacifica*, some argued that it could be helpful to be able to identify patterns:

> *Something cool about this app is that you can actually track the progress of what's going on. Which can be a good thing because if someone really wants to feel better, for example, it could help them and motivate them even more.* [Female, Group 2]

However, 1 participant felt that:

> *Seeing the graph if you don't see any progress, that can frustrate you.* [Female, Group 1]

Another said:

> *This is more for like elderly, or people in their forties, like that age category, because especially for younger—we don't—I don't know, personally I wouldn't want to go to this app because I wouldn't like to record my feelings and write it down.* [Female Group 2]

Notifications were also viewed as something that could also be motivating or demotivating and that should therefore be personalizable. Participants in Group 4, for example, shared differing perspectives on the use of notifications, with 1 female and 1 male participant agreeing that they liked reminders and notifications to keep them engaged with an app, while another male participant stated that he always opted to turn them off. Participants from other groups similarly stated:

> *If it's daily it can become a chore. It just off puts people and mitigates the effects.* [Male, Group 1]

Another indicated that notifications could even be a source of anxiety saying:

> *It shouldn't bother you. It should never pester you. It's meant to stop anxiety, not increase it.* [Female, Group 3]

## Social Connection

Some of the apps considered in this study contained features that allowed social connection with others. Participants across the groups voiced a range of perspectives on this subject, pointing out both pros and cons of these features. Several participants felt that despite the convenience of being able to access support on one's phone, this was no substitute for face-to-face contact. One participant argued:

> *I think all these apps, they can get unhealthy when people use them as a crutch and they get addicted to them instead of getting proper health, because their*

> *mental health will be deteriorating but they won't really care because they'll be like, "as long as I'm using this app I'm fine." They won't go out and talk to someone. They won't get help and will just use it as a crutch.* [Female, Group 1]

Others felt that there were some distinct disadvantages to accessing peer support communities. Groups 2 and 3 particularly discussed this in some detail. Despite some agreement that:

> *When you know that someone else shares the same feelings as you, you could maybe be supporting each other.* [Female, Group 2]

Others in the group argued that there was the potential to be given inaccurate advice. One participant said the following:

> *Whoever is going on the app is going to get a lot of conflicting information.* [Female, Group 2]

Similar viewpoints were expressed in other groups, such as this statement:

> *I don't necessarily just want to speak to 'randos' who are in the same position as me. I don't really see how that would be productive.* [Female, Group 3]

Others felt that existing social platforms would be preferable. As 1 participant said:

> *You may as well go on the internet and some of the more popular sites where everyone is using it and get more responses then. Probably someone who is in your situation has already posted something related to where you are.* [Male, Group 1]

Similar conflicting views were shared about the anonymity of online forums. One participant said the following:

> *If it's online then you're more inclined to talk to other people because they don't know where you are* [Male, Group 1]

Another said:

> *I definitely think it would be nice to be a bit anonymous. Especially if I'm feeling a bit sad, I don't always want other people to know about that.* [Male, Group 4]

However, others argued that the anonymity could give license to some users to use online forums in an unhelpful way:

> *People can be spreading negative energy towards other people. When people talk about depressing stuff it can make you depressed.* [Female, Group 2]

As another pointed out:

> *I think the best place for someone who is an absolute psychopath to push people over the edge would be a mental health app where a bunch of mentally ill people are trying to get help from strangers.* [Female, Group 3]

The range of perspectives shared within the groups prompted suggestions from participants about how the relative benefits and drawbacks could be negotiated. Some participants felt that it would be better if the apps connected individuals with professionals. One participant said the following:

> *Maybe there could be this little online chat with someone who could actually offer support.* [Female, Group 2]

However, participants in Group 3 argued that this could also be off-putting to some:

> *If you're going to connect to a psychologist or a psychiatrist then you're not talking to a stranger. They've got an identity in your mind. They're an authority type person who you're talking to.* [Male, Group 3]

Another participant shared a personal anecdote that illustrated this, saying:

> *I went to one of these apps when I was 13 or 14 and talking to someone, and after I finished talking to them it made me afraid that they were going to find me. I just quit the app and I was never looking at this again.* [Female, Group 3]

Other suggestions were that social forums would need to be highly moderated or that social features should be on an opt-in, opt-out basis.

### Credibility

Participants agreed that app materials needed to be carefully worded to gain credibility with users. When materials were perceived as unoriginal or clichéd, containing too much information that was readily available elsewhere, this was off-putting to participants. For example, participants in Groups 1, 2, and 4 felt that the content of Mood Mission did not provide anything unique. As 1 participant stated:

> *The gist of relaxing, focusing and just breathing deeply is in almost every other meditation, so you don't really need another one. Common knowledge basically.* [Male, Group 1]

Another participant from the same group similarly said about *Mindshift*:

> *A quick Google search would probably bring up all of this and more and you don't have to download the app.* [Male, Group 1]

For others, it was the use of language that they perceived as clichéd that was unappealing. When speaking about *Headspace*, 1 participant said the following:

> *It can get irritating because it just falls back on the whole cliché thing. I don't like them using euphemisms when it comes to mental health.* [Female, Group 1]

On the other hand, apps that took a unique approach to managing moods and mental health, such as *Music eScape*, were of interest to the participants. A number of participants across the groups liked the concept of using music to manage their mood:

> *I'm a music person so one hundred percent I would definitely use that.* [Female, Group 1]

However, users in Group 2 agreed that the lack of a clear mental health message in this app created the potential for the app to be used ineffectively. As articulated by 1 participant:

> *What if somebody wanted to go from happy to sad? There's something kind of questionable about that feature even being there. It's not really a positive mental health app—you can be happy and then go to aggressive if you wanted to. So it's not really focused on positive mental health* [Female, Group 2]

Nevertheless, 1 dissenting voice in Group 2 pointed out that the more subtle approach to mental health found in this app could have appealed to people less willing to engage with content about mental health.

Others disliked that the language used in some apps could be:

> *A bit dumbed down, like they're for kids.* [Female, Group 4]

As another participant put it:

> *You don't want it to be shameful. You don't want to be talked down to. You want to be spoken to in an encouraging way where you actually want to motivate yourself to get better.* [Female, Group 3]

For others, knowing that the information contained in the app was scientifically based or that the app had been developed by experts was important to credibility. Thus, it was important to participants that the language used in the app gave the user confidence in the app and its content.

## Discussion

### Principal Findings

The aim of this study was to explore the responses of young people to six currently available mental health apps and to determine the features that they found appealing and useful in those apps. This study revealed that young people have clear views about how mental health apps should work to benefit them.

The data were organized into six themes: accessibility, motivation, social connection, and credibility, and the 2 crosscutting themes of personalization and simplicity. Some of our findings, such as the importance of apps being easy to access and easy to use, are common findings in the literature about development of eHealth apps. For example, Crane et al [34], conducted think-aloud sessions and interviews with users of an app to reduce excessive alcohol consumption, and found that making the app easy to use and navigate through as well as avoiding excessive text or options were important to users. Criteria like this are found in common tools for evaluating app appeal and usability [35]. However, this study revealed some additional criteria that add to an understanding of how young people respond to mental health apps.

### Personalization

One key finding of this study was that participants valued the capacity to demonstrate autonomy, and to personalize their experiences with the apps from content to appearance. User wanted to be able to customize both the visual aspect of the app and the way they interacted with app content.

In general, trends are shifting in favor of models of personalized care and treatment strategies across multiple areas of health care [36]. At the heart of these trends are principles derived from theories such as Self-Regulation Theory, which argues that a sense of personal control and empowerment is important to motivating individuals to successfully meeting personal challenges [37]. Personalization in health care has been found to help individuals to develop greater autonomy and capacity to self-manage their well-being [38]. The literature on eHealth interventions similarly highlights the need for personalizability. For example, a content analysis of Web reviews of apps for bipolar disorder found that users commonly complained about features that did not meet the differing needs of individuals and asked for apps to be more customizable [39]. One study of user perspectives of an app to promote physical activity similarly found that personalization was an important factor in user engagement [40]. Thus, app developers need to keep in mind that a one-size-fits-all approach is unlikely to satisfy different users' preferences and needs.

As the need to balance standardized procedures with personalization presents a challenge to developers, future research should explore the development of innovative interventions that can adapt and respond to a variety of user needs and preferences. Tailoring matrixes have been effectively used in eHealth interventions in the past to personalize content based on feedback to user responses [41], and such models provide a basis for further innovation in this area.

### Balancing Simplicity With Credibility

Another key point that emerged from this study is the need to balance informativeness and credibility with simplicity. Participants did not want to see material that was clichéd, repetitive, or unoriginal. They wanted to see scientific evidence and to know that the information had credibility. This is in contrast to some previous studies which have shown that users sometimes integrate apps into their health management without regard for the evidence-base or clinical effectiveness [39]. It may be that young users are becoming more aware of the proliferation of apps that are developed by private and corporate developers [42]. Even participants from the youngest age group in this study expressed that they did not want to be *talked down to* or to feel the app was just for kids. However, it was important that information be presented simply, with minimal amounts of text that is easy to find and absorb.

Theoretical frameworks for eHealth development such as the Technology Acceptance Model similarly highlight the importance of perceived ease of use to the user, as well as perceived usefulness in increasing user engagement [43]. Simplicity and ease of use is particularly important for app developers to consider in mental health contexts, as depression and anxiety are associated with a lack of motivation [44](2) and impaired concentration [45]. Thus, apps that contain large amounts of text or complex materials are unlikely to be engaging to young people, particularly those experiencing mental health difficulties. A key challenge for app designers, therefore, is to develop features that are perceived as effective, useful, and informative but that involve low levels of user burden.

One key point to this that was revealed in this study is that participants appreciated apps that focused on 1 feature such as meditation, and that approached mental health in a unique way

such as in *Music eScape*. In fact, given the importance that music has in the daily lives of young people, with up to 18 hours/week invested in listening to it [46], music provides an avenue for engaging young people in learning about mental health that has potential for further exploration. Users in this study were particularly intrigued with this way of exploring mental health given their high level of intrinsic interest in music. Nevertheless, participants identified significant drawbacks from this app, in that it did not cater for users who do not store a variety of music on their phone nor did it help users understand how to use music effectively. Previous research has also demonstrated that not all music has a beneficial effect on mental health [47,48]. Future app development could look at building on music streaming platforms that cater to a wide variety of tastes while providing guidance to users about making helpful choices.

Game-based apps may also provide another useful tool for engaging young people in learning about mental health. Studies have demonstrated some positive effects of game-based programs [49]. However, even game-based apps tend to be primarily of interest to young people when they are already engaged in addressing their mental health (15), suggesting that more work is needed to develop apps that provide a level of interest and interaction that is sufficient to engage young people who are otherwise averse to learning about mental health. Furthermore, depression is commonly associated with internet addiction and excessive online gaming [50] and some types of games have been associated with increased depression [51]. This highlights the need for a careful approach to development of game apps for mental health, such as the work by the Games for Emotional Mental Health Lab in The Netherlands (see, eg, Schoneveld et al [52]).

### Social Features

The study further highlighted some of the pros and cons of social features in mental health apps. While young people might appreciate knowing that other people feel the same way as them and appreciate the opportunity to express their experiences in an anonymous environment, participants in this study were aware of the potential for misinformation or even abuse when seeking advice from nonprofessionals.

This illustrates a paradox that has been previously observed in Web contexts that some researchers call "the online disinhibition effect" [53], referring to the tendency to both self-disclose (benign disinhibition) and to act out (toxic disinhibition) more than usual in anonymous contexts. Other scholars have similarly concluded that social networking features in an app are a *gamble* because of the need to balance the potential for negative and positive effects [54]. Thus, peer communications in online mental health settings require careful planning to ensure that they are both safe and helpful for psychologically vulnerable individuals. Moderation of Web communications may need to be in place, and measures should be taken to preserve user confidence in anonymity when linking to professional mental health services as well.

User-centered and participatory design frameworks may be particularly important in developing solutions to the design challenges noted above [55]. Participatory design frameworks integrate young people at all stages of the research process as co-researchers and co-designers of interventions. Hagen et al [55] suggest a 6-stage approach to co-design in which young people are involved in focus groups, co-design workshops, and other studies to: (1) identify a health issue, (2) define the factors contributing to the problem, (3) position the problem in the context of current evidence, (4) develop an intervention concept, (5) create prototypes and test models, and (6) test and evaluate the resulting intervention. Co-design of mental health interventions alongside young people can do much to contribute to the appeal of such interventions and the degree to which they will be engaging and relatable to their target market. Future research and development of smartphone apps for mental health should therefore be focused on the use of evidence-based strategies as well as engaging end users throughout the development and evaluation processes.

This study was limited to some degree in the use of focus groups as a methodology. Although this methodology can be useful for drawing out multiple perspectives, there is some possibility that group dynamics in some way shaped the perspectives expressed by participants. In particular, as the groups contained people both with lived experience of depression and those without, this may have discouraged more personal expressions from participants with experience of mental illness. The fact that members of the groups were known to each other can also influence how people communicate about potentially personal topics. While the group moderator and methods of analysis attempted to take these factors into consideration, results should be read with this limitation in mind. The study is further limited by the small number of apps considered and the relatively small amounts of interaction time that participants had with each app, which may have reduced their capacity to develop a comprehensive viewpoint of app functionality. Nevertheless, this may reflect the reality of how users make decisions about app use, with studies demonstrating that young people tend to engage fleetingly with apps and to rapidly discard those that do not meet their expectations [22]. Future studies should look at a wider range of mental health apps and could consider allowing users to engage with them over longer periods of time.

## Conclusions

On the whole, this study demonstrates that mental health apps need to cater to the individuality of the users. Features to improve user experience and engagement include personalization by developing customizable content and user interfaces, as well as providing feedback and progress tracking for the individual, on an opt-in, opt-out basis. Overburdening users with a lot of reading and other content is not appealing to many young users, leading to a lack of engagement with many currently available apps. It is therefore crucial to develop concrete and action-oriented features with a fun and entertaining design to motivate millennials to learn about mental health.

In summary, we make 3 key recommendations for the future development of smartphone apps for both the treatment and diagnosis of mental health issues: (1) end users should be closely involved in all stages of the design process from problem identification to evaluation and testing, (2) app designs need to incorporate innovative ways to provide customizable content

that can adapt and respond to individual user needs and preferences, (3) increase user engagement by balancing informativeness with simplicity and building on highly interactive activities that young people are already engaged in such as music listening and gaming.

## Conflicts of Interest

None declared.

Multimedia Appendix 1
Focus group discussion guide.
[PDF File (Adobe PDF File), 21 KB - mental_v6i10e14385_app1.pdf ]

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## Abbreviations

**CBT:** cognitive behavioral therapy
**eHealth:** electronic health

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Original Paper

# Effectiveness of a Mental Health Service Navigation Website (Link) for Young Adults: Randomized Controlled Trial

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## Abstract

**Background:** Mental health and substance use disorders are the main causes of disability among adolescents and young adults yet fewer than half experiencing these problems seek professional help. Young people frequently search the Web for health information and services, suggesting that Web-based modalities might promote help-seeking among young people who need it. To support young people in their help-seeking, we developed a Web-based mental health service navigation website called *Link. Link* is based on the Theory of Planned Behavior and connects young people with treatment based on the type and severity of mental health symptoms that they report.

**Objective:** The study aimed to investigate the effect of Link on young people's positive affect (PA) compared with usual help-seeking strategies immediately post intervention. Secondary objectives included testing the effect of Link on negative affect (NA), psychological distress, barriers to help-seeking, and help-seeking intentions.

**Methods:** Young people, aged between 18 and 25 years, were recruited on the Web from an open access website to participate in a randomized controlled trial. Participants were stratified by gender and psychological distress into either the intervention arm (Link) or the control arm (usual help-seeking strategies). Baseline, immediate postintervention, 1-month, and 3-month surveys were self-reported and administered on the Web. Measures included the PA and NA scales, Kessler psychological distress scale (K10), barriers to adolescent help-seeking scale (BASH), and the general help-seeking questionnaire (GHSQ).

**Results:** In total 413 young people were recruited to the trial (intervention, n=205; control, n=208) and 78% (160/205) of those randomized to the intervention arm visited the *Link* website. There was no evidence to support a difference between the intervention and control arms on the primary outcome, with PA increasing equally by approximately 30% between baseline and 3 months in both arms. NA decreased for the intervention arm compared with the control arm with a difference of 1.4 (95% CI 0.2-2.5) points immediately after the intervention and 2.6 (95% CI 1.1-4.1) at 1 month. K10 scores were unchanged and remained high in both arms. No changes were found on the BASH or GHSQ; however, participants in the intervention arm appeared more satisfied with their help-seeking process and outcomes at 1 and 3 months postintervention.

**Conclusions:** The process of prompting young people to seek mental health information and services appears to improve their affective state and increase help-seeking intentions, regardless of whether they use a Web-based dedicated youth-focused tool, such as *Link*, or their usual search strategies. However, young people report greater satisfaction using tools designed specifically for them, which may encourage future help-seeking. The ability of Web-based tools to match mental health needs with appropriate care should be explored further.

**Clinical Trial:** Australian New Zealand Clinical Trials Registry ACTRN12614001223628; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=366731

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**KEYWORDS**

adolescent; young adult; internet; web archives as topic; mental health; mental disorders; help-seeking behavior; mental health services; affect

## Introduction

### Background

Mental ill health is a leading health burden affecting 1 in 4 young people worldwide [1-3] with detrimental effects on relationships, academic achievement, work life, and general well-being [4], which often continue into adulthood [5]. Following investment in mental health reforms in Australia to provide accessible mental health services to young people [6], the rates of help-seeking for mental health problems appear to be improving; however, between 35% and 65% of those in need still fail to seek professional help [7].

Barriers to help-seeking for mental health problems among young people are well documented [8]. Young people may not recognize their symptoms as a mental health problem or know that effective treatments exist [9,10]. Some young people may not be ready to seek help [4] or their symptoms may go undetected by health professionals [11]. The stigma associated with mental illness may also prevent young people from seeking help [12]. Not knowing where or how to access services, perceived costs and inconvenience in accessing care, and fears of being judged or of breaches in confidentiality are other important barriers perceived by young people [10]. Interventions that reduce these barriers and provide a positive experience of help-seeking are needed, particularly interventions that facilitate access to treatments [13] and those that aim to increase young people's readiness to seek help [14].

Most young people have lived their entire lives in a digital media–saturated world and are highly likely to use the internet to search for health information [15-18]. This suggests that electronic health interventions have the potential to facilitate help-seeking among young people. However, a recent systematic review of Web-based interventions to increase mental health help-seeking revealed poor quality studies and little evidence of impact on actual help-seeking behavior or on the likely precursors of help-seeking, such as mood, perceived barriers, and intentions to seek help [16]. Furthermore, internet interventions often lack or neglect to outline a theoretical foundation, limiting understanding about which elements of a program may be beneficial and why [16].

In response to the deficiencies identified in the literature, we developed *Link*, a website designed to assist young people to find accessible Web-based and computer-based mental health services appropriate for their mental health needs. *Link* was developed in accordance with the Medical Research Council guidelines for complex interventions [19,20]. We undertook a comparative review of relevant behavior change and help-seeking theories and selected the Theory of Planned Behavior on which to base our program logic and ultimately the functional elements of the technology design; a description of this process has been previously published [21]. In the development phase, participatory design [22] with young people was used to understand the features important to include in *Link* that would facilitate youth engagement [23]. The program logic of *Link* thus proposes that by improving attitudes, beliefs, and perceived control of help-seeking, and reducing barriers toward help-seeking, positive affect (PA), and intentions to seek help will increase, which in turn will increase actual help-seeking behaviors [24].

We conducted a pilot randomized controlled trial (RCT) of *Link* with 51 (intervention, n=24; control, n=27) young people aged between 18 and 25 years [25]. Results indicated that *Link* was well accepted by young people and that a larger RCT investigating the effectiveness of *Link* was feasible with minor refinements, including simplifying the sign-up process and removing a link to Google for the control participants. The pilot study also revealed, in keeping with other studies, that help-seeking intentions and behaviors were difficult to define, with no current psychometrically sound measures routinely used in previous studies [26], and that a primary outcome measure other than help-seeking intentions and behaviors should be used in the RCT. On the basis of young people's typical barriers to seeking help, theoretical considerations, and the availability of a well-validated measure, we chose PA immediately after using a help-seeking strategy as the primary outcome. The theoretical considerations were based on the construct of PA and its potential role as an intermediary in help-seeking. PA reflects the degree to which a person feels alert, active, and enthusiastic [27]. High PA is characterized by energy, concentration, and engagement. It was hypothesized that young people concerned about their mental health and facing barriers to seeking help, such as knowing where to go, what to expect from each service, and perceived stigma and isolation [28], would experience rapid relief of distress when engaging with the features of *Link*, such as immediate return of tailored options for seeking help, personal stories from others with the same symptoms, practical self-care tips, and preparation for what to expect when accessing a service. PA was thus hypothesized to promote engagement with the help-seeking process. This potential intermediary role of PA for help-seeking intentions and behaviors can also be explained by its association with increased coping strategies, positive meaning of issues, connections with others, self-esteem, and validation from others [29].

### Objectives

The primary objective of this study was to assess the impact of *Link* on young people's PA compared with usual help-seeking strategies immediately post intervention. Secondary objectives were to compare the intervention and control participants on measures of PA 1 and 3 months after using *Link* and on negative affect (NA), psychological distress, barriers to seeking help, and help-seeking intentions at 1 and 3 months postintervention.

# Methods

## Study Design

This was an Australian-based individually randomized controlled trial conducted between November 27, 2014 (first participant recruited) and July 4, 2015 (last follow-up survey completed). All study procedures were conducted on the Web. People aged between 18 and 25 years were randomly allocated in a ratio of 1:1 to either the *Link* (intervention) arm or the usual help-seeking strategy (control) arm. Both arms were followed for 3 months. A secure server at the University of Newcastle, Australia (QuON) was used to manage the trial phases and to collect and store deidentified survey responses. The study was approved by the University of Melbourne Human Research Ethics Committee (ID.1341063.4).

## Participants

### *Eligibility Criteria*

Participants were eligible if they were aged between 18 and 25 years, living in Australia, and had sufficient English and computer literacy to complete the survey measures and navigate the *Link* website.

### *Recruitment*

A digital marketing company (Profero) was responsible for participant recruitment. The marketing strategy was in English and comprised electronic direct mail, social media, Web-based advertising (eg, Facebook, Gumtree, and Google), and snowballing. Web-based advertisements were directed at young adults between the ages of 18 and 25 years who lived in Australia (Facebook; Multimedia Appendix 1), anyone who searched for mental health information and lived in Australia (Google; Multimedia Appendix 1), and under the community advertisements on Gumtree. Those who clicked on the link to the study in the advertisement were assessed for eligibility using a Web-based form and young people fulfilling the inclusion criteria were invited to participate in the study. Short message service (SMS) text messaging and email reminders were sent to the participants 6 to 10 days after a positive eligibility assessment (for baseline survey), the randomization date (for postintervention survey), the due date for the 1-month survey, and the due date for the 3-month survey. Participants were reimbursed with an Aus $15 gift card for completing each of the first 2 surveys and an Aus $20 gift card for completing the final survey.

## Intervention

*Link* is a self-directed mental health help-seeking service navigation website designed to guide young people to appropriate Web-based and computer-based sources of mental health information and care. It was designed by the research team in conjunction with young people and developed by the software company Tigerspike. The theoretical basis and rationale for each feature of *Link* has been published previously [23,24].

Multimedia Appendix 2 shows screenshots from a computer or tablet of how users move through the program. On the landing page (slide 1), clicking on *get started* guides users through a 3-step self-assessment process. First, the user is asked to select from a list of symptoms, expressed in language co-designed by young people, the one that best reflects how they are feeling (slide 2). The symptoms map to 8 domains: anxiety and depression; bullying; alcohol and drug problems; issues with eating, weight, and body image; relationship difficulties; suicidal intent; and self-harm. Second, users are asked to rate the degree to which the symptoms are affecting them using an interactive pictorial 5-point sliding scale ranging from 1=*I'm OK* to 5=*It's a huge deal* (slide 3). Third, they select their service preference, that is, face-to-face, phone helpline, Web-based chat or email therapy, or Web-based information and self-help (slide 4). On the basis of information provided in steps 1 to 3, *Link* presents 3 service recommendations from a directory of 31 youth-friendly services (slide 5). Users can click for more service options if required. Information is provided for all services including what to expect when using the service, how the service works, the cost of the service (if any), and a link to the service's website or location (slide 6). The program also recommends a suitable service modality based upon the severity of the issue. For example, if the user selected *online information* as a service preference for severe thoughts of self-harm, *Link* would also suggest a 24-hour telephone helpline. An emergency contact button also appears at the top of each page for users experiencing high levels of distress (slide 7).

To accommodate those young people who are unable to explain exactly what is bothering them, a list of symptoms is displayed (slide 8). Clicking on the most fitting possibility produces a number of options that map to the 8 domains described above (slide 9). Once the user confirms their main issue, they will re-enter the *Link* program (at slide 3).

Mental health facts and peer-stories were also embedded in *Link*. These features were designed to engage users, influence subjective norms around help-seeking, and increase mental health literacy. Users could access *Link* using either a computer, tablet, or mobile phone. These different platforms were all considered in the design of *Link*, with the mobile display also shown (slide 10). Intervention participants could use *Link* as often as they wished throughout the study, up to the time they completed their last follow-up measure, or they were more than 3 weeks past the due date for their 3-month follow-up survey. This provided them with the opportunity to explore multiple problems that they may have experienced during the study period.

## Study Protocol

Young people who met the eligibility criteria and provided informed consent registered for the trial using their email address and a self-generated password. Email addresses and passwords allowed all participants to login and complete surveys at each wave and use the *Link* program (intervention arm only). Immediately following registration, all participants completed the baseline survey, after which they were randomly allocated to receive *Link* (intervention arm) or be directed to a page with the following instructions (control arm):

> *We want to know what you normally do to seek help. Please search for information and support for an issue or problem you are currently facing using strategies you normally use to seek help*

Individuals who partially completed the baseline survey or did not complete the randomization process were sent email and SMS reminders 4, 7, and 14 days after beginning the enrollment process. Individuals who completed the enrollment process in less than 28 days were considered enrolled in the study.

Immediately after randomization, participants were provided with a link to the postintervention survey to be completed immediately after using the *Link* program (intervention arm) or they undertook usual help-seeking strategies (control arm), which may have been the same day as they were randomized. Participants were sent reminders via email and SMS with the link to the survey 1, 4, and 7 days later. Participants who did not complete the postintervention assessments within 14 days from completing baseline were considered nonresponders.

A month after completing the baseline survey, participants received an email and SMS providing a link to the 1-month follow-up survey, with reminders sent 1 and 2 weeks later. Participants who did not complete this survey after 3 weeks were considered nonresponders. After 3 months from baseline, participants received an email and SMS to complete the 3-month follow-up survey. Reminders were sent 1 and 2 weeks later. Participants who did not complete the 3-month follow-up survey within 3 weeks from the first reminder were treated as nonresponders.

Checks for valid input data were programmed into QuON, so that only valid survey responses could be entered. Some questions had to be answered before continuing to the next page. All activity in *Link* was tracked, recorded, and linked to the intervention participants' unique identification number. The study design also included an economic evaluation which is described in full in a companion paper [30].

### *Measurement Time Lines*

All outcome measures were collected from both arms at baseline, 1 month, and 3 months postintervention. PA and NA and satisfaction were also measured 2 weeks (immediately) after randomization in both arms to capture effects after first using their respective allocated intervention.

## Primary Outcome Measure

### *Positive Affect*

PA was measured using the PA scale of the positive and negative affect scale (PANAS) [27]. A PA score was calculated by adding the 10 PA items. The PA score can range between 10 and 50, with higher scores representing higher level of PA. The 10-item PA scale has high internal consistency, is valid and reliable over a 2-month period, and is sensitive to mood fluctuations if used with short-term instructions (eg, now) or to stable traits if used with longer-term instructions (eg, past year) [27].

## Secondary Outcome Measures

Secondary outcomes included PA at all other follow-up points, and the other measures described below.

### *Negative Affect*

NA was measured using the 10-item NA scale of the PANAS [27]. NA reflects an individual's degree of subjective distress arising from mood states, such as anger, guilt, fear, and nervousness. Low NA is characterized by a state of calmness and serenity. NA is related to self-reported stress, poor coping, and frequency of negative events. Developed alongside the PA scale, the NA scale is also highly internally consistent, largely uncorrelated, and stable at appropriate levels over a 2-month time period (Cronbach alpha reliabilities for intercorrelations and internal consistency reliabilities range from .86 to .90 for PA and from .84 to .87 for NA, with reliabilities unaffected by the time instructions used) [27]. The NA scale was used to indicate if there was an immediate benefit of using *Link* and if any harms arose from either arm. The 10 NA items were added to calculate a total NA score ranging between 10 and 50, with lower scores representing lower levels of NA.

### *Psychological Distress*

Psychological distress was measured using the Kessler psychological distress scale (K10) [31]. The K10 has good precision in the 90th to 99th percentile range of the population distribution (standard errors of standardized scores in the range 0.20 to 0.25) and maintains consistent psychometric properties across major sociodemographic subsamples [31]. The K10 strongly discriminates between community cases and noncases of structured clinical interview for diagnostic and statistical manual of mental disorders (IV) [31]. The K10 comprises 10 questions asking about the frequency of depressive and anxiety symptoms in the past 4 weeks. Each item is rated on a 5-point scale (1=none of the time and 5=all of the time) and scores are summed to a possible range of 10 to 50, with higher scores indicating higher distress. For the random allocation, participants with a K10 score less than 20 at baseline were classified as likely to be well, whereas participants scoring 20 or more were classified as likely to have a mental disorder. The K10 is a reliable measure with all items of relevance to young people [32].

### *Barriers to Help-Seeking*

Barriers to seeking help for mental health problems were measured using the barriers to adolescents seeking help (BASH) scale [9], adapted by Wilson [33]. This is an 11-item scale that includes questions around knowledge of available resources, mental health stigma, and attitudes to help-seeking. Each item is scored on a 6-point Likert scale (1=strongly agree and 6=strongly disagree); items are reverse scored and added so that higher mean scores indicate increased barriers to help-seeking. The BASH scale has good test-retest reliability, internal reliability, and validity among adolescents [9]; however, it showed no variance in our pilot study and so was not chosen as the primary outcome [25].

### *General Help-Seeking Questionnaire*

The general help seeking questionnaire (GHSQ) [33] includes 12 items asking how likely the individual is to seek help for an emotional or personal problem from different services and people. When tested in a population of high school students, the GHSQ was found to have satisfactory reliability and validity and was considered a suitable measure of help-seeking intentions when applied to a range of contexts [33]. Sources of help were classified as informal (eg, intimate partner, friend, parent, and relative/family member); formal (eg, mental health professional,

doctor/general practitioner, minister/religious leader, hospital, and medication prescriber); Web-based/phone (phone helpline and Web-based tools/apps); and none (do not seek help from anyone). Each statement was answered on a 7-point Likert scale from 1 (extremely unlikely) to 7 (extremely likely). All items in the formal (4 items), informal (5 items), and Web-based/phone categories (2 items) were averaged for a total score. This measure also showed little variance in the pilot study, which, along with being in the review of measures not psychometrically robust, was why it was not a primary outcome this study [25,26].

### *Satisfaction With Link*

Participants were also asked 10 items adapted from Retolaza [34] about whether their expectations were met in the postintervention and 1-month and 3-month follow-up surveys [25]. Each item was scored on a 5-point Likert scale (strongly disagree, disagree, neither agree or disagree, agree, and strongly agree).

### *Baseline Characteristics*

Demographic information included age, gender, education and employment status, and language spoken at home. Participants were also asked to rate their perception of their mental health at baseline using a 5-point scale from *perfect no illness or problems* to *severe illness* [35]. Participants were asked about their health service use in the past 6 months and whether they had searched the Web for mental health information or services in the previous 2 weeks.

### *Help-Seeking Strategy After Randomization*

Both arms were asked about the method they used to seek help in the first 2 weeks (immediate), 1 month, and 3 months after randomization mainly to gain an understanding of methods used by the control arm.

## Sample Size

A sample size estimate of 214 participants (107 per arm) was based on the PA scale of the PANAS with a minimal clinically significant difference in mean scores between the two arms of 2.7, assuming a standard deviation of 7.9, 80% power, and 5% significance level [27]. To test our primary hypothesis that participants in the intervention arm would, on average, report an increase in PA immediately after using *Link* compared with participants in the control arm, we based our sample size calculations on a 1-tailed independent *t* test. Owing to the high attrition rates commonly observed in Web-based recruitment [36-38], the sample size was inflated by two-thirds to 336 young adults (168 participants in each arm).

## Randomization and Masking

A 32-character unique identification code comprising letters and numbers was assigned to each participant. After completing the baseline measures, participants were randomly allocated to either the intervention or control arm using a random allocation sequence generated internally by the QuON computer software (University of Newcastle). Randomization was stratified by gender (male, female) and psychological distress (K10 score <20 and K10 score ≥20; K10 was completed as a baseline measure) using random sequences of block sizes of 4, 6, or 8 within each stratum and an allocation ratio of 1:1. A statistician not involved with the research oversaw this procedure to ensure accuracy and blinding of the research team. Researchers and statisticians involved in the data analysis were blind to the allocation of participants until after data analysis was completed. It was not possible to blind participants to the study arm to which they were assigned as the study information stated that they would be asked to look for services either through usual methods or a Web-based program.

## Data Monitoring and Use

Regular monitoring of survey data on the QuON database and tracking data on the *Link* website was conducted by the researchers by reviewing the tracking logs to ensure that data were being recorded.

## Statistical Analysis

Stata version 13.1 [39] was used for all analyses that used an intention-to-treat approach [40]. Descriptive statistics were used to compare participant baseline characteristics, baseline outcome measures, and health service use between the study arms. Help-seeking strategies used postrandomization and responses to the satisfaction with search strategies (dichotomized according to whether they responded as *Strongly agree/Agree* or *not*) were summarized using counts and percentages by study arm for each follow-up time.

Linear mixed-effects models with random intercepts were used to estimate differences in mean outcome between the study arms at each time point using restricted maximum likelihood estimation. Individual participant data were treated as random effects and an unstructured correlation structure was used to account for the repeated measures. All regression analyses (except K10 score) included randomization stratification factors of gender (male and female) and baseline K10, dichotomized as high (K10 >20) and low/moderate (K10 ≤20) probability of mental disorder and time of follow-up (baseline, immediate, 3 months, and 6 months) as fixed effects. An interaction term between the study arm and follow-up time was also included, except at baseline where the study arm means were constrained to be equal.

We were unable to fit a linear mixed-effects regression model for the PA and NA scores at 2 weeks (immediate) as they were correlated with their respective scores at baseline. Thus, for these 2 outcomes at 2 weeks, we used linear regression to estimate the mean differences in the outcome between study arms, with adjustments for gender and baseline K10 dichotomized score. In a secondary analysis, estimates for all outcomes were also adjusted by whether participants had searched the Web for mental health services in the 2 weeks (yes/no) before commencement of the study. Goodness of fit of the models were assessed using residual plots.

Under the fitted linear mixed-effects model, missing data were assumed to be missing at random. A sensitivity analysis was performed using a pattern-mixture model to assess the robustness of this assumption for the PANAS (details provided in Multimedia Appendix 3).

# Results

## Overview

Participant flow through the study is shown in Figure 1. The *Link* study website was visited by 7073 people. Of these, 658 (653/7073, 9.3%) met the eligibility criteria and provided consent. Of those consenting, 481 (481/653, 73%) participants completed the baseline survey with 68 (68/481,14.1%) discontinuing at this point, leaving 413 (413/481, 85.9%) participants for randomization. Attrition rates over time were similar between the 2 arms. Characteristics between young people who withdrew and those who completed the study were similar, with the mean age of participants at baseline being 20.7 (SD 2.3) and 21.3 (SD 2.1) in the intervention and control arms, respectively (0 missing responses in both arms). Results are presented in Multimedia Appendix 4.

Baseline characteristics of participants are summarized in Table 1. The mean age of participants was 20.1 (SD 2.3) and 21.3 (SD 2.4) in the intervention and control arms, respectively (0 missing responses in both arms). Over 80% of the participants were female and 14% from non-English speaking backgrounds. In total, 37% (148/405) of participants reported moderate-to-severe mental health ratings and 68% (278/411) reported 2 or more psychological issues. Baseline characteristics were similar in both arms. Health service use was also similar (Table 2) except that a larger proportion of intervention participants (38.5%) had searched the Web for mental health services in the previous 2 weeks compared with control participants (26.0%).

## Outcomes

### *Primary Outcome*

There was no evidence to support a difference between arms for mean PA at any of the follow-up time points postintervention (Table 3). However, Figure 2 shows that compared with mean baseline PA score, both arms showed approximately 30% improvement at 3 months' follow-up.

**Figure 1.** Trial flow diagram. Nonresponders were participants who did not complete the remaining surveys (note: the denominator used for the percentages was the number of participants allocated to the intervention arm (n=205) and the control arm (n=208), respectively).

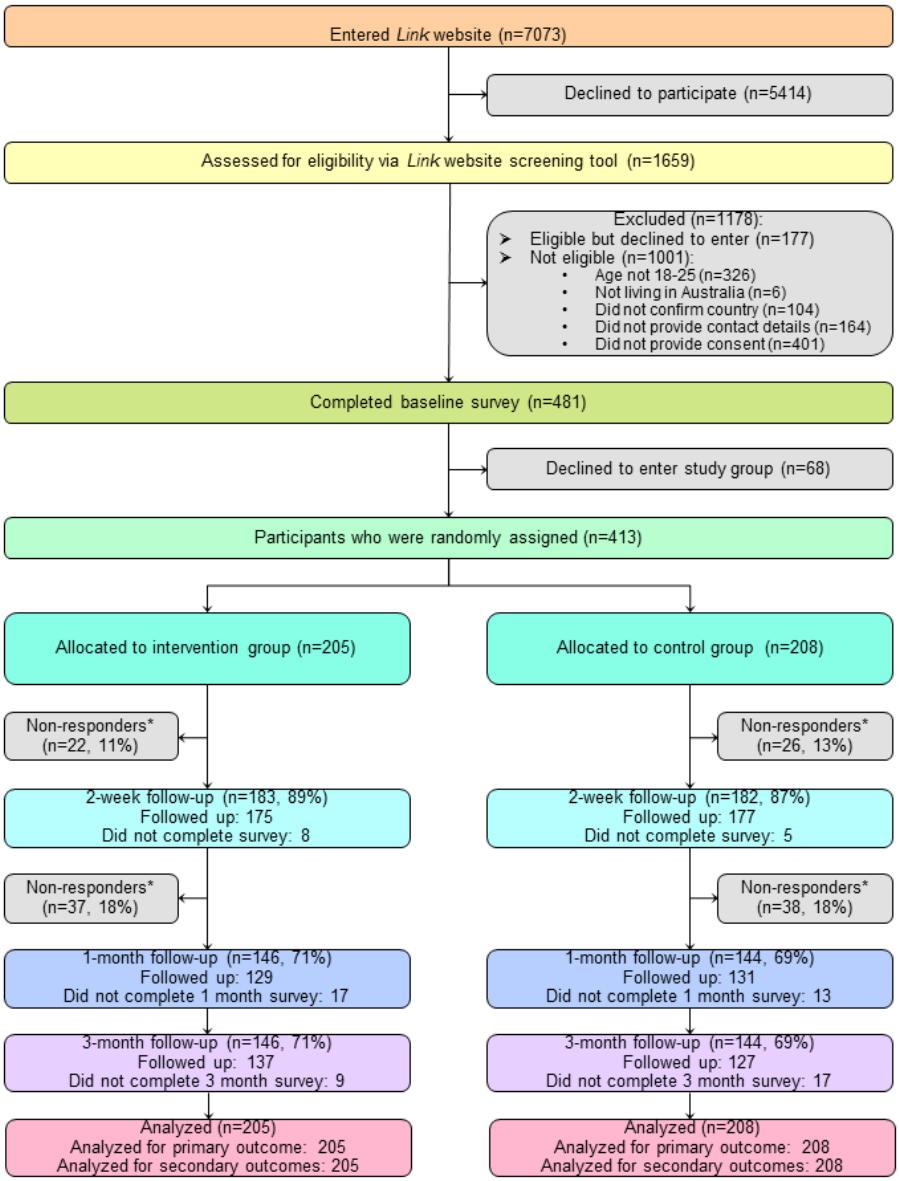


**Table 1.** Participant characteristics by intervention and control arms at baseline (percentages may not sum to 100% because of rounding and totals may vary because of missing responses; counts and percentages presented unless otherwise stated).

| Participant characteristic | *Link* (n=205) | | Control (n=208) | |
|---|---|---|---|---|
| | Value, n (%) | Value of missing responses[a], n (%) | Value, n (%) | Value of missing responses[a], n (%) |
| Female | 171 (83.4) | 0 (0) | 173 (83.2) | 0 (0) |
| Neither working nor studying | 14 (7.9) | 28 (13.7) | 16 (9.0) | 28 (13.5) |
| Socioeconomic advantage[b] | 92 (44.9) | 65 (31.7) | 102 (49.0) | 68 (32.7) |
| Rural[a] | 52 (37.1) | 65 (31.7) | 43 (30.5) | 67 (32.2) |
| English not spoken at home | 32 (15.6) | 0 (0) | 25 (12.0) | 0 (0) |
| Aboriginal or Torres Strait Islander | 4 (2.0) | 4 (2.0) | 6 (3.0) | 5 (2.4) |
| **Highest education level** | | 1 (0.5) | | 0 (0) |
| Did not complete secondary school | 10 (4.9) | — | 14 (6.8) | — |
| Completed/partially completed years 11/12 | 104 (51.0) | —[c] | 99 (47.6) | — |
| Certificate or diploma | 47 (23.0) | — | 48 (23.1) | — |
| Undergraduate degree | 37 (18.1) | — | 41 (19.7) | — |
| Post graduate degree, masters, or PhD | 6 (2.9) | — | 6 (2.9) | — |
| **Mental health rating (K10)** | | 6 (2.9) | | 2 (1.0) |
| No illness/problems | 21 (10.6) | — | 26 (12.6) | — |
| Some symptoms but no disease | 68 (34.2) | — | 60 (29.1) | — |
| Minor illness | 34 (17.1) | — | 48 (23.3) | — |
| Moderate illness | 61 (30.7) | — | 57 (27.7) | — |
| Severe illness | 15 (7.5) | — | 15 (7.3) | — |
| **Self-reported issues[d]** | — | 1 (0.5) | — | 1 (0.5) |
| **Number of issues reported** | | | | |
| None | 22 (10.8) | — | 16 (6.3) | — |
| One | 40 (19.6) | — | 58 (28.0) | — |
| Two or more | 142 (69.6) | — | 136 (65.8) | — |
| **Issue reported by participants[d]** | | | | |
| Often stressed, worried, or down | 162 (79.4) | — | 165 (79.7) | — |
| Often stressing about body, food, or exercise | 104 (51.0) | — | 123 (59.4) | — |
| Worried about my drug or alcohol use | 16 (7.8) | — | 12 (5.8) | — |
| Harming myself | 9 (4.4) | — | 16 (7.7) | — |
| Thinking about ending my life | 23 (11.3) | — | 26 (12.6) | — |
| Being bullied on the Web, school, or work | 4 (2.0) | — | 5 (2.4) | — |
| Having problems with people close to me | 66 (32.4) | — | 57 (27.5) | — |
| **Primary and secondary outcomes** | | 0 (0) | | 0 (0) |
| Positive affect, mean (SD) | 22.9 (8.3) | — | 23.1 (7.8) | — |
| Negative affect, mean (SD) | 20.1 (7.8) | — | 20.8 (9.3) | — |
| Psychological distress (K10), mean (SD) | 27.9 (9.2) | — | 27.7 (9.5) | — |
| Barriers to Seeking Help, mean (SD) | 37.6 (9.6) | — | 37.7 (9.0) | — |

[a]Number of missing responses presented as count and percentage of total allocated to the intervention arm (n=205) and control arm (n=208), respectively.

[b]Index of Relative Socio-Economic Advantage and Disadvantage Australian Bureau of Statistics.

[c]Not applicable.

[d]Subcategories are not mutually exclusive.

**Table 2.** Health service use by the intervention and control arms at baseline (percentages may not sum to 100% because of rounding).

| Health service use | *Link* (n=205), n (%) | Control (n=208), n (%) |
|---|---|---|
| **Health services type/treatments last 6 months** [a] | | |
| GP[b] | 135 (65.9) | 128 (61.5) |
| Psychologist | 47 (22.9) | 56 (26.9) |
| Psychiatrist | 18 (8.8) | 27 (13.0) |
| Headspace service (GP, psychologist, counsellor) | 23 (11.2) | 22 (10.6) |
| Other | 16 (7.8) | 12 (5.8) |
| **Use of health services/treatments in last 6 months combinations (mutually exclusive)** | | |
| Not using any services | 59 (28.8) | 60 (28.9) |
| GP only | 72 (35.1) | 68 (32.7) |
| GP and psychologist | 23 (11.2) | 29 (13.9) |
| GP and psychiatrist | 3 (1.5) | 4 (1.9) |
| GP and headspace | 10 (4.9) | 1 (1.0) |
| GP and 1 other service | 6 (2.9) | 4 (1.9) |
| GP and 2 services | 14 (6.8) | 14 (6.7) |
| GP and 3 or more services | 7 (3.4) | 7 (3.4) |
| 1 service (not GP) | 11 (5.4) | 13 (6.3) |
| 2 or more services (not GP) | 0 (0) | 7 (3.4) |
| Web-based mental health search, last 2 weeks | 79 (38.5) | 54 (26.0) |

[a]Subcategories not mutually exclusive.

[b]GP: general practitioner.

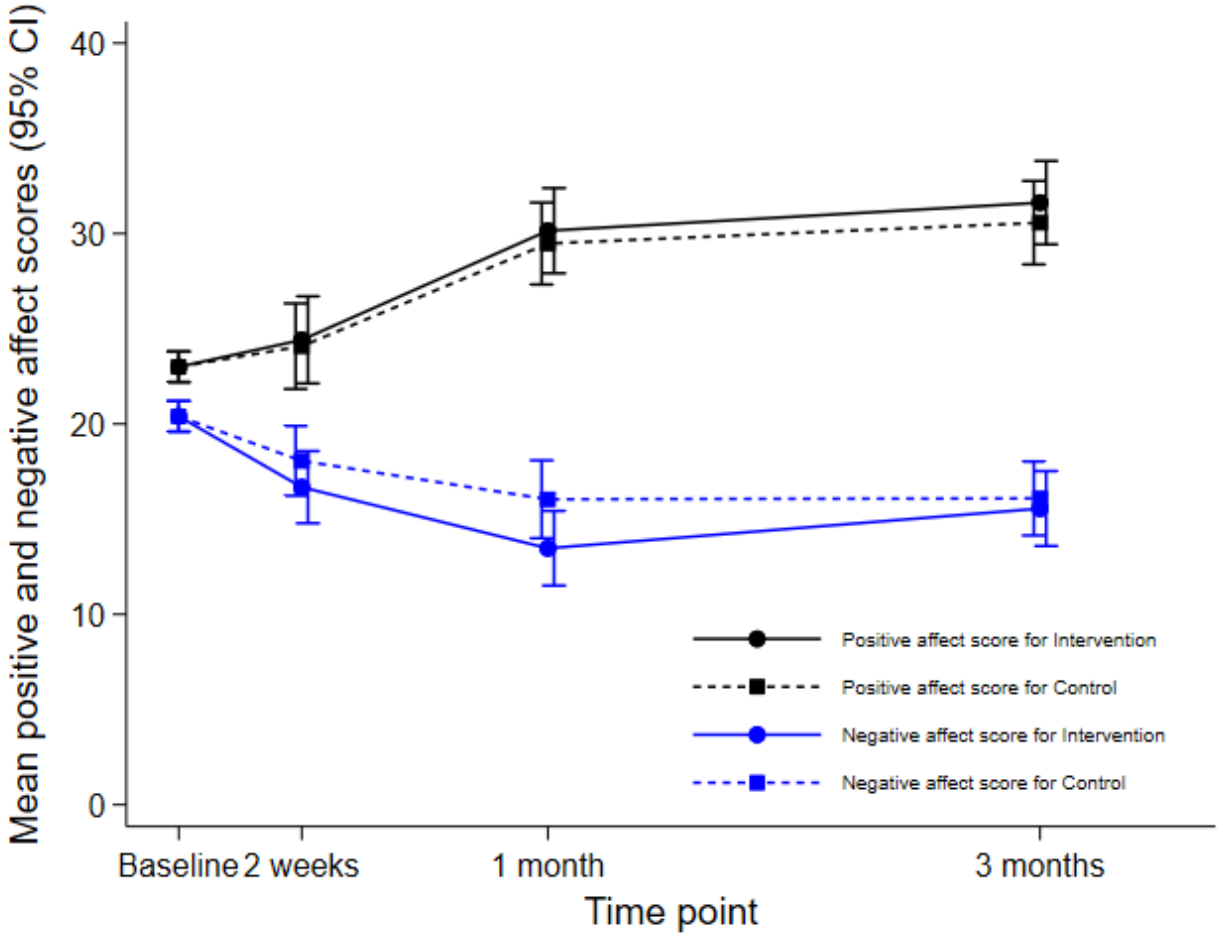
**Table 3.** Estimated means and between-arm differences on primary and secondary outcomes at each follow-up time (N=413). Estimated using linear mixed-effects regression, except for outcomes PA and NA immediately postintervention that were estimated using linear regression. All models were adjusted by gender, K10, and whether participants had searched for Web-based mental health services in the last 2 weeks. Estimates using model with no adjustment for Web-based health services search were similar (not shown).

| Outcome | *Link*, n=205 | | Control, n=208 | | Difference | 95% CI | *P* value |
|---|---|---|---|---|---|---|---|
| | Mean | 95% CI | Mean | 95% CI | | | |
| **Positive affect** | | | | | | | |
| Baseline[a] | 23.0 | 22.2 to 23.8 | 23.0 | 22.2 to 23.8 | —[b] | — | — |
| Immediate | 24.4 | 22.1 to 26.7 | 24.1 | 21.8 to 26.3 | 0.3 | −1.1 to 1.8 | .65 |
| 1 month | 30.2 | 27.9 to 32.4 | 29.5 | 27.3 to 31.6 | 0.7 | −1.0 to 2.4 | .44 |
| 3 months | 31.6 | 29.4 to 33.8 | 30.6 | 28.4 to 32.8 | 1.0 | −0.7 to 2.8 | .24 |
| **Negative affect** | | | | | | | |
| Baseline[a] | 20.4 | 19.6 to 21.3 | 20.4 | 19.6 to 21.3 | — | — | — |
| Immediate | 16.7 | 14.8 to 18.6 | 18.1 | 16.2 to 19.9 | −1.4 | −2.5 to −0.2 | .02 |
| 1 month | 13.5 | 11.5 to 15.4 | 16.0 | 14.0 to 18.1 | −2.6 | −4.1 to −1.1 | .001 |
| 3 months | 15.6 | 13.6 to 17.5 | 16.1 | 14.1 to 18.0 | −0.5 | −2.0 to 1.0 | .49 |
| **Psychological distress (K10)** | | | | | | | |
| Baseline[a] | 26.2 | 24.1 to 28.3 | 26.2 | 24.1 to 28.3 | — | — | — |
| 1 month | 24.2 | 22.0 to 26.5 | 25.2 | 22.9 to 27.4 | −0.9 | −2.4 to 0.6 | .23 |
| 3 months | 23.4 | 21.1 to 25.6 | 24.4 | 22.1 to 26.6 | −1.0 | −2.5 to 0.6 | .21 |
| **Barriers to seeking help** | | | | | | | |
| Baseline[a] | 34.9 | 32.7 to 37.2 | 34.9 | 32.7 to 37.2 | — | — | — |
| 1 month | 35.4 | 33.0 to 37.9 | 35.0 | 32.6 to 37.5 | 0.4 | −1.3 to 2.0 | .65 |
| 3 months | 33.8 | 31.4 to 36.3 | 34.6 | 32.1 to 37.0 | −0.8 | −2.5 to 1.0 | .41 |

[a]Estimated mean (95% CI) of baseline outcome for the two study arms are the same because they were constrained to be equal in the mixed-effects model.

[b]Not applicable.

**Figure 2.** Estimated mean positive and negative affect scores at baseline, immediately postintervention, 1 month, and 3 months for intervention and control arms.




### *Secondary Outcomes*

There was evidence to support a reduction in the mean NA for the intervention arm compared with the control arm at the immediate and 1-month follow-up time points (Table 3). However, the intervention effect diminished at 3-month follow-up. Sensitivity analyses for PA and NA scores showed that the findings are unlikely to change when the departures from missing at random assumption are assumed to occur in the same way in both study arms. Study conclusions could change if departures from the missing at random assumption differed in the 2 study arms, but we considered this an unlikely scenario as the participants with missing data were similar in the 2 study arms (see Multimedia Appendix 3 for details).

Mean scores on the K10 and the BASH remained relatively stable for the duration of the study for both arms and there was no evidence to support between-arm differences at any time point. There was, however, weak evidence to support that there was greater intention to seek general help at 3-month in the intervention arm compared with the control arm (Difference −0.22, 95% CI −0.44 to −0.009; Table 4). There was no difference between *Link* and the young people in the control group in how likely they were to *not seek help from anyone*; however, at 1 and 3 months, they were, on average, less likely to *not seek help from anybody* compared with the baseline responses.

**Table 4.** Estimated means and between-arm differences and respective 95% CI on the general help seeking questionnaire at baseline, 1 month, and 3 months (N=413; estimated using linear mixed-effects regression adjusted for gender, K10, and whether participants had searched for Web-based mental health services in the last 2 weeks).

| Help-seeking behavior | *Link*, (n=205) | | Control, (n=208) | | Difference | 95% CI | *P* value |
|---|---|---|---|---|---|---|---|
| | Mean | 95% CI | Mean | 95% CI | | | |
| **Total score** | | | | | | | |
| Baseline[a] | 3.7 | 3.4 to 3.9 | 3.7 | 3.4 to 3.9 | —[b] | — | — |
| 1 month | 3.4 | 3.1 to 3.7 | 3.4 | 3.2 to 3.7 | 0.046 | −0.17 to 0.26 | .67 |
| 3 months | 3.6 | 3.4 to 3.9 | 3.4 | 3.1 to 3.7 | −0.22 | −0.44 to −0.009 | .04 |
| **Informal** | | | | | | | |
| Baselinea[a] | 4.1 | 3.8 to 4.4 | 4.1 | 3.8 to 4.4 | — | — | — |
| 1 month | 4 | 3.6 to 4.4 | 4.1 | 3.8 to 4.5 | 0.12 | −0.19 to 0.44 | .44 |
| 3 months | 4.3 | 4.0 to 4.7 | 4.1 | 3.7 to 4.4 | −0.27 | −0.60 to 0.052 | .1 |
| **Formal** | | | | | | | |
| Baseline[a] | 3.3 | 3.0 to 3.7 | 3.3 | 3.0 to 3.7 | — | — | — |
| 1 month | 2.8 | 2.4 to 3.1 | 2.8 | 2.4 to 3.1 | 0.0042 | −0.25 to 0.26 | .97 |
| 3 months | 3 | 2.6 to 3.3 | 2.8 | 2.8 to 3.2 | −0.20 | −0.45 to 0.054 | .12 |
| **Web-based/phone** | | | | | | | |
| Baseline[a] | 3.7 | 3.4 to 4.0 | 3.7 | 3.4 to 4.0 | — | — | — |
| 1 month | 3.7 | 3.3 to 4.1 | 3.7 | 3.6 to 4.1 | 0.031 | −0.29 to 0.35 | .85 |
| 3 months | 3.9 | 3.5 to 4.3 | 3.7 | 3.3 to 4.1 | −0.21 | −0.54 to 0.13 | .23 |
| **None (do not seek help from anyone)** | | | | | | | |
| Baseline[a] | 3.3 | 2.9 to 3.8 | 3.3 | 2.9 to 3.8 | — | — | — |
| 1 month | 2.2 | 1.7 to 2.7 | 2.4 | 1.9 to 2.9 | 0.17 | -0.26 to 0.60 | .45 |
| 3 months | 2.2 | 1.8 to 2.7 | 2.2 | 1.7 to 2.7 | -0.047 | -0.45 to 0.36 | .82 |

[a]Estimated mean (95% CI) of baseline outcome for the two study arms are the same because they were constrained to be equal in the mixed-effects model.

[b]Not applicable.

### *Link* Use and Satisfaction

Of the 205 people randomized to the intervention arm, 160 (160/205, 78%) visited the *Link* website and 159 (159/160, 99%) moved beyond the first page. At all 3 follow-up time points, a greater proportion of intervention participants reported the information they found with their respective search strategies helpful and felt surer of themselves compared with the control arm (Table 5). At 1 and 3 months, a greater proportion of participants in the intervention arm reported they had found treatment for their problems compared with the control arm participants. Young people in the intervention arm at the immediate and 3-month time points were more likely to feel that they had been guided to an appropriate service, although this was not evident at 1-month.

**Table 5.** Satisfaction with the search strategies used by study arm for each follow-up time point (count and percentage of participants in the intervention, n=205, and control arm, n=208, who Strongly agreed or agreed to each item).

| Benefit of search strategy | Immediate | | 1 month | | 3 months | |
|---|---|---|---|---|---|---|
| | *Link*, n (%) | Control, n (%) | *Link*, n (%) | Control, n (%) | *Link*, n (%) | Control, n (%) |
| Search helped my mental health decisions | 90 (43.9) | 101 (48.6) | 59 (28.8) | 54 (26.0) | 82 (40.0) | 78 (37.5) |
| I found helpful information | 125 (61.0) | 105 (50.5) | 71 (34.6) | 60 (28.8) | 91 (44.4) | 69 (33.2) |
| I understood the information | 140 (68.3) | 130 (62.5) | 84 (41.0) | 90 (43.3) | 97 (47.3) | 89 (42.8) |
| My questions were answered | 91 (44.4) | 79 (38.0) | 40 (19.5) | 42 (20.2) | 59 (28.8) | 58 (27.9) |
| I found treatment for problems | 60 (29.3) | 58 (27.9) | 36 (17.6) | 30 (14.4) | 60 (29.3) | 49 (23.6) |
| My symptoms/problems improved | 52 (25.4) | 66 (31.7) | 39 (19.0) | 45 (21.6) | 70 (34.1) | 62 (29.8) |
| I was guided to appropriate services | 98 (47.8) | 87 (41.8) | 43 (21.0) | 48 (23.1) | 77 (37.6) | 57 (27.4) |
| I felt surer of myself | 81 (39.5) | 67 (32.2) | 55 (26.8) | 46 (22.1) | 83 (40.5) | 64 (30.8) |
| My mood was more positive | 81 (39.5) | 78 (37.5) | 52 (25.4) | 54 (26.0) | 83 (40.5) | 77 (37.0) |
| Searching helped me understand my problems better | 88 (42.9) | 98 (47.1) | 65 (31.7) | 63 (30.3) | 87 (42.4) | 68 (32.7) |

### Help-Seeking Strategy After Randomization

Help-seeking results were difficult to interpret because of missing responses to these questions (percentage with missing responses: 15% at immediate time point, 34% at 1-month, and 33% at 3-month follow-up; Multimedia Appendix 5). Of those who responded, the proportion of young people who reported they did not need help across time points was less than 3%. The majority of the participants reported using at least 1 search strategy, with a greater percentage in the intervention arm compared with the control arm at each follow-up time (Multimedia Appendix 5; Table 1). Of those who did seek help, at the immediate time point (up to 2 weeks postrandomization), more young people in the intervention arm used one or more websites or Web-based services to seek help, compared with the control arm (33.5% vs 15.1%), and fewer of the intervention arm used formal (19.8% vs 35.5%) or informal (18.0% vs 27.1%) sources of support (Multimedia Appendix 5; Table 2). Numbers of young people seeking help via phone lines were small in both the arms across all time points. Help-seeking appeared less frequent at both 1- and 3-month follow-up points than immediately after randomization for young people in both the study arms, with young people from the intervention arm more likely to use Web-based sources of help (website/Web-based service and/or other Web-based method) and young people from the control arm more likely to seek help from formal and informal sources of support.

## Discussion

### Principal Findings

This study tested whether *Link*, a website designed to guide young people to appropriate Web-based and computer-based sources of mental health information and care, was effective in increasing psychological well-being and reducing barriers to seeking help for mental health problems. Our results showed that *Link* did not increase PA immediately post intervention compared with usual search strategies. Instead, we found that young people using *Link* and those using their usual search strategies had a similar increase in PA of approximately 30% between baseline and 3 months.

There was, however, a greater reduction in mean NA immediately postintervention and at 1-month for the young people using *Link* compared with the usual search strategies with confidence intervals at 1 month including the hypothesized clinically important value of 2.7, indicating that *Link* did have a short-term benefit in reducing NA. The difference between the arms diminished at 3 months. NA reflects self-reported stress, poor coping, and frequency of negative events; low scores for NA indicate a state of calmness and serenity [27]. The results of this study suggest that NA might be a better measure of immediate benefit and an indicator of any harms of using an intervention to facilitate help-seeking.

There was no difference in general psychological distress between the two arms. Instead, mean K10 scores remained high (ie, >23) for both the arms over time. High levels of distress reported at study entry may indicate that young people with mental health problems are interested in Web-based tools to facilitate help-seeking. Improvement in K10 score might only be expected once the young person was in a therapeutic intervention rather than in the seeking help phase. Higher satisfaction scores among the intervention arm suggests that young people found a youth-focused tool, such as *Link*, to be acceptable.

There was no change in either arm for participants' perceptions of the barriers or intentions to seek help for mental health problems. However, both arms ranked that they were less likely to not seek help from anybody at 1 and 3 months postintervention than they were at baseline.

Importantly, the economic evaluation of *Link* found that there were quality of life improvements and lower costs in the *Link* arm compared with the control arms [30]. From an economic viewpoint *Link* may be a more efficient use of resources.

### Comparisons With Previous Studies

Recent studies confirm that young people with higher mental health needs are prepared to engage with Web-based strategies

to seek help [41,42]. Other digital mediums have been investigated for their potential to address the health care needs of young people. Social media supported interventions have been shown to support weight loss in overweight adolescents [43] and smoking cessation in young adults [44]. A UK study of young people with chronic health conditions found that digital communication was valued by the young people and can assist re-engagement with their clinical specialist teams [45]. Digital storytelling may also have merit as an engagement strategy for health services to use with young people [46]. A recently published Australian study showed that marginalized young people used technology to explore options for their health care and recognized the potential of technology in making the health care system easier for them to navigate and engage with [47]. The value of a tool such as *Link*, specifically designed to promote help-seeking, is not only in facilitating awareness of the types of reputable services available to adolescents when they do need to access them but also in providing information on other issues known to cause access barriers, such as costs, what to expect when visiting the service, and confidentiality, alongside peer stories about the benefits of health care access and tips for well-being.

A study on young people accessing a Web-based mental health support service in Australia (eheadspace) found that the youth had high to very high levels of psychological distress but were at an earlier stage of illness than those presenting to their face-to-face service, which might explain our finding that young people using *Link* were less likely than the control arm to prefer formal sources of mental health care [48]. The potential utility of technology, such as social media, to address health issues affecting young people [43,44] needs to be balanced against other recent studies on potential risks of the internet for adolescents with mental health disorders [49]. The ethical implications of using digital technologies in clinical interactions with young people are only beginning to be explored [50] and include such considerations as how best to promote autonomy in patient's control over their health care versus dependence on the technology and maintaining confidentiality of interactions. A program such as *Link* is not a clinical tool but a health service navigation tool and the users remain anonymous. However, to increase the chance that young people in need find the tool at a time that would most benefit them, nonclinical Web-based mental health information services might embed a pathway to *Link* from their information pages on mental health issues, so that users can be directed to a range of support options based on their level of distress and support preferences. Furthermore, social media could also be engineered to recognize postings on emotional distress from young people and feed a posting about *Link* to these individuals; this type of intelligence could capture those who would otherwise not proactively seek help. Attitudes to this level of social media artificial intelligence have not yet, to our knowledge, been explored nor has the effectiveness of this approach in promoting mental health help-seeking.

The results of our final outcome trial are timely, as experts urge for consideration of robust policy frameworks to ensure Web-based supports for the mental health of young people are effective, appropriate, and engaging [51]. Our work is timely also because of the pending results of a trial of a similar intervention in Canada, ThoughtSpot, co-designed with young people to enable postsecondary school young people to access mental health support services [52,53]. Given the paucity of evidence for Web-based help-seeking interventions [16], the results of our trial and the ThoughtSpot trial will be important to compare in building our understanding of mental health help-seeking interventions and the degree to which they are effective and efficient.

## Strengths and Limitations

Strengths of the trial include increased precision of estimates as the retention was at least 70% at 3-month follow-up, which was higher than what had been assumed for the sample size estimation. There were also similar withdrawal rates between arms and comparable characteristics between those who withdrew and those who completed the study. Intervention and control arms were well balanced with regard to baseline characteristics and outcome measures were stratified by factors assumed to be associated with the outcome and intervention (gender, recent Web-based mental health searching, and K10 score), demonstrating good internal validity.

A limitation of the study is that the primary outcome, positive PANAS score, was self-reported. To respond accurately, participants must interpret the questions correctly, be aware of their emotional state and feelings, and not be influenced by social desirability bias. Participants were also not blind to whether they received the intervention or not, which might have led to response bias. In addition, as our trial recruited on the Web, the control arm condition of prompting participants to use usual help-seeking strategies might have meant that even control participants used Web-based modalities to seek help, which were encompassing of more conditions than *Link*, a similar issue to what we found in our pilot when we directed control arm participants to Google. This might account for the improvements in PA also seen in the control arm. Although there are more missing values, our data on help-seeking strategies postrandomization (Multimedia Appendix 5) suggest that just under 50% of the control arm seemed to use Web-based sources for help-seeking. Participants in both arms needed to rely on accurate recall when asked about their help-seeking strategies in each follow-up survey; however, recall time periods were short (ie, 2 weeks, 1 month, and 3 months).

The inclusion criteria were broad; however, our findings can only be generalized to young Australians aged 18 to 25 years who use Facebook, Gumtree, and/or Google to search for mental health related services or topics.

## Conclusions

Searching the Web for mental health services and information is common among young people. The process of being prompted to seek mental health information and services appears to improve mood and increase help-seeking intentions among young people, regardless of whether they use a dedicated Web-based youth-focused tool, such as *Link*, or their usual search strategies, which may also include online. However, young people report greater satisfaction using tools designed specifically for them, which may encourage future help-seeking.

The ability of Web-based tools to match mental health need with appropriate care should be explored further.

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## Authors' Contributions

LS and KB conceived of the study and, also with SK, the study design; LS, SK, and KB designed the tool in conjunction with young people and the ReachOut study team and Tigerspike, the digital agency; SK implemented the trial and prepared a preliminary draft of the paper and analysis; ST and PC conducted the statistical analyses, produced the tables and figures, and interpreted the results; LS completed the first draft of the paper and revisions; SD refined the first draft. CM designed the economic evaluation and input into this paper. AD analyzed and reported on help-seeking strategies used postrandomization and tracking of participants through the trial. All authors read each draft and commented and refined the paper for final submission.

## Conflicts of Interest

None declared.

Multimedia Appendix 1
Google and Facebook advertisements.
[PDF File (Adobe PDF File), 113 KB - mental_v6i10e13189_app1.pdf ]

Multimedia Appendix 2
Screenshots showing Link.
[PDF File (Adobe PDF File), 4906 KB - mental_v6i8e13189_app2.pdf ]

Multimedia Appendix 3
Sensitivity analyses for the missing data assumption.
[PDF File (Adobe PDF File), 43 KB - mental_v6i8e13189_app3.pdf ]

Multimedia Appendix 4
Baseline characteristics of participants who withdrew by intervention and control arms.
[PDF File (Adobe PDF File), 103 KB - mental_v6i8e13189_app4.pdf ]

Multimedia Appendix 5
Help-seeking strategies used.
[PDF File (Adobe PDF File), 167 KB - mental_v6i8e13189_app5.pdf ]

Multimedia Appendix 6
CONSORT-EHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 96 KB - mental_v6i10e13189_app6.pdf ]

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## Abbreviations

**BASH:** Barriers to Adolescents Seeking Help
**GHSQ:** General Help-Seeking Questionnaire
**K10:** Kessler psychological distress scale
**NA:** Negative Affect
**PA:** Positive Affect
**PANAS:** Positive and Negative Affect Schedule
**SMS:** Short Message Service

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Original Paper

# A Novel Mobile Tool (Somatomap) to Assess Body Image Perception Pilot Tested With Fashion Models and Nonmodels: Cross-Sectional Study

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## Abstract

**Background:** Distorted perception of one's body and appearance, in general, is a core feature of several psychiatric disorders including anorexia nervosa and body dysmorphic disorder and is operative to varying degrees in nonclinical populations. Yet, body image perception is challenging to assess, given its subjective nature and variety of manifestations. The currently available methods have several limitations including restricted ability to assess perceptions of specific body areas. To address these limitations, we created Somatomap, a mobile tool that enables individuals to visually represent their perception of body-part sizes and shapes as well as areas of body concerns and record the emotional valence of concerns.

**Objective:** This study aimed to develop and pilot test the feasibility of a novel mobile tool for assessing 2D and 3D body image perception.

**Methods:** We developed a mobile 2D tool consisting of a manikin figure on which participants outline areas of body concern and indicate the nature, intensity, and emotional valence of the concern. We also developed a mobile 3D tool consisting of an avatar on which participants select individual body parts and use sliders to manipulate their size and shape. The tool was pilot tested on 103 women: 65 professional fashion models, a group disproportionately exposed to their own visual appearance, and 38 nonmodels from the general population. Acceptability was assessed via a usability rating scale. To identify areas of body concern in 2D, topographical body maps were created by combining assessments across individuals. Statistical body maps of group differences in body concern were subsequently calculated using the formula for proportional z-score. To identify areas of body concern in 3D, participants' subjective estimates from the 3D avatar were compared to corresponding measurements of their actual body parts. Discrepancy scores were calculated based on the difference between the perceived and actual body parts and evaluated using multivariate analysis of covariance.

**Results:** Statistical body maps revealed different areas of body concern between models (more frequently about thighs and buttocks) and nonmodels (more frequently about abdomen/waist). Models were more accurate at estimating their overall body size, whereas nonmodels tended to underestimate the size of individual body parts, showing greater discrepancy scores for bust, biceps, waist, hips, and calves but not shoulders and thighs. Models and nonmodels reported high ease-of-use scores (8.4/10 and 8.5/10, respectively), and the resulting 3D avatar closely resembled their actual body (72.7% and 75.2%, respectively).

**Conclusions:** These pilot results suggest that Somatomap is feasible to use and offers new opportunities for assessment of body image perception in mobile settings. Although further testing is needed to determine the applicability of this approach to other populations, Somatomap provides unique insight into how humans perceive and represent the visual characteristics of their body.

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**KEYWORDS**

body image; body perception; body representation; body image disorder; eating disorder; mobile health; mental health; mobile app; digital health

## Introduction

Accurately perceiving the overall state of the body is a key sensory task necessary for health maintenance in humans [1] and can be subdivided into two domains: (1) interoception, the process by which the brain senses and perceives internal body signals such as the feeling of one's heartbeat, breath, or intestines [2], and (2) exteroception, the process by which the brain senses and perceives external body signals, such as the sight, sound, shape, or texture of an object [3]. Clinicians rely on patients to have an accurate translation from sensation to perception during diagnostic assessment of medical and psychiatric symptoms and treatment selection and delivery. However, in certain cases, perceptual inaccuracy (ie, discrepancies between the person's receipt of body signals and his/her corresponding interpretation) is an important diagnostic characteristic contributing to the expression of mental health disorders, for example, perceived physical flaws in body dysmorphic disorder, body image disturbance in eating disorders, and distressing body sensations in somatic symptom disorders [4]. Adequately characterizing these body misperceptions poses a significant challenge in mental health settings.

Body dissatisfaction, defined as unhappiness with self-perceived flaws in body features, is an especially common issue for women [5], particularly negative body attitudes that are often related to perceptions of the visual appearance of body regions such as the abdomen, hips, and thighs [6]. Self-discrepancy theory, in relation to body dissatisfaction, proposes that negative feelings and thoughts toward oneself stem from disparities between the size/weight/shape of individuals' current versus their ideally desired body figure. Therefore, body dissatisfaction is often measured by the difference between an individual's perceived current body figure and their body figure ideal, utilizing a menu of standardized body silhouettes to choose from. Body dissatisfaction assessed in this way has been shown to be significantly associated with symptoms of eating disorders [7-9] and other psychiatric conditions such as depression [10]. Despite these findings, a failure to identify the specific negative thoughts and feelings associated with body dissatisfaction might result in an incomplete picture of body perception. Additionally, there are non–weight-related body characteristics that are not typically included in standard measurements of body dissatisfaction including perceived abnormalities of excessive sweating, emitted odors, shape of facial features, and skin condition.

Disturbances of body perception often occur in individuals with psychiatric disorders. For instance, individuals with anorexia nervosa tend to overestimate characteristics of certain body areas relative to healthy comparisons [11] and may perceive body parts such as their waist, hips, bust, and face as much larger than they actually are, even when emaciated [12,13]. This form of body image disturbance is a core diagnostic feature of the disorder [4], a significant predictor of relapse [14], and an indicator of poor outcome [14-16]. Misperceptions of appearance are also a core feature of body dysmorphic disorder, a psychiatric condition that affects men and women in nearly equal proportions and commonly co-occurs with anorexia nervosa [4,17-19]. Disturbances in perception of body size and shape in these clinical populations have been associated with specific neurobiological signatures, providing initial insights into the pathophysiology of abnormal body image perception. For example, several studies have linked body image disturbance to abnormal functioning in cortical visual systems in anorexia nervosa and body dysmorphic disorder [20-22]. Moreover, when viewing their own bodies, individuals with anorexia nervosa display abnormal activity in visuospatial processing regions such as the inferior parietal lobule and precuneus [23-27] as well as the occipitotemporal cortex (including extrastriate body area) [28]. When viewing others' bodies, individuals with anorexia nervosa demonstrate increased activation of the superior parietal lobule, inferior and middle frontal gyri, thalamus [24], and amygdala [26]. Weaker connectivity between precuneus and midtemporal regions when viewing others' bodies has also been observed in anorexia nervosa [29]. In addition, weaker connectivity from the left fusiform body area to the left extrastriate body area has been associated with increased body size misjudgment in anorexia nervosa [30]. Thus, in both anorexia nervosa and body dysmorphic disorder, there is evidence of disturbances in extended body processing networks, including visual sensory systems, that may be associated with perceptual abnormalities and contribute to abnormal body perception.

It is less clear if and how nonclinical populations differ in body image perceptions. Discordant body perceptions (eg, body dissatisfaction or seeing one's self as "fat" when slim) have been theorized to be strengthened and intensified for some women by social media and media image exposure [31-33]. Fashion models, and other models, are disproportionately exposed to both social media and media image focus on their own bodies. They are selected for this occupation largely on the basis of their physical appearance, and they regularly receive explicit feedback on the details of their visual appearance. Fashion models also experience frequent measurements of body parameters that can be associated with critiques about their body, both in terms of modifiable characteristics such as weight and body shape and unmodifiable characteristics such as height. It is unclear if membership in this group is associated with

enhanced or altered perceptual accuracy for the human body overall, for specific body areas, and heightened emotional responses to body concerns.

Most current body perception assessments rely on language-based methods such as verbal interviews and questionnaires. Verbal interviews typically involve an in-person discussion with a clinician or researcher, which is time intensive, requires specialized training, and may lack the degree of specificity needed for capturing an accurate snapshot of body-related perceptions or concerns. For example, it can be challenging to describe in words exactly how large one perceives a particular area of their body to be. Questionnaire-based scales measuring body image perceptions typically assess attitudes about the body, both negative [34] and positive [35]. However, there is still a need for body image assessments that include the perceptual details about individual body concerns, emotions, distress, or specific body areas (eg, stomach, thighs, and bust). One way of assessing the perceptual details of body image is to use visually based tools. The most commonly employed methods use still photographs [5] or 2D drawings of a silhouetted figure, for example, the Stunkard Figure Rating Scale [36], which depicts several different-sized versions of a basic body outline. The individual selects the body figure that overall best represents how they perceive their current and ideal body size/shape. Unfortunately, these methods obscure considerable body details, rendering, at best, a gestalt proxy for whole body perception. Computer-based tools have been previously created as an additional or alternative to questionnaires and visually based assessments [37-39], and more recently, have utilized 3D avatars that can be manipulated by individuals [40]. However, these tools in their current format may also have certain limitations, including a reduced ability to manipulate different body areas independently (such as the width or length of body parts) and they may lack assessments of non–size-related perceptual concerns (eg, perspiration, body odor, or a skin condition). In addition, none of the aforementioned tools are deployed on mobile devices, which may be important in facilitating longitudinal, home-based assessment and tracking clinical trajectory [41].

To address existing gaps in the ability to accurately assess body perceptions, we developed Somatomap, a novel mobile tool intended to quantitatively and qualitatively assess different aspects of body image perception in 2D (ie, mapping body concern, types of concern, and emotions associated with concern) and 3D (ie, measuring the degree of disturbance of body image perception for body part sizes and shapes). In this manuscript, we describe the development of this tool for assessing body image perception and results of pilot feasibility and usability testing in female fashion models and in a general population reference sample. Given the greater attention and feedback applied to their own visual body characteristics as a function of their occupation, we hypothesized that fashion models might (1) perceive concerns with areas of the body that distinctly differ from nonmodels, and (2) that they would be more accurate in estimating the size of their body parts and overall body size. Finally, we predicted that the Somatomap tool would be sensitive to detecting both kinds of differences.

## Methods

### Somatomap

We developed Somatomap as a Web-based self-assessment tool for measuring body image perception in 2D and 3D. The 2D assessment displays a picture of an androgynous manikin; the user is asked to imagine this manikin as their own body and draw directly upon it to outline an area where they perceive a body concern (Figure 1). We used an androgynous manikin to obviate the need for spatial normalization or registration when performing statistical comparisons across individuals with different body sizes and shapes (eg, male/female or obese/slender). Users subsequently answer questions detailing specific characteristics of this concern. To capture emotional experiences that are often related to appearance concerns, they provide associated emotion ratings (eg, by selecting face emotion icons with associated labels such as “sad,” “disgusted,” “ok/fine,” “other [please be specific]”). Visual icons/emoticons accompany written labels to help illustrate the different types of perceptual and affective experiences a user might experience. The process is repeated separately for each concern. The 3D assessment displays a virtual avatar in 3D, enabling participants to rotate and view it from different angles; the user is asked to imagine the avatar as their own body and to adjust the skin and hair color as well as the size of individual body parts to reflect the perceived characteristics of their current body (Figure 2). The 3D avatars were created with 3D scans from a male and a female human volunteer using a 3D camera (Eva Lite Scanner, Artec Inc, Santa Clara, CA) and 3D software (Studio 11 Professional, Artec Inc) to create a male and female 3D mesh. These 3D meshes were imported individually into modeling software (Maya, Autodesk Inc, San Rafael, CA) to add modification ability. Within Maya, each 3D scan was cleaned into a fully smoothed mesh. The faces were altered for anonymity and to facilitate identification with a generic avatar. We selected 13 different regions of the body to modify independently: neck, shoulders, torso, bust, bicep, forearm, hands, hips, waist, buttocks, thighs, calves, and feet. Each region was modified into a maximum and minimum version using the blend shape functionality of the modeling software. The resulting Unity 3D Web plugin was uploaded into the Chorus platform. Using the Web-based display, participants could view the avatar from all angles, manually select each body area, and then use a horizontal slider control to adjust the size of the area (moving between two extreme body sizes). Importantly, each body area could be adjusted independent of the others, allowing for a variety of combinations.

Somatomap was built on Chorus, a HIPAA (Health Insurance Portability and Accountability Act)-compliant visual development platform for creating mobile Web, text-messaging, and interactive voice apps [42]. Chorus is a hosted service provided through the University of California Los Angeles [42]. Chorus apps including Somatomap are compatible with mobile phones, tablets, and desktops that have access to major Web browsers (such as Google Chrome, Apple Safari, and Firefox). This mobile compatibility enables users to complete assessments at home with devices they already have. All data are encrypted between devices and the centralized server.

**Figure 1.** Somatomap 2D. Step-by-step screenshots of avatars and a subsample of possible body concerns and emotion ratings that can be endorsed for the 2D assessment. Participants first indicate one area of body concern by outlining it on the avatar (top left and top right), with the ability to zoom in by double tapping the figure to indicate body concerns for smaller areas or areas with more detail (top right). They are then asked to select the type of concerns pertaining to the body area (bottom left shows a subsample with several concerns selected; users can also enter a unique concern if theirs is not listed). Finally, they are asked to choose the feelings pertaining to the area of body concern (bottom right shows a subsample) or enter their own feelings. Participants then repeat this process for each body concern. The top right depicts three different examples of body concern outlines.

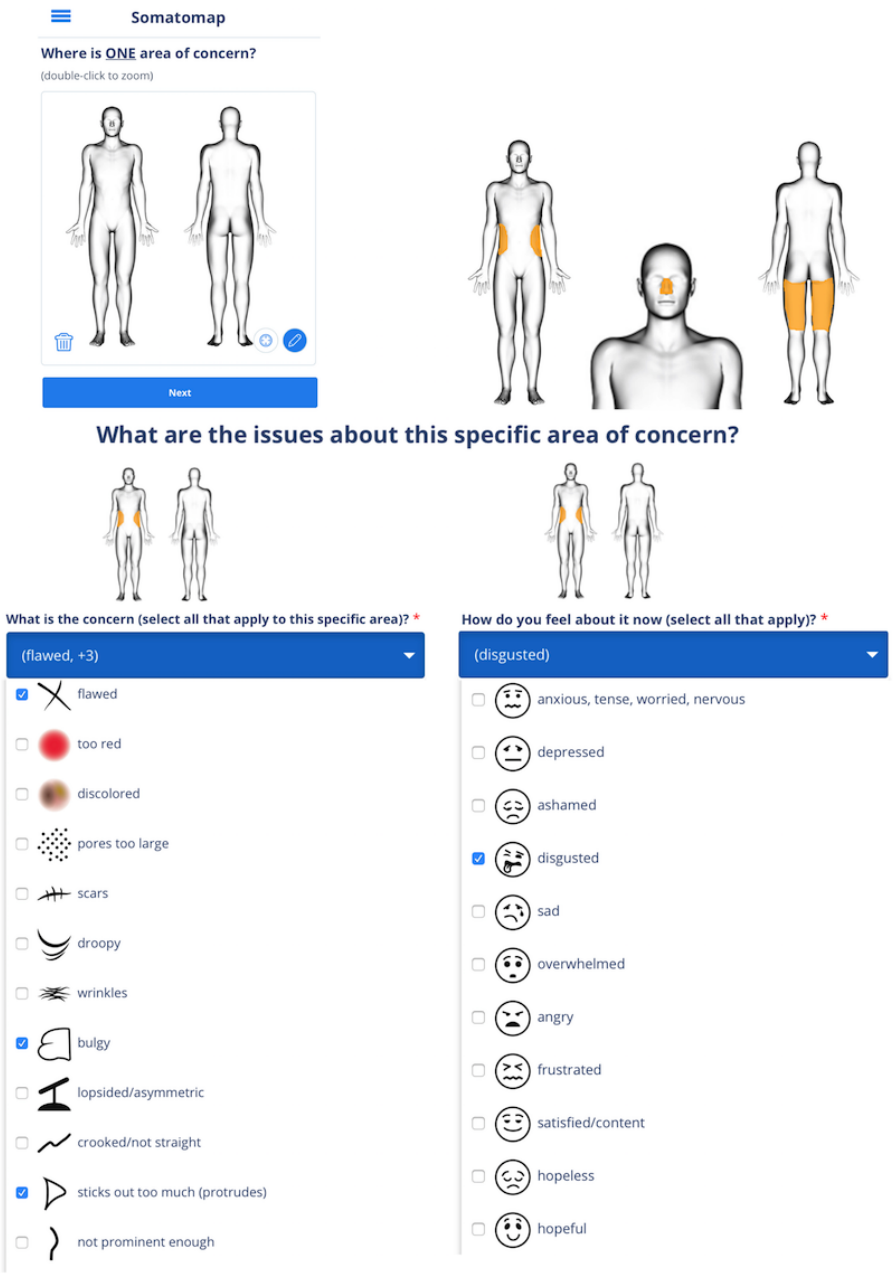
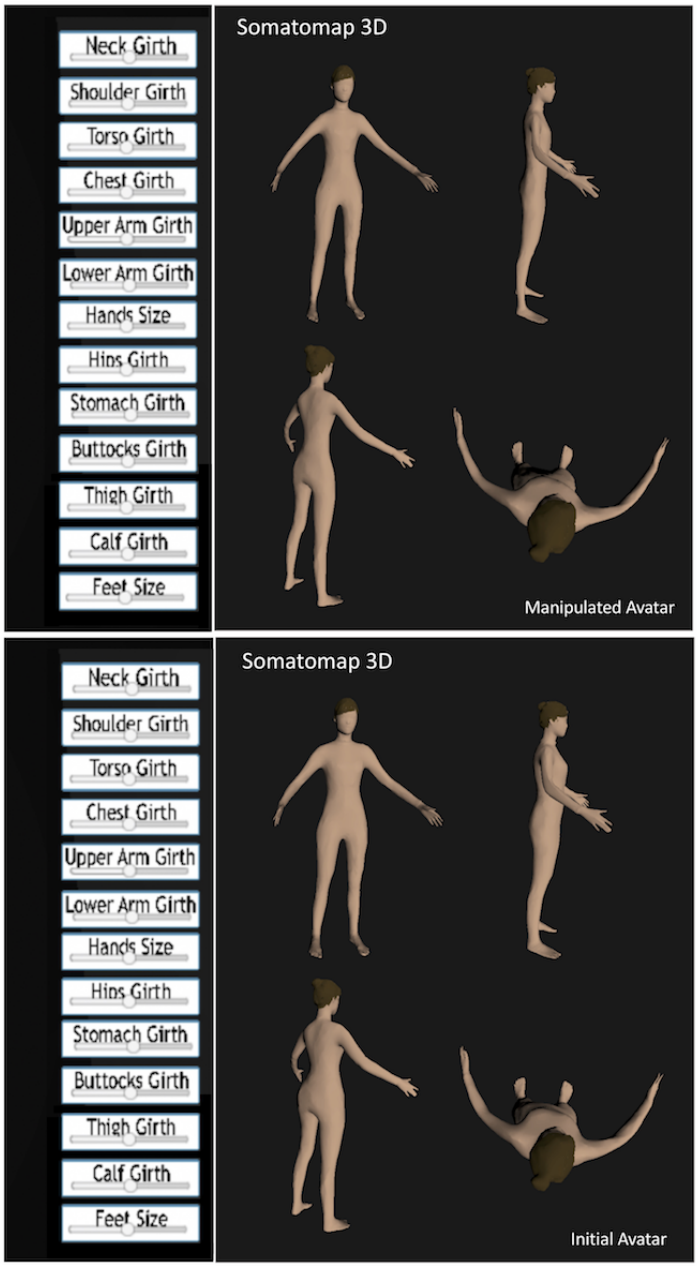


**Figure 2.** Somatomap 3D. Step-by-step screenshots of avatars for the 3D assessment. Bottom: 3D avatar shown at the start of the assessment. Participants were instructed as follows: "Please use the sliders at the left to create what your body looks like today." Participants could rotate the avatar to view it from multiple angles as they manipulated the sliders (screenshots show examples of different orientations). Only a single avatar is visible at any given time. Top: Example of a final avatar after manipulating the sliders (shown from multiple angles matching the original avatar).




## Participants

We recruited a sample of 65 female fashion models (age=23.4 [SD 5.5] years) from professional modeling agencies in the United Kingdom. Models were initially recruited telephonically and asked to visit their agency; all who were contacted came in. We also recruited a sample of nonmodels (n=38; age=25.4 [SD5.2] years) from the general UK population through flyers and social media. Neither group was informed about the study hypotheses in advance of the study, and none declined to participate after arriving for the consenting procedure and evaluation in either group.

## Data Collection

The study was approved by the School of Psychology Ethics Review Board at the University of Nottingham. Testing sessions occurred for fashion models at their modeling agencies and for nonmodels at the University of Nottingham. Prior to the experiment, each participant provided written informed consent. Participants were seated at a laptop computer to complete demographic questions adapted from the PhenX toolkit [43], and three assessments (Somatomap 2D, Somatomap 3D, and 3D usability assessment) were presented on a laptop using the Chorus [42] platform. The order in which Somatomap 2D and Somatomap 3D were presented was counterbalanced.

In Somatomap 2D, participants were asked to outline a specific area of body concern on a 2D human manikin using a laptop

trackpad (13-inch MacBook Air, Apple Inc). Once the outline is drawn, the interior automatically fills in, resulting in an "area of concern." This procedure gave participants maximum flexibility to trace any body region they chose, with pixel-level specificity. They then entered details about their concern by selecting each type of concern and the emotions surrounding the concern and used a slider to indicate the magnitude of the body concern. If they had more than one body concern, they repeated this procedure for each individual area of concern.

In Somatomap 3D, participants could rotate a 3D human avatar in multiple directions and adjust body areas independent from one another. Participants were instructed as follows: "Please use the sliders at the left to create what your body looks like today." The 3D usability assessment was an online questionnaire asking about their experience of using the app. Questions asked how difficult/easy and frustrating/enjoyable the tool was to use and assessed the degree of identification with the original avatar (before moving the sliders) and the final avatar (after completing moving the sliders).

After completing all body image perception ratings, each participant's shoulders, bust, biceps, waist, hips, thighs, and calves were measured with a tape measure following a standardized protocol adapted from the PhenX toolkit [43]. Each participant's actual body mass index (BMI) was calculated by using a stadiometer for height and a bioimpedance scale (Tanita Inc) for weight. The entire study, including the consent, physical measurements, and debrief, took approximately 30 minutes.

### Statistical Analysis

#### *Somatomap 2D*

Proportional maps of body concern for each group were generated from Somatomap 2D tracings by collapsing across all areas of body concerns. This approach to proportionally display body concerns is similar to our previously published studies involving body maps of cardiac sensation [44-46]. Each pixel in the proportional body map thus represented the proportion of participants reporting some type of concern in that area of the body. To statistically evaluate between-group differences in body concern, we calculated a proportional z-score statistic for each pixel, following our previous method [46]. To estimate the *P* value for the calculated z-value, we utilized permutation testing, a statistical resampling method. Permutation testing assumes that under the null hypothesis, the group labeling of participants (model or nonmodel) is arbitrary and that one can estimate the probability distribution of the test statistic under the null hypothesis by randomly relabeling participants and computing the test statistic. We used 5000 permutations, similar to our previous study [46]. To calculate *P* values for each pixel, we compared the *z*-value from the actual sample to the number of occurrences of a *z*-value in the resampled set that were equal or larger to the true *z*-value. Maps were cluster corrected and spatially smoothed using a Gaussian kernel with full width half maximum of 6 pixels, and pixels with *P* values<.05 were considered significant [46].

#### *Somatomap 3D*

Perceived body measurement values were converted from arbitrary units to centimeter units via piecewise linear interpolation, using the actual body part sizes of the initial female volunteer who was scanned to create the 3D avatar. Body parts were measured using an in-engine ruler for three situations: when the slider was set to 0.5, when it was set to 0, and when it was set to 1. Separate linear interpolations for values between 0 and 0.5 and for values between 0.5 and 1 were computed. Premeasured values for the 0.5 setting allowed for calculations of the appropriate scale factor by multiplying by the amount of relative change for each part computed earlier. For example, "0" on the slider might actually mean the foot is 75% of its size when the slider is at "0.5," and "1" on the slider might mean the foot is 130% of its size when the slider is at "0.5." Such measurements and calculations were performed independently for each model and their constituent body parts. Discrepancy scores (in centimeters) were then calculated by subtracting the actual body measurement from the perceived body measurement for each of the seven body areas physically measured.

A multivariate analysis of covariance was used to determine if there were group differences in the actual body measurements, the 3D body measurements, and the discrepancy scores. Covariates included BMI, height, and weight. If the multivariate analysis of covariance results were significant, post hoc analysis using analysis of covariance was used to determine which specific variables showed differences between models and nonmodels.

## Results

### Participant Demographics

Key demographic data are included in Tables 1 and 2. We performed *t* test comparisons and Chi-square statistics between model and nonmodel participants to determine any significant differences between the two groups. There was no significant difference for overall race/ethnicity ($\chi^2_4$=4.9; *P*=.29), and family income was comparable between models and nonmodels ($t_{88}$=1.07, *P*=.29). Models had a significantly lower BMI (*P*<.001), which was driven by differences in height (*P*<.001) but not body weight (*P*=.69). Nonmodels also reported completing significantly higher levels of education than the models ($\chi^2_5$=41.1; *P*<.001).

**Table 1.** Demographic characteristics of female fashion models (n=65) and nonmodels (n=38) analyzed by t test.

| Characteristics | Model, mean (SD) | Nonmodel, mean (SD) | *t* (*df*) | *P* value |
|---|---|---|---|---|
| Age (years) | 25.4 (5.2) | 23.4 (5.5) | 1.7 (80.9) | .09 |
| Height (cm) | 175.9 (5.1) | 162.5 (6.3) | –11.2 (65.3) | <.001 |
| Weight (kg) | 57.5 (4.4) | 56.9 (8.4) | –0.4 (48.7) | .69 |
| Body mass index (kg/m$^2$) | 18.6 (1.2) | 21.3 (2.8) | 5.7 (44.2) | <.001 |

**Table 2.** Demographic characteristics of female fashion models (n=65) and nonmodels (n=38).

| Characteristics | Model, n (%) | Nonmodel, n (%) |
|---|---|---|
| **Race/ethnicity** | | |
| Caucasian | 44 (67.7) | 21 (55.3) |
| Asian (including East Indian) | 5 (7.7) | 7 (18.4) |
| Black | 3 (4.6) | 3 (7.9) |
| Hispanic/Latino | 1 (1.5) | 2 (5.3) |
| Mixed race | 12 (18.5) | 5 (13.1) |
| **Highest level of education completed** | | |
| Graduate school | 2 (3.1) | 7 (18.4) |
| University graduate | 12 (18.5) | 25 (65.8) |
| Some university | 6 (9.2) | 3 (7.9) |
| High school/A level/GED[a] | 32 (49.2) | 3 (7.9) |
| Some high school/A level/GED | 9 (13.8) | 0 (0) |
| Less than high school/A level/GED | 4 (6.2) | 0 (0) |

[a]GED: general educational development.

## Somatomap 2D

Proportional body maps showed that models perceived body concerns in similar as well as distinct areas compared with nonmodels (Figure 3). The number of areas of body concern ranged from 0 to 6 per individual for models (mean 1.2 [SD 0.9]) and from 0 to 4 per individual for nonmodels (mean 1.4 [SD 1.0]), which was not significantly different between groups ($t_{102}$=1.3, *P*=.19). The number of body concern types (eg, acne, bloated, bulgy, and too thin) ranged from 0 to 11 per individual for models (mean 2.4 [SD 2.2]) and from 0 to 12 per individual for nonmodels (mean 2.8 [SD 2.5]), which was also not significantly different between groups ($t_{102}$=0.9, *P*=.35). The number of affective ratings (eg, frustrated and disgusted) ranged from 0 to 7 per individual for models (mean 1.7 [SD 1.4]) and from 0 to 8 per individual for nonmodels (mean 2.0 [SD 1.7]); this too was not significantly different between groups ($t_{102}$=0.9, *P*=.38; see Table 3 for frequency listings of participants endorsing each affective label in each group). The statistical body map analysis revealed several areas that were identified significantly more frequently for each group (*P*<.05) as follows: Models were more concerned with their thighs and buttocks than nonmodels, whereas nonmodels had more frequent concerns about their abdomen than the models (Figure 4). Specifically, 95.8% (46/48) of models who indicated concerns related to the thighs/buttocks described them as oversized (eg, bulgy, too large, protrudes, too fat, too much cellulite, or too much muscularity). Only 4.2% of models (2/48) with concerns related to the thighs/buttocks, described them as too thin and desired more muscle. With respect to nonmodels, 88.2% (15/17) who indicated abdomen concerns described their abdomens as oversized (eg, bloated, too fat, bulgy, too large, protrudes, or too round). Only 11.8% of nonmodels (2/17) with concerns related to the abdomen (eg, acne and flawed) were not size related. Both groups used similar emotions to describe their feelings about their body concerns (Figure 3). The intensity of emotion ratings related to each group's primary body concern—thighs/buttocks for models (mean 26.81 [SD 29.3]), and abdomen for nonmodels (mean 38.4 [SD 31.4])—was not significantly different ($t_{24}$=–1.30, *P*=.21).

**Figure 3.** Proportional maps of body image concerns and associated emotions in female fashion models (left) and nonmodels (right).

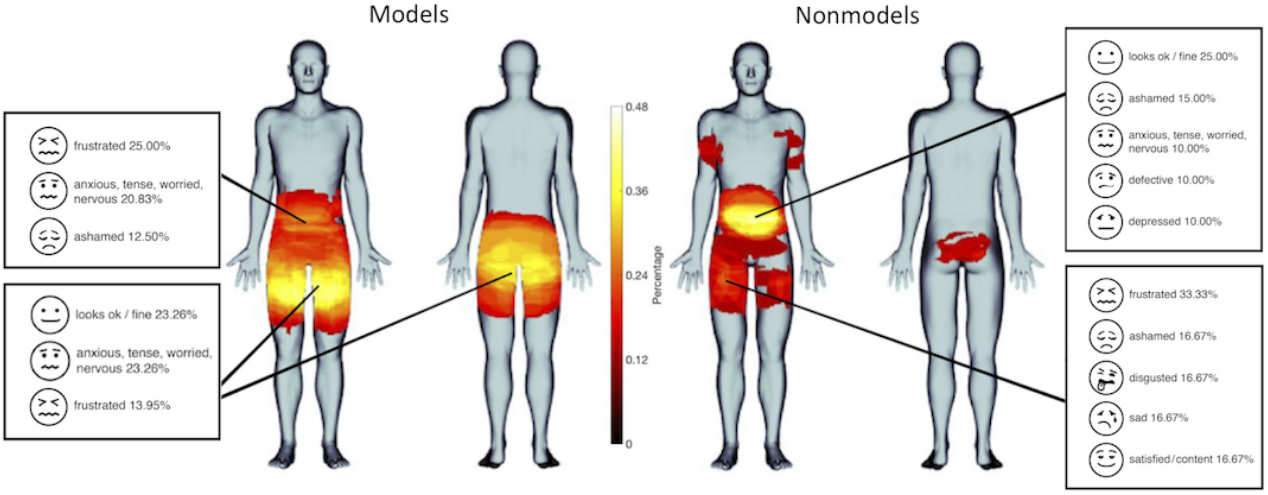
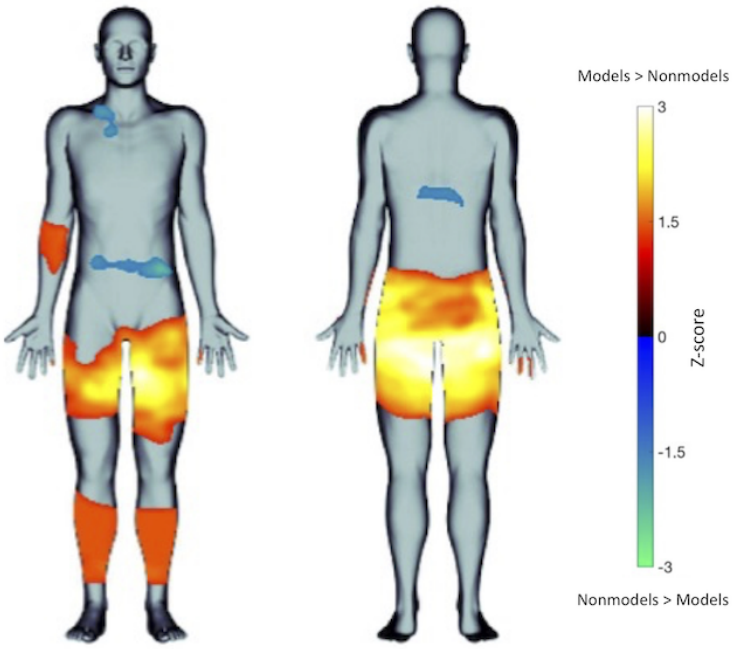



**Table 3.** Frequency and percentage of individual participants endorsing each affective rating per group (models: n=65, nonmodels: n=38).

| Affective type | Models endorsing affective rating, n (%) | Nonmodels endorsing affective rating, n (%) |
|---|---|---|
| **Negative type** | | |
| Frustrated | 19 (29.2) | 7 (18.4) |
| Anxious, tense, worried, nervous | 18 (27.7) | 3 (7.9) |
| Other (eg, defeated, annoyed, self-conscious, exhausted, not enough, silly, don't like) | 14 (21.5) | 9 (23.7) |
| Ashamed | 10 (15.4) | 9 (23.7) |
| Hopeless | 5 (7.7) | 4 (10.5) |
| Sad | 4 (6.2) | 6 (15.8) |
| Disgusted | 4 (6.2) | 4 (10.5) |
| Defective | 3 (4.6) | 3 (7.9) |
| Depressed | 2 (3.1) | 5 (13.2) |
| Fearful | 2 (3.1) | 1 (2.6) |
| Angry | 1 (1.5) | 2 (5.3) |
| Overwhelmed | 1 (1.5) | 0 (0) |
| Lonely | 1 (1.5) | 0 (0) |
| Numb/unreal/dead | 0 (0) | 1 (2.6) |
| Embarrassed | 0 (0) | 1 (2.6) |
| **Neutral/positive type** | | |
| Looks ok/fine | 18 (27.7) | 13 (34.2) |
| Hopeful | 8 (12.3) | 3 (7.9) |
| Satisfied/content | 2 (2.1) | 4 (10.5) |

**Figure 4.** Statistical body map evaluating differences in body image concerns between female fashion models (in warm colors) and nonmodels (in cool colors; statistical threshold: $P<.05$).




## Somatomap 3D

A summary of the actual and perceived body area sizes and discrepancies (perceived measure minus actual measurements) is listed in Table 4. The actual measurements for the shoulders and bust were not significantly different between models and nonmodels. However, significant differences were noted with actual sizes of the bicep, waist, hips, thigh girth, and calf girth, with models exhibiting smaller body measurements than nonmodels. Evaluation of discrepancy scores revealed that models and nonmodels were not significantly different for shoulders or thigh girth. However, models were significantly more accurate (ie, had lower discrepancy scores) in perceiving their bust, bicep girth, waist, hips, calf girth, and overall body (scaled average of all seven body scores). Models showed the smallest discrepancy between perceived and actual measurements of their bicep and hips (0.01 and 0.58 cm, respectively), whereas nonmodels showed the smallest discrepancy for the shoulders (0.59 cm). Nonmodels perceived each body area to be slimmer than it actually was (ie, all discrepancy scores were negative). The same was true for models, except for the bicep and hips, although to a lesser degree than nonmodels for most body parts (Table 4).

**Table 4.** Actual and perceived body measurements in female fashion models and nonmodels.

| Variable | Nonmodels, mean (SD) | Models, mean (SD) | *P* value[a] | Partial $\eta^2$ | Cohen f | *F* (df)[b] | Wilks Λ[b] | *P* value[b] |
|---|---|---|---|---|---|---|---|---|
| **Actual body measurements (cm)** | | | | | | 50.33 (7,91) | 0.205 | <.001 |
| Shoulder | 32.11 (2.22) | 35.18 (2.17) | .10 | 0.038 | 0.198 | | | |
| Bust | 85.76 (6.01) | 80.58 (3.99) | .20 | 0.021 | 0.144 | | | |
| Bicep | 28.61 (6.18) | 22.37 (2.30) | <.001 | 0.223 | 0.537 | | | |
| Waist | 74.11 (6.45) | 64.68 (4.94) | <.001 | 0.244 | 0.568 | | | |
| Hip | 96.11 (7.09) | 89.03 (4.65) | <.001 | 0.101 | 0.336 | | | |
| Thigh girth | 46.53 (7.09) | 44.58 (3.02) | <.001 | 0.094 | 0.322 | | | |
| Calf girth | 42.08 (6.09) | 32.51 (2.75) | <.001 | 0.450 | 0.904 | | | |
| Scaled body average | 0.98 (0.07) | 0.99 (0.05) | .98 | 0.000004 | 0.002 | | | |
| **Perceived body measurements (cm)** | | | | | | 4.85 (7,91) | 0.382 | <.001 |
| Shoulder | 31.55 (1.91) | 31.38 (2.05) | .94 | 0.00006 | 0.008 | | | |
| Bust | 79.18 (8.61) | 77.32 (8.42) | .09 | 0.040 | 0.205 | | | |
| Bicep | 24.24 (2.80) | 22.37 (2.20) | .21 | 0.019 | 0.141 | | | |
| Waist | 62.11 (2.77) | 60.31 (2.11) | .53 | 0.005 | 0.072 | | | |
| Hip | 90.97 (5.92) | 89.54 (5.73) | .20 | 0.021 | 0.147 | | | |
| Thigh girth | 34.45 (4.60) | 31.55 (2.73) | .18 | 0.027 | 0.166 | | | |
| Calf girth | 31.55 (4.12) | 29.60 (2.95) | .87 | 0.0005 | 0.021 | | | |
| Scaled body average | 0.98 (0.06) | 0.99 (0.04) | <.001 | 0.145 | 0.413 | | | |
| **Differences between actual and perceived measurements (cm)** | | | | | | 21.03 (7,91) | 0.205 | <.001 |
| Shoulder | –0.59 (2.58) | –3.83 (3.05) | .19 | 0.023 | 0.155 | | | |
| Bust | –6.54 (8.12) | –3.23 (8.75) | .03 | 0.060 | 0.253 | | | |
| Bicep | –4.34 (6.97) | 0.01 (2.76) | <.001 | 0.218 | 0.529 | | | |
| Waist | –11.91 (6.27) | –4.30 (5.20) | <.001 | 0.166 | 0.447 | | | |
| Hip | –5.04 (8.46) | 0.58 (6.13) | <.001 | 0.092 | 0.317 | | | |
| Thigh girth | –12.05 (9.07) | –12.95 (3.32) | .19 | 0.024 | 0.158 | | | |
| Calf girth | –10.53 (8.25) | –2.86 (3.54) | <.001 | 0.336 | 0.711 | | | |
| Scaled body average | –0.62 (0.42) | –0.046 (0.43) | <.001 | 0.162 | 0.440 | | | |

[a]*P* values corrected for multiple comparisons using the Benjamini-Hochberg procedure.

[b]Measured using multivariate analysis of covariance.

## Somatomap Usability Assessment

A total of 36 nonmodels and 65 models completed the usability rating questionnaire immediately after using the 3D portion of Somatomap (Table 5). Overall, participants found the map easy to use (score for models: 8.4/10; score for nonmodels: 8.5/10). Both groups reported that the final avatar was relatively close to their actual perceived body size (models: 72.7%, nonmodels: 75.2%), but they only identified with the original avatar at a moderate level (score for models: 4.9/10, score for nonmodels: 5.6/10). The groups differed only in terms of enjoyment, with nonmodels reporting higher levels of enjoyment with their experience using the app than models (score for models: 5.9/10, score for nonmodels: 7.4/10; $t_{70}$=2.91, *P*=.002). Qualitatively, participants commented that they "liked best" that the app was "easy to use," "fun to use," and "easy to control." Several reported that they enjoyed the visual nature of the tool, but also preferred having additional options for changing hair and skin type as well as control over more body areas.

**Table 5.** Somatomap usability assessment results.

| Usability questions | Models (n=65), mean (SD) | Nonmodels (n=36[a]), mean (SD) |
|---|---|---|
| 1. How easy was this app to use? (1 - extremely difficult to 10 - extremely easy) Please explain. | 8.4 (2.42) | 8.5 (1.76) |
| 2. What was your experience using this app? (1 - extremely frustrating to 10 - extremely enjoyable) Please explain. | 5.9 (2.34[b]) | 7.4 (2.43[b]) |
| 3. How much did you identify with the original avatar? (0 - not at all to 10 - completely) Please explain. | 4.9 (2.75) | 5.6 (2.34) |
| 4. How closely did the final avatar you created reflect your body? (0% - not at all to 100% - completely) Please explain. | 72.7 (20.17) | 75.2 (17.09) |

[a]Two participants were unable to complete the user experience questionnaire because they needed to get to work; therefore, n=36 instead of 38.

[b]*P*=.002.

## Discussion

In this study, we developed and pilot tested Somatomap, a novel mobile tool for assessing body image perception in both 2D and 3D. We tested this tool in female fashion models, who we hypothesized, given their profession, would have greater expertise with and therefore accuracy in estimating their body shape and size relative to female nonmodels. Both groups reported body concerns but in different areas, with models more concerned with the thighs/buttocks and nonmodels, with the abdomen/waist. Models were more accurate at estimating their overall body size, whereas nonmodels tended to underestimate the size of individual body parts, showing greater discrepancy scores for the bust, biceps, waist, hips, and calves, but not shoulders and thighs. Both groups reported high ease-of-use scores and felt that the resulting 3D avatar closely resembled their actual body, suggesting good usability experience with this tool. Overall, these pilot results suggest that Somatomap is feasible to use and capable of providing unique insight into how humans perceive and represent the visual characteristics of their body.

Body image perception is an inherently subjective phenomenon that is challenging to measure directly. To date, the standard methods for assessing body image perception in clinical settings have relied on verbal interviews, paper-based manikins, and still photographs [34-36,47]. Advantages of Somatomap 2D over lengthy paper-based or verbal interviews include the ease of visually representing one or more areas of appearance concerns, the ability to individually describe types of concerns and associated emotions for each area, and the ability to perform statistical body map comparisons to quantify and visually represent differences in areas of body concern. Somatomap 3D, as reported by participants in this study, is easy to use and able to closely approximate individual body types. This suggests good flexibility to visually represent how users perceive themselves, which is an advantage over other visually based tools that use fixed bodies to select from. Computerized assessments exist that assess separate characteristics of body image such as overall size or shape [37-40], but they do not provide the same individual body-part flexibility as Somatomap 3D. Another advantage of Somatomap 2D and 3D is the level of detail of information that may be obtained via assessments of individual body areas. Instead of merely assessing body image concern or dissatisfaction as a whole or overall, Somatomap 2D allows individuals to specify unique details associated with each area of concern, such as the physical characteristics and the associated affective experiences. Somatomap 3D, in combination with physical measurements, allows for quantification of perception discrepancy for *individual* body areas, rather than only for the body shape as a whole, as is common with other existing assessments (such as the Stunkard Figure Rating Scale).

We created Somatomap in an effort to achieve, as objectively as possible, an accurate digital snapshot of body image concerns, a quantification of perceptual accuracy between one's internalized and actual body form at the level of individual body parts, and an ability to relate the two. Statistical body maps in Somatomap 2D identified female fashion models as having significantly more concerns about the thighs (especially the inner thigh) being too large compared to the nonmodels. This particular body concern may reflect a trend toward the desirability of having a "thigh gap," that is, a gap or space between the thighs when standing upright with the feet together. For example, a 2015 online survey of 500 UK females found that 40% of women aged 16-65 years felt that they would feel more confident if they had a "thigh gap" [48]. Results from Somatomap 3D showed that both groups underestimated individual body areas, in agreement with studies suggesting that women tend to underestimate their body size in the general population [49], but not with studies suggesting women in the general population may overestimate their body size [12,13,50]. Models were also significantly more accurate at estimating their overall body size than nonmodels and were more accurate at estimating the size of their bust, biceps, waist, hips, and calves. Interestingly, when examining body discrepancy scores between groups in Somatomap 3D, the thighs were one of only two areas where the groups did not differ in their estimation ability, yet they were an area for which models endorsed significantly more frequent concerns than nonmodels in Somatomap 2D. These initial results suggest that in combination, Somatomap 2D and 3D have the ability to detect differences in body image perception for the same body part that is distinct.

These results in models and nonmodels may provide partial support for the social norm hypothesis, which states that judgments of body size/weight are influenced by visual proximity to different body types [51]. Given the ongoing obesity epidemic in nondeveloping and developing countries, this suggests that a recalibration of body sizes is underway,

leading to a perception that larger body sizes are "normal." Thus, according to this hypothesis, the nonmodels may have calibrated their body perception by comparing themselves mainly to the general UK population (ie, 61% of which are overweight or obese [52]), whereas the models may have calibrated their body perception by comparing themselves to their general peers (other slimmer-than-average fashion models). Despite a higher BMI than models, the nonmodel sample recruited in this study (in the healthy range on an average) exhibited a lower average BMI than the overall general UK population norms would suggest. This made them a fairly good comparisons for the models, but might have also potentially resulted in an underestimation of body image discrepancies for general UK female nonmodel samples overall.

By facilitating the accurate measurement of attitudinal and perceptual aspects of body image disturbance, the Somatomap tool may allow for subsequent characterization of the underlying neural mechanisms in clinical and nonclinical conditions. For example, as the pilot results suggest, it is plausible that this tool should be sensitive to detecting overestimation discrepancies of specific body areas (eg, waist, hips, and bust) that have been noted in individuals with anorexia nervosa [11-13] and others that have been observed in body dysmorphic disorder [17-19]. Pairing this tool with neurobiological measures such as functional magnetic resonance imaging or electroencephalography might help elucidate if and how previously described abnormalities of cortical visual systems [20-22] could be linked to misestimations of specific body areas, which, in turn, may contribute to body image disturbance in anorexia nervosa and body dysmorphic disorder. At the clinical level, it remains to be seen whether this tool can effectively and reliably measure distortions of body image perception in these disorders, and further studies will be required to determine the viability of this approach.

By providing better insights into the perceptual mechanisms, Somatomap may assist in the effort to uncover latent factors underlying body image disturbance in various psychiatric illnesses, reveal important information about illness course, and possibly contribute to the development of novel treatments. When developing Somatomap, we aimed to generate a mobile tool capable of deployment over a broad range of devices, physical locations, and settings (ie, research and clinical). The cross-platform compatibility and HIPAA-compliant encryption (via Chorus), along with the estimation that 80% of adults will own a smartphone by 2020 [53], represents a significant first step in this direction. Longitudinal deployment of this tool may assist clinicians in detecting the response of body image disturbance to existing clinical interventions and in the longitudinal tracking of illness course. Although speculative, it seems possible that this tool could also contribute to the development of novel interventions for body image disturbance. For example, virtual reality has shown therapeutic potential in helping recalibrate body perception discrepancies in anorexia nervosa. A recent virtual reality study [54] modulated the sense of ownership of a virtual body avatar using visuotactile stimulation and showed that it reduced overestimations of the abdomen for up to several hours. This kind of perceptual retraining might also be investigated with Somatomap using mobile devices, particularly in settings in which identification with the avatar can be maximized, and when access to virtual reality or other specialized equipment is difficult. Therefore, the Somatomap tool might potentially have a clinical impact in patients, such as deployment of the tool to assist clinicians in detecting the response to treatments targeting body image disturbance; longitudinal tracking of naturalistic illness course (ie, for remote surveillance of potential relapse or "flare ups" of body image disturbance); or integration as a component of novel perceptual retraining interventions, particularly in remote settings when access to specialized equipment such as virtual reality may be limited.

This study has several limitations. First, usability data were obtained from participants after using the 3D assessment portion of the tool. We did not collect separate usability data for the 2D assessment. Second, data collection occurred in a relatively small sample of women from the United Kingdom. Obtaining measures, and eventually norms, across a greater variety of different racial/ethnic, socioeconomic groups, and sexual/gender categories will be important for determining the generalizability of this approach to global populations. Third, the 2D manikin consisted of an androgynous figure, and it is unclear if a sex-specific figure would alter the type of assessments provided. However, having a consistently sized 2D model enabled us to perform statistical analyses across subjects more easily. Fourth, identification with the 3D avatar (before manipulation) was in the moderate range, and while it improved a lot after the final manipulation, it was not at the highest possible limit. Possible changes to further improve avatar identification might include offering more customizability of different features beyond the hair and skin color options currently supported in the generic avatar, increasing the number of areas that can be modified (ie, beyond the seven presented here), adding new body modification parameters such as height/length (ie, beyond the girth/width modification ability presented here), and improving avatar personalization, as it was recently noted that "personalized avatars significantly increase body ownership, presence, and dominance compared to their generic counterparts" [55]. As this was a pilot feasibility study, we did not examine test-retest reliability or formally compare results to existing body image assessment tools (such as the Stunkard Figure Rating Scale) to evaluate construct validity. We anticipate performing such evaluations after revising Somatomap on basis of the user experience data collected in this study. Finally, we did not perform clinical diagnostic evaluations or have access to medical records to determine the presence of eating disorders, body dysmorphic disorder, or other psychiatric disorders that could affect body perception in either sample.

Overall, these pilot results suggest that Somatomap is feasible to use and capable of providing unique insights into how humans perceive and represent the visual and size/shape characteristics of their body. Its advantages over commonly used tools include mobility; ease of use; customizable avatars that can flexibly represent users' bodies with a variety of body shapes and sizes; and most of all, the ability to visualize and statistically quantify body image perception at the level of both individual body concerns (Somatomap 2D) and perceptions of individual body part size and shape (Somatomap 3D). Future clinical applications

of this tool could include investigations of appearance concerns and body perception in disorders involving body image, such as eating disorders and body dysmorphic disorder. This potentially could be used both cross-sectionally as well as longitudinally to follow illness trajectory and changes over time with treatment.

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## Conflicts of Interest

ACA is founder of Insight Health Systems, Arevian Technologies, and Open Science Initiative. ACA developed the Chorus platform, which is licensed from the University of California Los Angeles to Insight Health Systems.

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## Abbreviations

**BMI:** body mass index


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Review

# Web-Based Cognitive Bias Modification Interventions for Psychiatric Disorders: Scoping Review

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## Abstract

**Background:** Cognitive biases refer to automatic attentional or interpretational tendencies, which result in individuals with addictive disorders to automatically attend to substance-related stimuli and those with anxiety disorders to attend to threatening stimuli. To date, several studies have examined the efficacy of cognitive bias modification, and meta-analytical studies have synthesized the evidence for overall efficacy. The clinical utility of cognitive bias modification interventions has previously been limited to the confines of a laboratory, but recent advances in Web technologies can change this.

**Objective:** This scoping review aimed to determine the scope of Web-based cognitive bias interventions and highlight their effectiveness.

**Methods:** Databases (PubMed and MEDLINE, EMBASE, PsycINFO, ScienceDirect, and Cochrane Central) were searched from inception to December 5, 2017. The following search terminologies were used: (“attention bias” OR “cognitive bias” OR “approach bias” OR “avoidance bias” OR “interpretative bias”) AND (“Internet” OR “Web” OR “Online”). The methods for this scoping review are based on the previously published protocol. For the synthesis of the evidence, a narrative synthesis was undertaken, as a meta-analysis was not appropriate, given the lack of reported effect sizes and the heterogeneity in the outcomes reported.

**Results:** Of the 2674 unique articles identified, we identified 22 randomized controlled studies that met our inclusion criteria: alcohol use disorder (n=2), tobacco use disorder (n=2), depressive disorder (n=3), anxiety and depressive symptoms in adolescents (n=3), obsessive-compulsive disorder (OCD; n=2), social anxiety disorder (n=9), and anxiety disorder (n=1). The sample sizes of these studies ranged from 16 to 434 participants. There is preliminary evidence to suggest that Web-based interventions could reduce biases among adolescents with heightened symptoms of anxiety and depression and among individuals with OCD.

**Conclusions:** This is the first scoping review that mapped out the scope of cognitive bias modification interventions for psychiatric disorders. Web-based interventions have been applied predominantly for social anxiety and addictive disorders. Larger cohorts must be used in future studies to better determine the effectiveness of Web-based cognitive bias interventions.

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**KEYWORDS**

cognitive bias; attention bias; psychiatry; eHealth

## Introduction

### Background

Cognitive biases include automatic, attentional approach tendencies and interpretational tendencies [1]. These automatic processes are believed to be implicated in psychiatric disorders such as addictive disorders and social anxiety disorders [2-4]. Cognitive biases cause individuals with addictive disorders to automatically attend to substance-related stimuli in their environment and those with social anxiety disorders to attend to threatening stimuli. The dual-process theoretical model suggests that these automatic processes arise as a result of increased processing of automatic stimuli, with a corresponding inhibition in normal cognitive control processes [5]. For individuals afflicted with anxiety disorders, when presented with an ambiguous stimulus, anxious individuals tend to make threatening interpretations of the stimuli presented, whereas nonanxious individuals tend to make more positive or benign interpretations [6].

The initial evidence for cognitive biases emerged from experimental psychology, and further research has demonstrated that such biases are amenable to modification. Targeting these automatic biases is important, as conventional psychological therapies, such as cognitive behavioral therapy, typically target only the conscious cognitive control processes and not these underlying automatic biases. Attentional biases can be retrained using either the dot-probe or visual-probe task. These tasks involve pairing the probe (either an asterisk or arrow) with the neutral word or the neutral image all the time [7]. In the visual-probe task, participants are typically presented with a fixation cross at the center of the computer screen, followed by a pair of images (one related to the threatening or triggering stimulus and the other a neutral stimulus, both of which are similar in complexity). Both the stimuli would then disappear, and a probe will appear on the screen. Following the disappearance of the probe, participants are required to indicate the position of the probe on the screen as quickly as possible. The repeated pairing of the probe with the neutral word or neutral image thus facilitates a shift in the attentional focus. Approach biases are retrained using the approach/avoidance task (AAT) [8]. In the AAT, participants are required to either push or pull the images, irrespective of the nature of the stimulus [8]. Interpretative bias modification involves training participants to make positive interpretations through ambiguous scenarios or the word sentence association task [9]. Typically, in the ambiguous scenarios or the word sentence association task, participants are presented with descriptions of a scenario that is ambiguous in terms of emotional valence. Following the disappearance of the ambiguous scenario, participants are presented with a word fragment that would disambiguate the scenario in an anxiety-irrelevant way [6]. Other cognitive bias modification tasks commonly used also include the modified Stroop task and the visual search bias modification task. In the modified Stroop task, participants are presented with both threatening and neutral words, in varying colors, and participants are then asked to name the color of the words while ignoring the semantic content of the word [10]. In the visual search task, participants are asked to identify a target stimulus among a series of distracting stimulus.

To date, several studies have examined the efficacy of cognitive bias modification, and meta-analytical studies have synthesized the evidence for overall efficacy. For substance addictions, Cristea et al [11] reviewed 25 randomized trials (18 for alcohol use disorders and 7 for smoking use disorders) and concluded that bias modification was effective with an effect size of 0.60 (Hedges G). However, they reported no effects of bias modification on other addiction outcomes or on craving [11]. A commentary published [12] in response to this meta-analysis [11] highlighted that a mixture of clinical and nonclinical studies has been included in the evidence synthesis and that, if only clinical studies were considered, the qualitative synthesis demonstrated that there was a significant effect of bias modification. For anxiety and depressive disorders, there remain to be small effect sizes (Hedges G of 0.37) for bias modification based on a previous evaluation of 49 trials [13]. Subsequently, Jones et al [1] in their review of meta-analyses for bias modification reported that attention bias and cognitive bias modification for interpretation did modify biases, with an effect size of 0.24 to 1.16 and 0.52 to 0.81, respectively. There was more evidence for bias modification for anxiety symptoms when compared with depressive symptoms [1]. In addition, Jones et al [1] concluded that both attention bias and cognitive bias modification for interpretations were more effective when delivered in the confines of the laboratory. A laboratory setting enables greater supervision and resultant compliance with the task, given the repetitiveness and monotonous nature of the intervention.

The clinical utility of cognitive bias modification interventions has previously been limited to the confines of a laboratory, but the recent advances in Web technologies can change this. Electronic health, which refers to the process by which health processes and health care are communicated and transferred by an electronic medium and includes Web-based interventions, telephone-delivered therapy, and short message service text messaging, has facilitated this transformation [14]. Web-based therapies also allowed therapy to be delivered across geographical locations and at any time. This new technology is used to deliver conventional therapies, such as cognitive behavioral therapy, as well as cognitive bias modification. To date, there have since been several studies published that have evaluated the effectiveness of Web-based cognitive bias modification. Wittekind et al [15] have previously reported how a Web-based AAT reduced cigarette consumption, cigarette dependence, and compulsive drive among individuals who smoke. Similarly, Blackwell et al [16] used Web technologies for the delivery of cognitive bias modification targeting imagery and interpretation and reported that bias modification was effective in reducing anhedonia symptoms among individuals who were depressed.

### Objectives

Thus, although there have been more Web-based cognitive bias modification interventions, there remains no review that has scoped out the disorders that such interventions target and the effectiveness of these interventions. Given this, the primary

objective of this scoping review was to determine the areas in which Web-based cognitive bias modification has been applied. The secondary objective was to synthesize the effectiveness of these interventions and to determine the change in symptoms for the individual psychiatric disorders following bias modification.

## Methods

### Overview

The methods of this scoping review were based on the previously published review protocol [17]. Articles were identified using a search through the following databases: PubMed and MEDLINE, EMBASE, PsycINFO, ScienceDirect, and Cochrane Central. The following search terminologies were used: ("attention bias" OR "cognitive bias" or "approach bias" or "avoidance bias" or "interpretative bias") AND ("Internet" OR "Web" OR "Online"). The search strategy was modified in accordance to suit the different databases. The databases were searched from inception to December 5, 2017. The search terminology "mobile devices" was not included in our search strategy, as the intent of our search was to identify Web-based interventions. We have previously published another review that has reviewed all the published mobile-based interventions [18].

### Inclusion and Exclusion Criteria

Only articles in the English language were included. Articles were included if (1) the condition examined was a psychiatric disorder, (2) the diagnosis confirmed either using a structured clinical interview or a questionnaire, and (3) cognitive bias modification was delivered through a Web-based modality. Articles were excluded if (1) the intervention failed to include a validated measure for attention bias or cognitive bias, (2) the intervention was delivered using a mobile device or delivered in the form of a game, and (3) cognitive bias modification was part of a pharmacological trial.

### Conditions or Domains Studied

This scoping review was limited to the exploration of Web-based cognitive bias modification for psychiatric disorders.

### Participants

Adult, children, and adolescent populations are included in this review. There were no restrictions on the participants who are included in these studies.

### Intervention and Exposure

The intervention that has been examined is a Web-based cognitive bias modification task. The tasks included are Stroop task, visual-probe/dot-probe task, cognitive bias modification for interpretations, and the visual search task.

### Comparator

Participants are compared with individuals who have received either a placebo or sham training intervention.

### Outcome

The outcome was whether there were changes in biases following the cognitive bias modification intervention.

### Selection of Articles

Articles were deidentified before data extraction. Selection of the relevant publications was conducted independently by 2 authors (MWBZ and JBY). First, articles were screened based on their titles and abstracts. The shortlisted articles were evaluated against the inclusion and exclusion criteria. Disagreements between the 2 authors were resolved through a discussion with a third author (GS). An electronic form was used to record the reasons for the inclusion and the exclusion of the articles.

### Data Extraction

The following information was extracted from each of the articles: (1) publication details (names of the authors and the year of publication), (2) the sample size in the studies, (3) the number of participants in each of the allocated intervention arms (for a randomized trial), (4) study design (cross-sectional, case-controlled, or randomized controlled trial), (5) psychiatric diagnosis of participants, (6) cognitive bias task used, and (7) outcomes of cognitive bias modification (primary outcomes refer to whether biases are present and could be subjected to modification and secondary outcomes refer to other clinical outcomes). The extracted data were cross-checked by another author (JBY) and recorded on a standardized electronic data collation form.

### Statistical Analysis

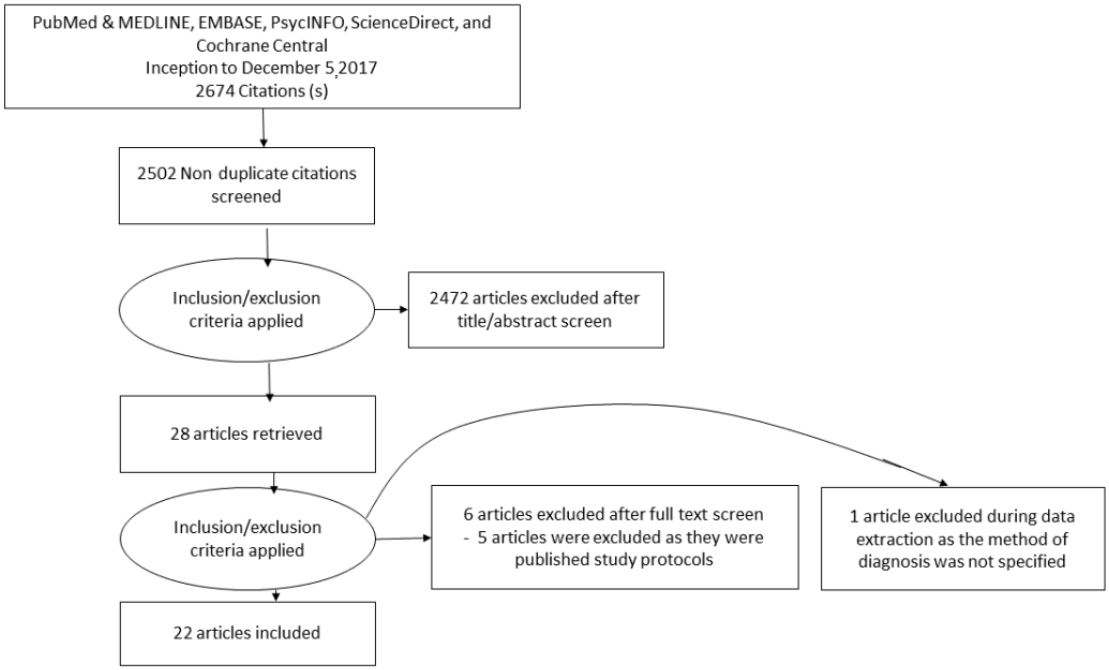
A narrative synthesis of the effectiveness of Web-based cognitive bias modification for each of the different psychiatric disorders was performed.

## Results

### Findings

A total of 2674 unique articles were identified across all the databases using the predefined search strategy. Of 2674 articles, 172 duplicated articles were removed. On screening of the titles and the abstracts, 2472 papers were excluded as they were not relevant. The full texts of 30 papers were downloaded and screened against the inclusion and exclusion criteria. Moreover, 5 papers were excluded, as they were published protocols, and 1 additional paper was excluded, as it did not specify the method of ascertaining the psychiatric diagnosis. A total of 22 papers were included in this review, which was a combination of both pilot and randomized controlled trials. The sample sizes of these studies ranged from 16 to 434 participants. Figure 1 provides an overview of the selection process of the articles. Multimedia Appendix 1 provides an overview of the characteristics of the included articles [9,15-37].

**Figure 1.** Overview of selection of studies.




## Scope of Web-Based Cognitive Bias Modification Interventions

Web-based cognitive bias modification has been evaluated for alcohol use disorder (2 studies), tobacco use disorder (2 studies), depressive disorder (3 studies), anxiety and depressive symptoms in adolescents (3 studies), obsessive-compulsive disorder (OCD; 2 studies), social anxiety disorder (9 studies), and anxiety disorder (1 study).

## Alcohol and Tobacco Use Disorders (4 Studies)

A total of 4 studies evaluated bias modification for addictive disorders. All identified studies recruited their participants by Web mechanisms (Web-based advertisement, websites, and forums), except for the study by Cougle et al [19], in which participants were recruited using doctors' referral and from the local community (by means of advertisements). Across all the 4 studies, the mean ages of participants were in the 40s with a predominance of females in 3 studies [15,19,20]. In addition, 2 studies included participants with alcohol use disorders [19,21] and 2 included participants with tobacco use disorder [15,20]. Only Cougle et al [19] reported the use of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), diagnostic criteria in ascertaining the diagnosis for the participants, whereas Wittekind et al [15] and Elfeddali [20] reported the use of questionnaires for diagnosis. Wiers et al [21] reported using a questionnaire and self-report for diagnosis. Two studies used the AAT [15,21], and the 2 other studies used the attention bias modification task [19] and interpretative bias modification task [19,20].

Furthermore, 2 studies for alcohol use disorder [19,21], which involved 58 and 136 participants, did not suggest that there was a clear benefit of cognitive bias modification. Wiers et al [21] and Cougle et al [19] reported a reduction in alcohol consumption in intervention and control groups (sham controls and healthy video controls), thus providing no evidence to support bias retraining for reducing alcohol consumption. However, Cougle et al [19] reported that bias modification led to reductions in trait anger and hostility.

Wittekind et al [15] and Elfeddali et al [20] provided preliminary evidence for the effectiveness of the approach and avoidance modification task in smoking. Wittekind et al [15], in their study that included 257 participants reported a reduction in the number of cigarettes smoked and smoking compulsion in participants, whereas Elfeddali et al [20] who in their study included 434 participants reported that bias modification was not effective in continued abstinence.

## Depressive Disorders (3 Studies)

A total of 3 studies [22-24] evaluated bias modification for depressive disorders, and 1 study [22] evaluated cognitive bias modification in conjunction with standard internet-based cognitive behavioral therapy. Of 3 studies, 2 recruited participants from the university and the community, and 1 study [22] recruited participants through a research unit. The participants of all 3 studies were predominantly females, but there was heterogeneity in the mean ages. Moreover, 2 studies [16,22] ascertained diagnosis using the diagnostic interview and Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) diagnostic criteria, whereas a study by Pictet et al [23] ascertained the diagnosis of participants using a questionnaire. All studies used cognitive bias modification for interpretation.

Of 3 studies, 2 (which involved 69 and 101 individuals) suggested that there was a change in interpretative biases [22,23], with effect sizes of 0.62 to 2.40 and 0.86, respectively. Anhedonia, which refers to the lack of interest, was a secondary

outcome assessed in 2 studies [16,23], but only Pictet et al [23] found a significant reduction in the overall anhedonia scores.

### Anxiety and Depressive Symptoms in Adolescents (3 Studies)

A total of 3 studies examined bias modification for mixed anxiety and depressive symptoms in adolescents. All the studies included secondary school students from the Netherlands. There was a predominance of female participants with mean ages between 14 and 15 years. All studies confirmed the diagnosis of anxiety or depressive symptoms using the Screen for Child Anxiety-Related Emotional Disorders and the Child's Depression Inventory. For bias modification, 1 study used cognitive bias modification for interpretative bias [24], and the remaining 2 studies [25,26] used attentional visual search.

De Voogd et al [27] reported that attentional bias was significantly reduced in groups that received visual search bias modification. The group size comprised 38 individuals. There was also enhanced attention for positive information following training [26]. Training effects (reduction in biases) were greater for participants who have completed more training sessions. Only 2 of the 3 studies suggested that there was preliminary evidence of a reduction in symptoms of anxiety and depression following training.

### Anxiety Disorders

#### *Panic Disorders With or Without Agoraphobia, Social Anxiety Disorders, Posttraumatic Stress Disorder, and Generalized Anxiety Disorders (1 Study)*

One study [28], involving 47 participants (24 allocated to intervention and 23 allocated to control), examined bias modification in individuals with a range of anxiety conditions. Individuals sampled were from an anxiety center or medical center. The most common anxiety condition was that of panic disorder, with or without agoraphobia, followed by generalized anxiety disorders and posttraumatic stress disorder. Diagnoses were ascertained using the structured clinical interview for the DSM-IV. Those who (24 participants) received the intervention tended to make more positive interpretations. For the secondary outcome of anxiety scores, both groups (intervention and control) had a reduction.

#### *Obsessive-Compulsive Disorders (2 Studies)*

Two studies examined bias modification in participants with OCDs. Salemink et al [29] recruited adolescent participants (mean age range 15.1-15.6 years) from a treatment facility, whereas Weil et al [30] recruited participants who had a past diagnosis of OCDs. The sample size in Salemink et al was 16 participants, whereas the sample size in Weil et al was 101 participants. In a study by Salemink et al [29], participants were males, and in a study by Weil et al [30], most participants were females. For the diagnosis of OCDs, it was ascertained by the DSM-IV-TR in a study by Salemink et al [29] and using questionnaires in a study by Weil et al [30]. Cognitive bias modification for interpretation and the AAT was used for bias intervention, among the relatively small sample of individuals. Cognitive bias modification for interpretations reduced the speed with which individuals made OCD-related interpretations. In both studies, there was a reduction of symptoms related to OCD and distress caused by OCD symptoms following the intervention.

#### *Social Anxiety Disorders (9 Studies)*

Nine studies evaluated bias modification in participants with social anxiety disorders. Of 9 studies, 7 recruited participants through advertisements or Web mechanisms. Sportel et al [31] and de Hullu et al [25] recruited adolescents from regular secondary schools. All the studies included mostly female participants. Eight studies ascertained the diagnosis of social anxiety disorders by means of a clinical interview and 1 study [9] by means of a questionnaire. Stroop task was used in 1 study, visual-probe or dot-probe task in 5 studies, and cognitive bias modification for interpretations in 3 studies.

Biases were found to be present in 7 studies [33,35-37]. For bias modification, 4 studies provided preliminary evidence that bias modification was not effective [31,33,35,37]. Although Boettcher et al [33] reported no changes in biases, the authors did report that there was a significant improvement in social anxiety symptoms following the intervention. Similarly, Neubauer et al [36] also reported a small, although significant, reduction in social anxiety symptoms, despite there being no changes in overall biases. Sportel et al [31] and Brettschnieder et al [34] reported that bias modification was effective, and there was a corresponding reduction in secondary outcome measures (anxiety).

## Discussion

### Principal Findings

This is the first scoping review that maps out the areas in which Web-based cognitive bias modification has been applied and the accompanying findings. Our findings demonstrate that Web technologies have been widely applied for cognitive bias modification for several psychiatric disorders, such as alcohol disorder and social anxiety disorder. Most of the published studies have examined the utility of Web-based cognitive bias modification for social anxiety disorders (9 studies) and addictive disorders (4 studies). Studies involving adolescents with heightened symptoms of anxiety and depression and individuals with OCDs reported positive findings. For depressive disorders, addiction disorders, and social anxiety disorders, there were both positive and negative studies.

One of the key findings from this review is that Web-based cognitive bias interventions have been evaluated among individuals with a diverse range of psychiatric disorders but predominantly for anxiety disorders. The increase in the number of studies conducted evaluating Web technologies in the delivery of cognitive bias modification is expected, given the inherent advantages of using Web technologies. Unlike conventional cognitive bias interventions, Web interventions do not need a therapist, and this enables the intervention to be disseminated to multiple clients [19]. Web technologies also remove geographical barriers that might limit participants from receiving bias interventions [34]. More importantly, Web technologies enable participants to receive the intervention beyond the confines of a laboratory [16], perhaps in the comfort of their

own home. As these benefits become more widely recognized, we can expect more studies examining Web-based cognitive bias interventions, together with studies capitalizing on other modalities, such as mobile technologies. Mobile technologies have additional advantages, as they do not require individuals to be connected to the internet to receive the intervention and that it also facilitates individual engaging in training tasks in high-risk situations.

Although the use of Web technologies for the delivery of cognitive bias interventions for psychiatric disorders appears promising, we found that there are studies reporting negative results for depressive disorders, addictive disorders, and social anxiety disorders. Our findings are consistent with Calbring et al and Neubauer et al [35,36] in their head-to-head trials. They reported fewer positive results for Web interventions compared with interventions conducted in the confines of the laboratory. There are several reasons as to why Web cognitive bias modification is less effective in comparison with laboratory-delivered interventions. Studies have reported Web bias modification to be less effective for individuals with social anxiety disorders, as the arousal levels of participants are lesser compared with when the intervention is administered in the laboratory environment, given that in the laboratory environment, participants who are socially anxious are required to interact with others [35,36]. In addition, participants who undertake a Web intervention are more likely to be distracted (such as being disturbed by others) during bias retraining [35]. There is less control over a Web intervention compared with a laboratory-based intervention. De Voogd et al [27] reported that in their study, participants did not adhere to the timelines for training, with some participants failing to undertake the intervention for some days and other participants condensing the training sessions into a few days. Some studies may have failed to have demonstrated significant results because of reduced power with participant attrition [27]. The lack of a positive finding might be also be attributed to the poor motivation when training on the Web for highly repetitive tasks. The lack of a positive finding might also be because of the small sample sizes included in some of these studies. The inclusion of a small sample might have affected the ability to detect any meaningful statistically significant result. The negative findings should not deter future research, examining the potential of Web bias modification interventions, as there remain studies demonstrating positive findings of Web interventions and there remain multiple advantages of a Web approach. Future studies should consider the limitations of existing published studies, as mentioned above. Gamification technologies could be considered to minimize the repetitiveness of tasks, and there have since been studies [38] reporting increased motivation following the incorporation of gamification features. Elements of motivational support could be included in training tasks to minimize attrition and improve compliance to tasks.

In addition, from our scoping review, it seemed that in some studies, a reduction in cognitive biases is associated with an improvement in other psychiatric outcomes (eg, a reduction in interpretative biases is associated with reduced anxiety), but such a finding is not consistent across the studies. This implies that although there might be a reduction in overall biases, it might not directly translate to an improvement in clinical symptoms. In a review of cognitive bias modification for substance use disorders by Cristea et al [11], such inconsistencies have been previously highlighted. In their previous review, they found cognitive bias modification to be moderately effective, with an effect size of 0.60 (Hedges G). However, they did not find that cognitive bias modification helped in improving any of the other secondary outcomes, such as cravings. It might be possible that the change in biases does not immediately result in an improvement in clinical symptoms, and that more time might be needed [11]. There being a positive change in cognitive biases could also possibly be accounted for by participants getting better at the task, as the task used for bias retraining and assessment is the same [11]. Given this, it is important for future research to consider a longer follow-up interval to determine if the changes in biases would result in clinically significant changes in symptoms. Future research should also consider the methods used for assessment and modification, for example, using the visual-probe task for bias retraining, and the modified Stroop task for bias assessment.

This scoping review has several strengths. Our scoping review has helped to bridge the existing gap in the literature. From our review, we found that cognitive bias modification has preliminary effectiveness among adolescents with heightened symptoms of anxiety and depression and individuals with OCDs. These findings are promising, and there should be future adequately powered trials to better evaluate the effectiveness. Our review also highlights there being a need to further evaluate cognitive bias modification among other anxiety disorders, such as posttraumatic stress disorder and possibly that of psychotic disorders. We have undertaken a comprehensive review of the literature for Web cognitive bias interventions for a diverse range of psychiatric disorders, searching through several databases, which captured a proportion, if not all the published studies to date. We have based our scoping review on an a priori review protocol. We have specified the terminologies we have used for the search strategy and applied strict inclusion and exclusion criteria for the selection of the articles identified from the published literature. We have also used standardized data extraction forms. There remain several limitations to this review. As this review was intended to be a scoping review, we did not adhere to the guidelines for a systematic review. Although we have prepared a review protocol and published the protocol, we have not registered this review with PROSPERO. We have not undertaken any form of quality assessment or critical appraisal; hence, we were not able to determine the quality of the studies. We are unable to perform any concrete synthesis of our results, as we have not determined the quality of the studies, and we have included a mixture of randomized trials and pilot randomized trials. The evidence from pilot randomized trials might be misleading because of the small sample sizes.

## Conclusions

This is the first scoping review that has mapped out the scope of cognitive bias modification interventions for psychiatric disorders and their initial findings. Web-based interventions have been predominantly applied for social anxiety and addictive disorders. Larger cohorts must be used in future studies to better

determine the effectiveness of Web-based cognitive bias interventions.

## Conflicts of Interest

None declared.

Multimedia Appendix 1
Characteristics of the included studies.
[PDF File (Adobe PDF File), 213 KB - mental_v6i10e11841_app1.pdf ]

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## Abbreviations

**AAT:** approach and avoidance task
**DSM-5:** Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

**DSM-IV-TR:** Statistical Manual of Mental Disorders, Fourth Edition, Text Revision
**OCD:** obsessive-compulsive disorder

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Original Paper

# Automated Mobile Phone–Based Mental Health Resource for Homeless Youth: Pilot Study Assessing Feasibility and Acceptability

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## Abstract

**Background:** Youth experiencing housing instability have higher rates of mental health problems than their housed peers. Few studies have evaluated technological resources for homeless youth to determine how to effectively engage and reach them.

**Objective:** The primary aims of this pilot study were to establish the feasibility (as measured by phone retention rates) and acceptability (ie, participant ratings of resources) of delivering automated mental health resources via smartphone technology.

**Methods:** Youth aged 16 to 25 years (N=100) were recruited through homeless shelter agencies in the Chicago metropolitan area. Eligible participants completed a baseline assessment and received a smartphone with a 3-month data plan. The phone was preloaded with several apps designed to promote mental health wellness and provide real-time resources. One app specifically designed for this study, Pocket Helper 2.0, sent participants daily surveys and tips via push notification. The tips focused on coping and motivation, and the surveys assessed mood. This app also included an automated self-help system with brief cognitive behavioral interventions (5-10 min) and access to several interactive mobile tools, including a crisis text line, a telephone hotline, a crowd-based emotional support tool, and an app providing up-to-date information on social service and mental health resources for homeless youth in Chicago. Participants completed assessments at 3 and 6 months.

**Results:** Some individuals (23%, 23/100) experienced problems with the phones (eg, theft, loss, and technological issues) throughout the study. Participant retention at the midpoint was moderate, with 48% (48/100) of youth responding to the 3-month surveys. At 6 months, only 19% (19/100) of the total sample responded to the end point survey. Overall, 63% (30/48) to 68% (13/19) of respondents at both time points reported benefiting from the intervention; however, participant usage and satisfaction varied with the different features. At both time points, participants reported receiving the most benefit from the daily tips and daily surveys. Daily tips that were most preferred by participants involved motivational tips related to overcoming struggles and making progress in life. Aside from the tips and surveys, the most used features were the app providing up-to-date resources and the automated self-help system. Interactive features, including the telephone hotline and crowd-based emotional support tool, were the least used features and were rated as the least beneficial.

**Conclusions:** Automated mental health interventions seem to be an acceptable way to engage homeless youth in mental health support. The participants preferred fully automated features and brief interventions over features requiring interaction with others or more engagement. Future research should explore ways to retain homeless youth in interventions and evaluate the clinical impact of automated technology-based interventions for improving mental health.

**Trial Registration:** ClinicalTrials.gov NCT03776422; https://clinicaltrials.gov/ct2/show/NCT03776422

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**KEYWORDS**

mental health; young adult; homelessness; telemedicine; treatment; mHealth; mobile phone

# Introduction

## Background

### *Youth Homelessness*

Each night, thousands of young people across the United States experience housing instability. Most recent statistics from 2018 indicate that as many as 36,361 unaccompanied youth are counted as homeless on a given night [1]. In Chicago specifically, it was estimated that 80,384 people experienced homelessness in 2016, 11,067 of whom were unaccompanied youth aged 14 to 24 years [2]. Youth experiencing homelessness have very specific mental health needs that often go unaddressed because of barriers to accessing care. One barrier is that young people experiencing homelessness often have to focus on emergent and immediate needs—finding housing, securing their belongings, and seeking employment—so, out of necessity, mental health needs become lower priorities. Traditional services tend to require scheduling an appointment in advance and having reliable transportation to an office or clinic, both of which present challenges for young people experiencing homelessness. Even when young people experiencing homelessness receive services, these often do not adequately address the various stressors and challenges associated with homelessness. Therefore, it is important to explore novel ways of reaching this population and of providing resources consistent with the needs identified by the youth.

### *Technology as Means of Homelessness Engagement*

One avenue to reach young people experiencing homelessness might be through technology-based resources given the high levels of engagement with technology in this age group and the value of mobile technology as a resource for homeless individuals [3]. According to a 2019 survey by the Pew Research Center, 96% of US adults between the ages of 18 and 29 years own a smartphone [4], and 48% of them report that they go online *almost constantly* [5]. Importantly, technology access and use among individuals experiencing homelessness is also high, with approximately 44% to 62% of homeless individuals reporting ownership of a mobile phone [6]. One study that sampled 249 homeless individuals in an emergency department found that 70.7% of the sample owned a mobile phone [7], and another study sampling 169 homeless youth in an urban city found that 62% of them owned a mobile phone, although only 40% reported that they had a working phone [8]. Moreover, smartphone dependency, that is, those who have access to smartphones but not broadband internet access, is highest among the lowest income groups in the United States [4]. Access to mobile technology among individuals experiencing homelessness is particularly important because these devices act as a portal by which they connect to critical resources. Mobile phones may be the only way they can search for employment and other resources and stay connected with family members and care providers.

### *Technology & Mental Health*

Technology-based interventions are increasingly being used in the medical field to increase access to care, including technology-based treatments for mental health issues such as anxiety, depression, and substance use [9]. These interventions have been structured around teletherapy, text messaging, and mobile apps. Research has shown that technology-based interventions are a promising way to deliver mental health treatment to various populations, including college students [10] and individuals with schizophrenia and bipolar disorder [11]. Technology-based mental health treatment has also been effective in clinical and nonclinical populations in primary care, emergency departments, and outpatient settings as well as in community settings [12,13]. It has been proposed that technology holds the potential to overcome disparities present in traditional health service delivery [14]. However, very few mobile interventions have been attempted with homeless youth. Existing technology-based interventions in this population have largely focused on reducing HIV risk behaviors [15,16]. Studies have also used technology as a method for improving the accessibility of case management and maintaining communication between homeless youth and social workers [17,18]. Collectively, these studies have shown that mobile technology holds promise for engaging youth in care by offering convenience and a source of connection. Here we seek to extend this broader line of research to attempt to develop a mental health intervention for homeless youth using mobile technology.

In our previous pilot study, 35 shelter-based homeless youth (aged 18-24 years) were given the opportunity to schedule 3 coaching sessions of 30 min each over the phone with a doctoral-level therapist over the course of 1 month [19]. Subjects were allowed to reach out to the study coach via text messaging during the intervention period. In addition, a mobile app was created for the study that sent participants a daily survey to assess sleep and stress, and a daily tip, which focused on various coping skills or motivational messages. This app was specifically geared toward youth. Satisfaction with the intervention was high, and most participants completed the 3 counseling sessions (57%). Conflicts between the youth's availability and the coach's schedule contributed to as many as 20% of youth being unable to benefit from the counseling sessions. In addition, this study found that the self-reported benefit of the automated tips in the study app was higher than the self-reported benefit of the counseling sessions. It is possible that participants may have liked the automated features such as the tips because they were readily available when they needed them.

Although the preponderance of evidence suggests that human support is a critical element of the most engaging and effective

technological interventions [20-23], most recent research shows high rates of engagement and clinical benefit such as reductions in depression, anxiety, and other symptoms of psychopathology and increases in well-being, even from fully automated technological interventions [24-27]. These new interventions make use of emerging technologies such as virtual conversational agents or *chatbots* [27]. Therefore, it might be that newer fully automated technological interventions may be as impactful in engagement as those that include human support, especially for different subpopulations. Fully automated technological interventions could be appealing to youth experiencing homelessness because they are continuously available—they do not require appointments or scheduling during normal working hours and because developing trust with human supporters might present additional barriers. These are especially important factors to consider when designing apps or interventions for homeless youth whose schedules and circumstances are highly variable.

### Objectives

On the basis of participant feedback from the pilot study, and in an effort to provide the intervention to a larger group while addressing clinician-identified barriers, which included the difficulty of meeting youths' needs outside of working hours, this study sought to evaluate the feasibility and acceptability of a fully automated mobile phone–based intervention for homeless youth. In expanding the intervention to a larger group, we expanded recruitment to youth accessing emergency overnight shelters and drop-in centers who often have even fewer options for accessing reliable mental health care. Although previous research has shown that fully automated interventions typically have lower engagement than human-supported interventions [28], with early withdrawal from the interventions and poor retention, the goal of this study was to provide youth with real-time mental health resources. We also sought to test a variety of different technology-based tools (push notifications, stand-alone apps, crisis text line, telephone hotline, and social network support tool) to determine which intervention modalities the youth preferred. The primary aims of this study were to (1) evaluate the acceptability of the interventions, as measured by participant satisfaction ratings collected at 3 months and 6 months, and (2) evaluate the feasibility of the interventions, as measured by participant retention and phone loss rates.

## Methods

### Participants

Participants for this pilot study were recruited from December 2017 to January 2019 from 2 homeless shelter agencies located in Chicago, Illinois. Potential participants were referred to the study by their case manager, responded to flyers distributed in shelters, or were recruited from in-person information sessions carried out by study staff in shelters. Interested youth were screened at the shelter by a member of the study staff.

Eligibility criteria for this study intervention included the following: (1) age 16 to 25 years, (2) English speaking, (3) experiencing housing instability as defined by "lacking a fixed, regular, and adequate nighttime residence OR whose primary nighttime residence is a shelter, institution, or a public or private place not designed for, or ordinarily used as, a regular sleeping accommodation for human beings," sharing the housing of other persons because of loss of housing [or] economic hardship, frequent moves, poor housing quality (eg, living in severely overcrowded housing), or imminently leaving the foster care system [29], and (4) willingness and ability to comply with requirements of the study protocol. Exclusion criteria included (1) unwillingness to adhere to study procedures and (2) previous enrollment in the pilot study. General informational sessions about the study were held for youth at local homeless shelters. A total of 103 youth were screened, and 101 were enrolled in the program. In addition, 1 youth was ineligible because of age and 1 was uninterested after reviewing the informed consent form; 1 youth withdrew from the study after enrolling but before completing the baseline questionnaires and receiving the phone. Thus, the final study sample included 100 participants.

All participants were sent a set of midpoint surveys at 3 months. Of these 100 participants, 48 (48%) completed the surveys. Those who completed the 3-month surveys with valid data had their paid phone service and study participation extended for 3 additional months and were sent the same set of surveys at 6 months (end point). Of the 48 participants who had received the 6-month surveys, 19 (40%) completed the end point surveys.

### Procedures

This field trial was approved by the Rush University Medical Center institutional review board (IRB). If eligible, participants went through the informed consent process with a member of the study staff and then filled out a series of baseline assessments on an iPad. Under the Illinois Emancipation of Mature Minors Act (750 ILCS 30), a 16-year-old minor is mature enough to manage his or her own affairs. Thus, the Rush IRB granted permission for youth aged 16 to 17 years to consent for themselves without a parent or guardian. Baseline assessments collected information about demographics and trauma history. Although it is beyond the scope of this paper, it should be noted that data were also collected on a range of mental health symptoms. After completing these surveys, youth were provided with an Android smartphone (which was theirs to keep after the study was complete) with an activated 3-month, 5 GB per month data plan, a phone case, and headphones. Even if the participant already had a smartphone, they were given a new device and asked to use this device for the duration of the study. Participants were shown how to use a selection of the 15 apps downloaded on the phone and were given a handout describing the uses of all 15 apps (see Multimedia Appendix 1). Participants were then given tips on how to conserve cellular data and how to use the phone responsibly and safely in an urban space.

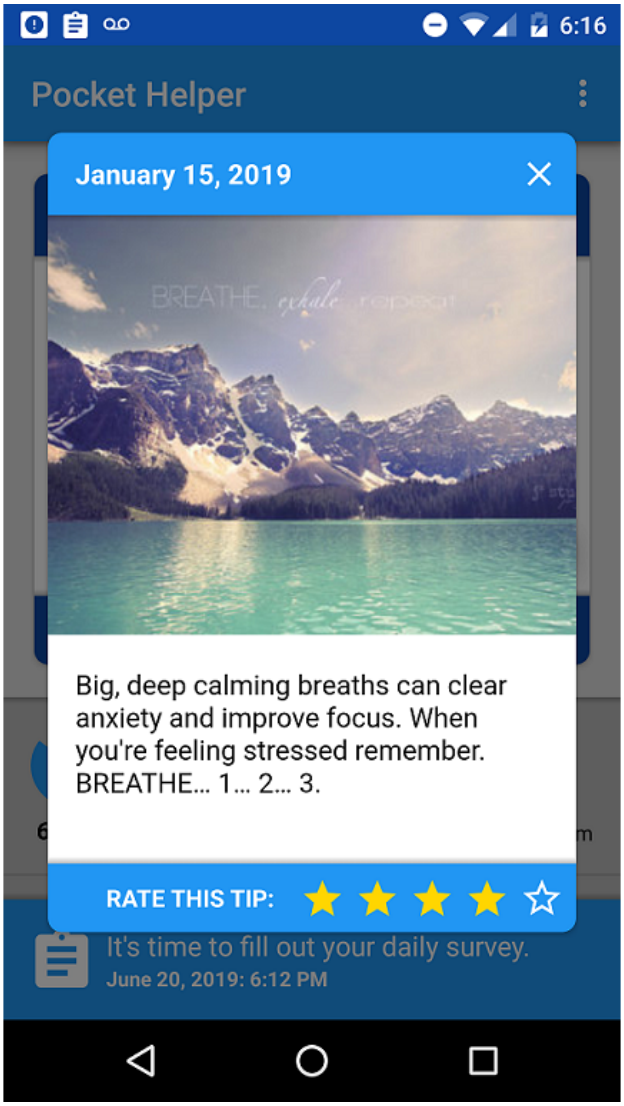
Participants were asked to engage in 2 activities daily while participating in this study. First, participants were sent a daily survey via the Pocket Helper 2.0 app that asked them to rate their stress level for the previous day on a scale from 1 to 7, pick 3 emotions from a list of positive and negative emotions that most accurately described how they felt that day, and then briefly state the biggest challenge they faced in the past day. Participant engagement in the study was gauged by their completion of daily surveys. Good engagement was defined as completing at least 50% of daily surveys in every 2-week period

of the study or 7 out of every 14 surveys. Good engagement was incentivized, and participants could earn a US $5 virtual Target gift card for every 2-week period that they had good engagement. This portion of the intervention was designed based on the principles of contingency management that has been shown to be effective in behavior change for youth [30]. Second, participants received a push notification for a daily tip sent to them via the Pocket Helper 2.0 app. The tips focused on mental health and provided various coping techniques and motivational messages (see Figure 1). Participants were asked to rate how much they liked each tip on a scale from 1 to 5 stars, with 5 being the highest rating of likability. The number of tip ratings was tracked but not incentivized. Participants were also not incentivized for using the other apps preloaded onto their phones.

Furthermore, 4 weeks before the 3-month midpoint date, participants were sent a link directing them to the midpoint survey. Participants were also sent a reminder to complete the survey via text or email each week up until the midpoint date. Surveys were sent out in advance because of the difficulty of engaging with these youth upon the first attempt to increase the likelihood that the surveys would be completed by the midpoint date. These surveys included a feedback questionnaire designed to assess the acceptability of different intervention components. If the participants completed the survey with valid responses (determined based on accurate responses to at least 4 of 6 validity items embedded in the survey), their paid phone and data service was extended for another 3 months. If they did not complete the surveys or did not get at least 4 validity items correct, participation in the program ended.

If participants received the 3-month extension, the program continued as described above. At 5 months, a set of end point surveys, identical to the midpoint surveys, were sent out. If participants completed the surveys and answered at least 4 validity items correctly, they received a virtual US $25 Target gift card. At the end of the 6-month study period, the phone company providing service, Sparrow Mobile, reached out to the participants with information on how they could continue their service with this provider. A member of the study team also reached out to the participants to offer other government resources for maintaining a phone service.

**Figure 1.** Example of a daily tip in the Pocket Helper 2.0 app.



## Mobile Phone Apps

The following mobile apps were included on each phone given to participants.

### *Pocket Helper 2.0*

Pocket Helper 2.0 is a mobile app designed specifically for this study. It is an updated version of an app that was developed for our previous pilot study [19]. The app offered several features, including a daily survey and a daily coping skills–focused tip (see Figure 1), sent to users via a push notification. Pocket Helper 2.0 also provided access to various platforms for participants to receive live emotional support (Koko, Illinois Warm Line, and Crisis Text Line, described in detail below) as well as an integrated support system that guides participants through brief cognitive behavioral interventions.

### *Koko*

Koko is a mobile intervention designed to provide emotional support. It is a further iteration of the Panoply platform that was tested as a Web-based intervention to facilitate cognitive restructuring through crowdsourcing [31]. Koko provides access to a peer network that provides emotional support, including support leveraging cognitive behavioral principles [32]. Users do not interact with other users directly but through a chatbot. Koko screens all the messages for indicators that a user might be an imminent danger to himself or herself or others and automatically initiates a crisis protocol in these situations.

### *Illinois Warm Line*

The Warm Line was developed by the Illinois Mental Health Collaborative for Access and Choice. Available Monday through Friday from 8 am to 5 pm, this is a telephone hotline that provides mental health support, mentoring, and advocacy from Peer and Family Support Specialists. There is no crisis support. This service is available for free throughout Illinois [33].

### *Crisis Text Line*

Unlike the Warm Line, the Crisis Text Line provides 24x7 text-based support specifically for individuals in a crisis. The service is available for free throughout the United States. Individuals can receive support through text from a trained crisis counselor. Crisis counselors help individuals using empathetic listening and collaborative problem solving to come up with a safety plan for the texter [34].

### *Pocket Helper 2.0 Support System*

The Pocket Helper 2.0 Support System is an automated system that provides brief (5-10 min) cognitive behavioral interventions, including strategies to promote relaxation, gratitude, emotion regulation, and effective goal setting.

### *IntelliCare Apps*

IntelliCare is a modular treatment suite consisting of 13 *miniapps*, each focused on a singular behavior change technique drawn from cognitive behavioral therapy and positive psychology [35]. Examples of apps include Purple Chill, which provides exercises youth can do to build relaxation and meditation skills; iCope, which sends users self-authored inspirational messages in times of stress; and Thought Challenger, which teaches users to identify and restructure unhelpful negative thought patterns. See Multimedia Appendix 1 for a description of all IntelliCare apps.

### *StreetLight Chicago*

StreetLight Chicago is a mobile app developed by Young Invincibles in collaboration with the Chicago Coalition for the Homeless with funding by the VNA Foundation. The app features up-to-date information on shelters, health clinics, emergency resources, and mental health services within the Chicago area [36].

## Assessment and Measurement

### *Demographics*

This 41-item questionnaire, developed by the study team, assesses demographic characteristics (eg, age, sex, sexual orientation, race, ethnicity, educational status, employment status, and pregnancy or parenting status), homelessness status, health and mental health history, treatment history, current medical insurance, and access to mobile technology. This questionnaire was administered at baseline, midpoint, and end point.

### *Childhood Trauma*

Possible trauma endured in childhood was assessed using 3 subscales (15 items) of the 28-item Childhood Trauma Questionnaire [37]. The selected scales were used to reduce participant burden and were focused on domains of interest. The 3 subscales contain 5 items each and assess physical, emotional, and sexual abuse. This self-reported measure asks participants to rate how often they experienced physical, emotional, and sexual abuse in childhood using a scale of 1 (never true) to 5 (very often true). Subscale scores range from 5 to 25, and total scores range from 15 to 75, with higher scores indicating a greater experience of childhood abuse. Clinically significant levels of abuse can be judged as follows on each subscale: physical (greater than 7), emotional (greater than 8), and sexual (greater than 5). This questionnaire was administered only at baseline to determine lifetime trauma exposure.

### *Anxiety*

The computer-adaptive Patient-Reported Outcomes Measurement Information System (PROMIS) Bank V10 Anxiety measure [38] assesses symptoms of anxiety in the past 7 days. This is a reliable measure that has been validated in numerous populations [39]. Participants select 1 of 5 responses ranging from never to always. A *t* score of 50 reflects the average rating for the US general population, and every 10 points represent 1 SD from the mean.

### *Depression*

The computer-adaptive PROMIS Bank V10 Depression measure [38] assesses symptoms of depression in the past 7 days. This is a reliable measure that has been validated in numerous populations [39]. Participants select 1 of 5 responses ranging from never to always. The scoring range for this measure is the same as the PROMIS Anxiety scale.

### *Feedback*

The perceived benefit of the study was assessed using a 16-item questionnaire developed by the study team. This questionnaire asked participants to rate the overall study and specific intervention tools. Questions asked participants to respond on a 5-point Likert scale with responses ranging from 0 (not at all) to 4 (a lot), with an option for 5 (not applicable, did not use feature). Qualitative responses on which features were liked / disliked and why youth preferred certain features were also collected. This questionnaire was administered only at midpoint and end point.

## Results

### Statistical Analysis

Data for this study were collected in REDCap, a secure Web app for managing online surveys. Descriptive analyses were run in SPSS 22 Premium to determine frequencies, means, and standard deviations of baseline demographic data and feedback data at the 3-month midpoint and 6-month end point of the study for participants who completed the assessments with valid data.

### Data Exclusion

Baseline data for 1 participant were lost because of internet connectivity issues at the shelter where they were enrolled. Data were analyzed for the remaining 99 participants.

### Sample

A total of 100 youth consented and were enrolled in the field trial. The average age of the sample was 20.03 years (SD 1.83, range 16-24). On average, the participants had been homeless 3.4 times (SD 3.5) over their lifetime and 2.3 times (SD 2.7) in the past year. The average age of the participants at the first episode of homelessness was 17.0 years (SD 3.9). Furthermore, the mean length of the current episode of homelessness was 8.2 months (SD 13.3), and on average, the longest episode of homelessness was 13.7 months (SD 17.9). At the time of enrollment, 35 participants (35%) were enrolled in school and 27 (27%) were employed. In addition, 6 (6%) participants were currently pregnant and 18 (18%) were a parent of a dependent-aged child. Notably, 41 (41%) of the participants already owned a mobile phone at the time of enrollment. Furthermore, 70 (71%) of the youth reported having received therapy or counseling for mental health issues in their lifetime and 38 (38%) reported being currently engaged in therapy or counseling. As illustrated in Table 1, most participants in our sample also reported enduring various forms of abuse in childhood. At baseline, average self-reported anxiety levels (mean 60.1, SD 9.7) and depression levels (mean 58.6, SD 10.2) were both elevated compared with the general population. See Table 2 for additional demographic characteristics.

**Table 1.** Self-reported abuse history of an urban sample of unstably housed youth based on Childhood Trauma Questionnaire score. (Childhood Trauma Questionnaire scores indicating a clinically significant level of abuse are detailed in the assessment description above.)

| Type of abuse | Mean (SD) |
|---|---|
| Physical abuse | 12.2 (6.4) |
| Emotional abuse | 15.1 (6.9) |
| Sexual abuse | 8.9 (6.3) |
| Total score | 36.2 (16.7) |

**Table 2.** Demographic characteristics of an urban sample of unstably housed youth (n=99).

| Characteristic | Value, n (%) |
|---|---|
| **Gender** | |
| Male | 53 (54) |
| Female | 39 (39) |
| Male to female transgender | 3 (3) |
| Female to male transgender | 4 (4) |
| **Sexual orientation** | |
| Straight or heterosexual | 75 (76) |
| Gay or lesbian | 9 (9) |
| Bisexual | 8 (8) |
| Other | 5 (5) |
| Refused | 1 (1) |
| Don't know | 1 (1) |
| Ethnicity (Hispanic or Latino) | 23 (23) |
| **Race** | |
| Black or African American | 57 (58) |
| American Indian or Alaskan Native | 2 (2) |
| Native Hawaiian or Pacific Islander | 2 (2) |
| White non-Hispanic | 10 (10) |
| Mixed | 19 (19) |
| Other | 5 (5) |
| Refused | 2 (2) |
| Don't know | 2 (2) |

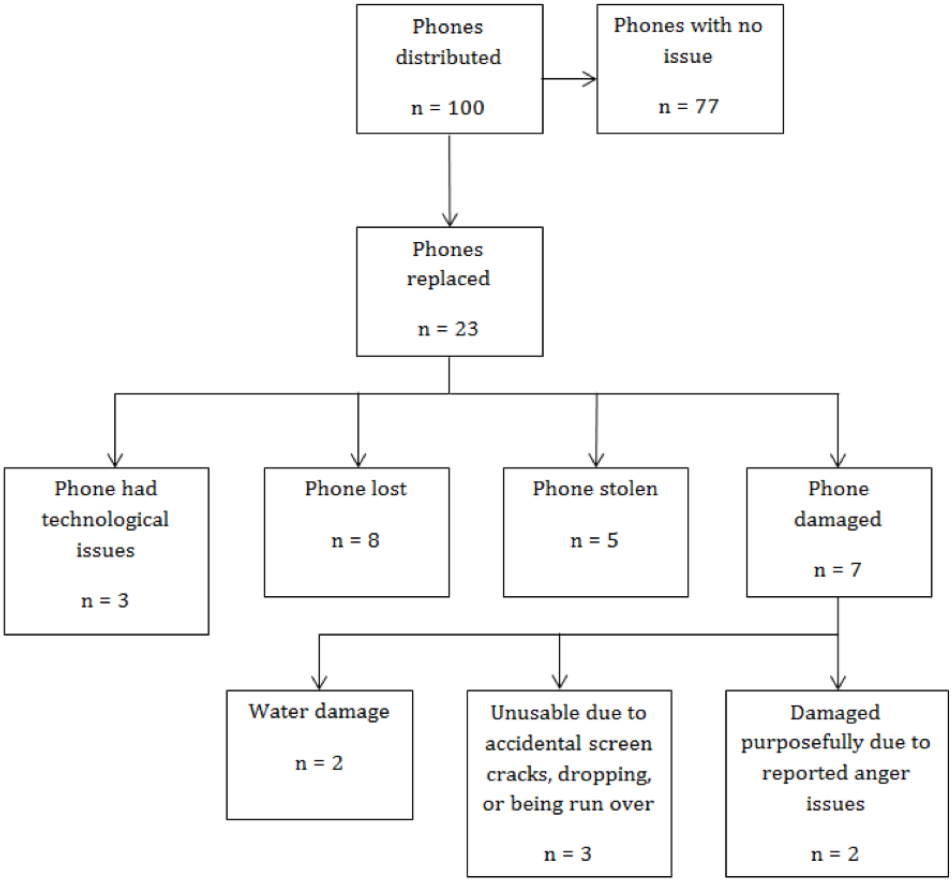
## Feasibility

Overall, 48 of the 100 participants (48%) completed the midpoint assessments, and all participants who completed these assessments provided valid data. Of the 48 who had received end point assessments, 19 (39%) completed the measures and all provided valid data. Although this retention rate is not high, it is consistent with rates reported from previous studies evaluating automated mental health interventions [21].

We evaluated whether there were differences in baseline characteristics of those who completed the assessments compared with those who did not complete the assessments. Those who did not complete the midpoint survey reported significantly lower levels of childhood emotional abuse at baseline (mean 13.47, SD 6.77) than those who completed the midpoint survey (mean 16.85, SD 6.67; $d$=0.50, $P$=.01). Those who did not complete the midpoint survey were also less likely to own a mobile phone at baseline ($\chi^2_1$=6.3; $P$=.01) and have medical insurance at baseline ($\chi^2_1$=5.9; $P$=.02) compared with those who completed the midpoint survey. At end point, those who did not complete the survey were more likely to have been hospitalized for a psychological problem in their lifetime than those who completed the survey ($\chi^2_1$=5.30; $P$=.02). Notably, these differences were no longer significant after Bonferroni correction for multiple testing. There was no association between completion status of the 2 assessments and other demographic characteristics (sex, sexual orientation, age, race, ethnicity, children, time spent homeless, school enrollment, employment status, receipt of psychotherapy, and psychotropic medication usage) or anxiety and depression symptom severity at baseline. Given the large number of tests conducted, these findings suggest that those who responded to the surveys were largely similar to those who dropped out of the study; however, there may be some meaningful differences between the groups, and the survey results should be interpreted in light of this potential bias.

Over the course of the study, 23 study phones were replaced (23%) across the 100 participants. Phones were replaced for various reasons including loss, theft, damage, and technical issues (see Figure 2).

**Figure 2.** Phone distribution and reasons for replacement.




## Acceptability

### *3 Months (Midpoint)*

At 3 months, overall satisfaction with the study was high. Of the 48 participants who completed the midpoint assessments, 35 (73%) would recommend the study to somebody else. In addition, 30 participants (63%) reported a moderate-to-high amount of benefit from the study. If participants indicated that they benefited in any amount from the study, they were asked to describe how. There were a number of reasons they stated including learning new coping skills and receiving motivation from the daily tips. The most common themes were being able to reflect on and contextualize their emotions via the daily survey and having access to a working cellphone.

The features included in the intervention were used to varying degrees at the 3-month midpoint. The StreetLight app was the most used feature, with 79% (38/48) of participants reporting that they had used the feature. The Pocket Helper 2.0 Support System was used almost as much, with 77% (37/48) of participants reporting usage. There was moderate usage of the IntelliCare apps (29/48, 60%) and the Crisis Text Line (28/48, 58%). Koko and the Illinois Warm line were the least used features. Just under half of the participants reported using Koko (23/48, 48%) and fewer reported using the Illinois Warm Line (20/48, 42%).

Figure 3 illustrates the perceived benefit ratings for each study component featured within Pocket Helper 2.0 and the separate StreetLight Chicago and IntelliCare apps. These data take into account all 48 participants who completed the midpoint survey, including those who indicated that they did not use a particular feature. The daily tips and daily surveys were reported to be the most helpful features with 85% (41/48) and 69% (33/48) of participants reporting that they benefitted at least a moderate amount, respectively. The StreetLight app was at least moderately helpful for 56.3% of participants (27/48), whereas the Pocket Helper 2.0 Support System, IntelliCare Apps, and Crisis Text Line were found to be at least moderately helpful for 33% to 38% of participants. Koko and the Illinois Warm Line were reported to be the least beneficial features, with only 13% to 15% of individuals reporting at least moderate benefit for both features.

Participants were also asked to select the feature they liked the most and the feature they liked the least in the Pocket Helper 2.0 app. Table 3 displays the percentage of people who selected each feature as being the most or least liked feature at the midpoint. The daily tips were reported to be the most liked feature (22/48, 46%), with the daily surveys close behind (21/48, 44%). The Illinois Warm Line was the least liked feature (13/48, 27%), followed by the daily surveys and Koko (9/48, 19%). Notably, there was much greater consensus on the most liked features compared with the least liked features. It is also interesting to note that the daily surveys dichotomized, with some youth reporting that they liked this feature and other saying that they disliked this feature.

**Figure 3.** Self-reported benefit of intervention features at the 3-month midpoint. N/A: not applicable.

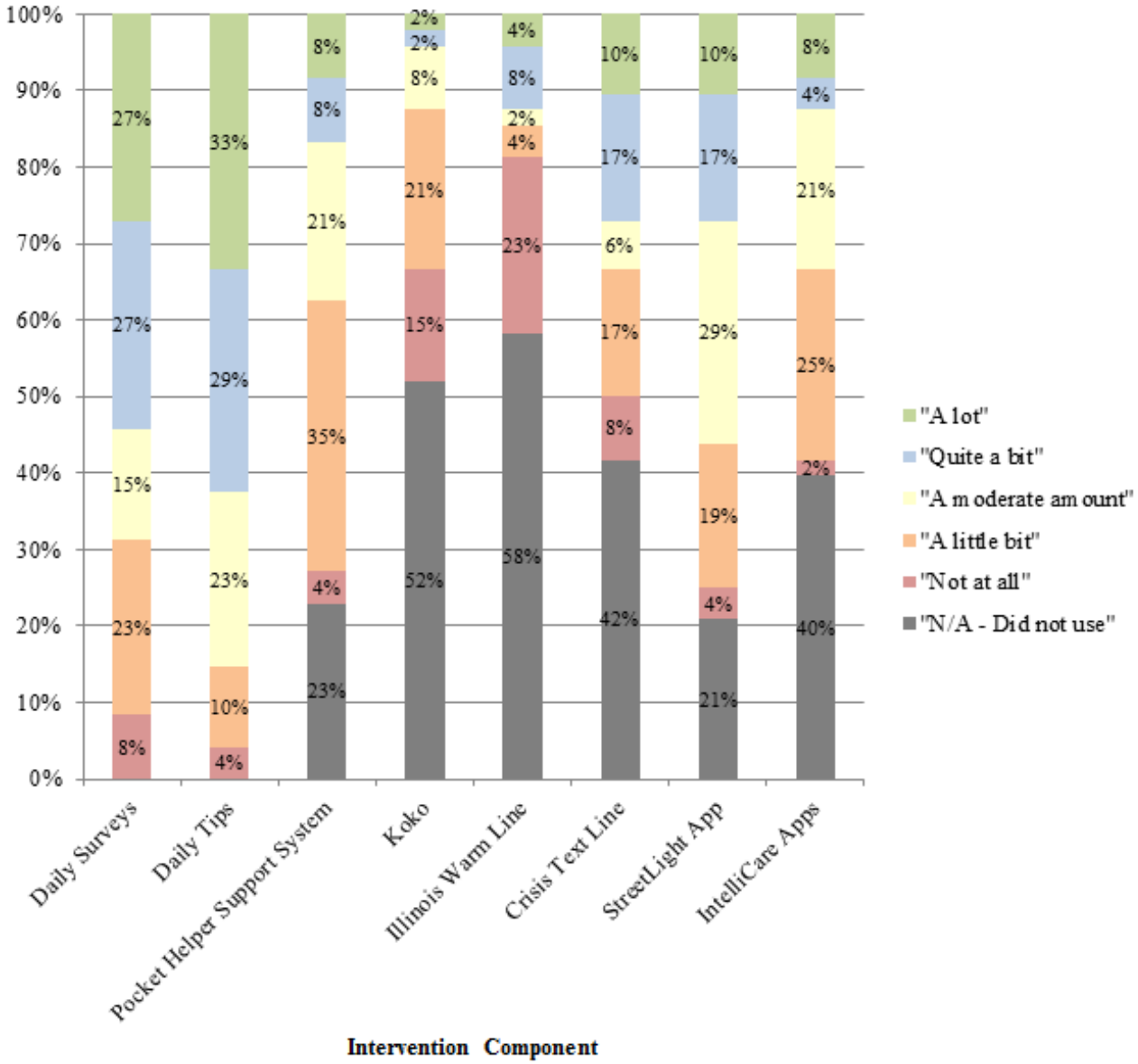



**Table 3.** Self-reported most and least liked features in Pocket Helper 2.0 app. (3 months, n=48; 6 months, n=19.)

| Pocket Helper 2.0 feature | Most liked feature at 3 months, n (%) | Least liked feature at 3 months, n (%) | Most liked feature at 6 months, n (%) | Least liked feature at 6 months, n (%) |
|---|---|---|---|---|
| Daily surveys | 21 (44) | 9 (19) | 7 (37) | 3 (16) |
| Daily tips | 22 (46) | 5 (10) | 8 (42) | 2 (11) |
| Pocket Helper 2.0 Support System | 3 (6) | 8 (17) | 2 (11) | 3 (16) |
| Koko | 1 (2) | 9 (19) | N/A | 6 (32) |
| Illinois Warm Line | 1 (2) | 13 (27) | 1 (5) | 4 (21) |
| Crisis Text Line | N/A | 4 (8) | 1 (5) | 1 (5) |

### *6 Months (End Point)*

In total, 19 of the youth who qualified to continue post-3-month assessment had completed the 6-month end point assessment at the time of study analysis. Satisfaction at 6 months was still high, with 16 participants (84%) reporting that they would recommend the study to somebody else. A majority of participants (13/19, 68%) reported that they benefited at least *a moderate amount*. Similar to the midpoint of the study, participants who benefited from the study were asked to describe how. There were multiple reasons stated, including being able to use the daily tips in times of stress and benefiting from tracking daily actions in one of the IntelliCare apps. Again, the

most common themes were motivation to reflect on day-to-day emotions via the daily survey and ownership of an active phone.

At the 6-month end point of the study, participants were asked again to report on their usage of the various apps. The Pocket Helper 2.0 Support System continued to be the most used feature, with 79% of participants (15/19) indicating usage. Also consistent with the 3-month data, StreetLight Chicago was the second most used feature with a similar usage rate of 74% (14/19). The usage of the IntelliCare apps and the Crisis Text Line remained similar to each other, although the usage rates of these dropped slightly compared with the 3-month time point. Eleven participants (57%) reported using the IntelliCare apps and 10 (53%) used the Crisis Text Line. The Illinois Warm Line and Koko were still the least beneficial features. However, the usage of the Illinois Warm Line remained the same while usage of Koko dropped noticeably from the 3-month time point. Eight participants (42%) reported using the Illinois Warm line, while only 6 participants (32%) reported using Koko. Only two of the 19 participants (11%) reported that they did not use any features other than the daily tips and surveys. Figure 4 illustrates the perceived benefit of each tool at the 6-month assessment. Similar to the midpoint data, the 6-month data included participants who reported that they did not use the various features. Consistent with the 3-month data, daily tips and daily surveys were rated as the most helpful features with 14 (74%) and 15 (78%) participants reporting at least a moderate benefit from the features, respectively. The StreetLight app, Pocket Helper 2.0 Support system, and IntelliCare apps were found to be at least moderately helpful for 26-42% of participants. Notably, the perceived benefit of the Crisis Text Line decreased from the midpoint to the end point with 16% (3/19) reporting at least a moderate benefit. The same number of participants reported a benefit from the Illinois Warm Line at 6 months. Similar to the midpoint, Koko was found to be the least helpful feature, with only 11% (2/19) of participants reporting at least a moderate benefit from the feature.

**Figure 4.** Self-reported benefit of intervention features at the 6-month end point. N/A: not applicable.

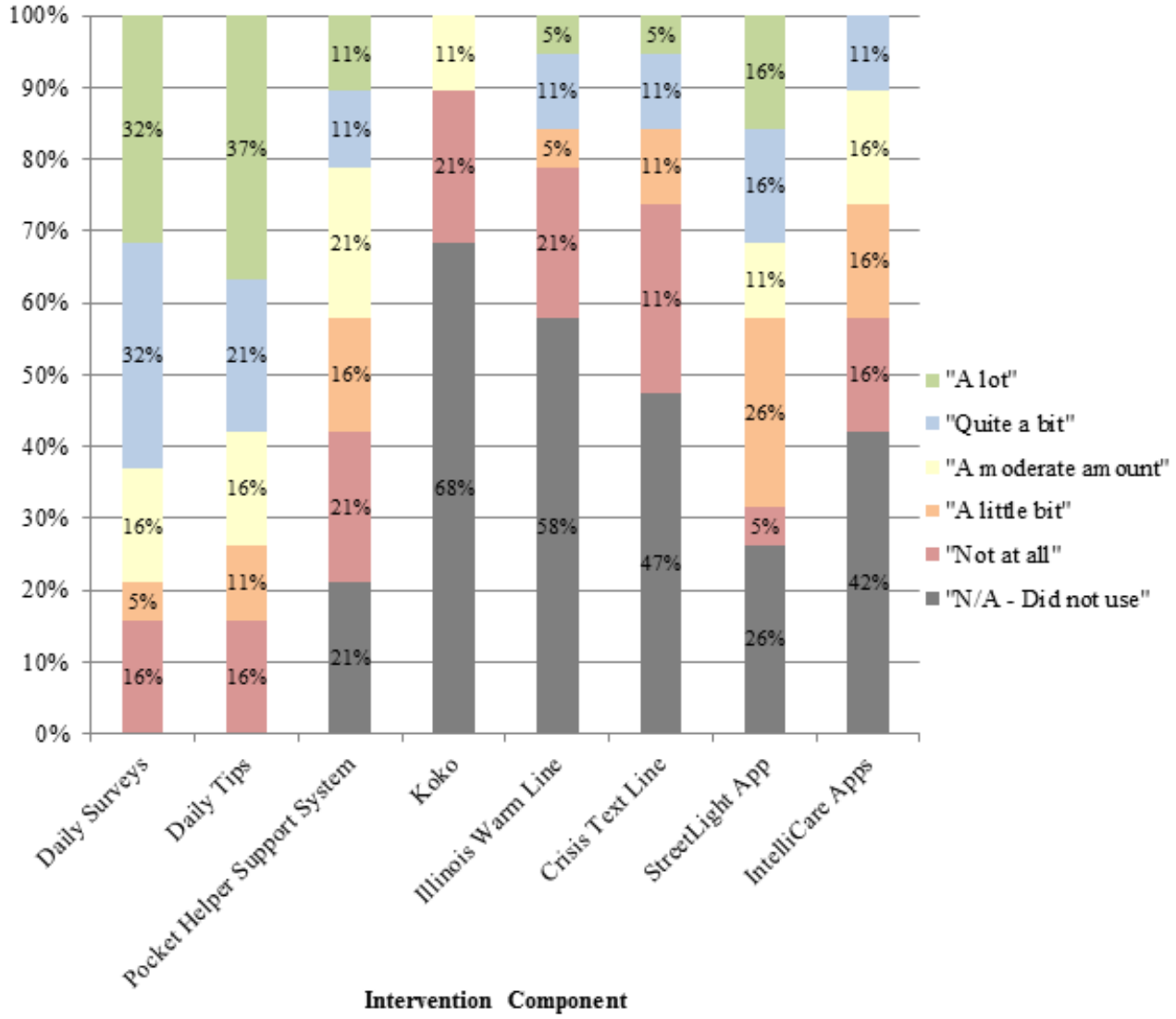


Table 3 also displays the percentage of participants who selected each feature as being the most or least liked feature at the end point. Participants overwhelmingly indicated the daily surveys (7/19, 37%) and daily tips (8/19, 42%) as their favorite features of the study app, Pocket Helper 2.0. In addition, 2 participants (11%) reported that their favorite feature was the in-app Pocket Helper 2.0 Support System, whereas 1 participant (5%) reported that they liked the Crisis Text Line and the Illinois Warm Line the most. Participants rated Koko (6/17, 32%) and the Illinois Warm Line (4/17, 21%) the lowest. Furthermore, 3 participants (16%) liked the daily surveys or Pocket Helper 2.0 Support System the least, 2 (11%) liked the daily tips least, and 1 (5%) liked the Crisis Text Line least.

### *Daily Tip Ratings*

As the daily tips were rated as the most favorable and beneficial intervention feature, the specific tip ratings were analyzed to identify whether any patterns emerged. A pool of 49 tips was created to be included in Pocket Helper 2.0 (See Multimedia Appendix 2 for a list of all tips). Youth were sent a different tip at random every day for the first 49 days until they had received every tip. Starting at day 50, tips were delivered based on the youth's rating of the tip, such that tips rated to be most liked over the first 49 days were sent more frequently starting on day 50. Therefore, participants' responses to the initial presentation of each tip in the first 49 days were analyzed.

On average, participants who had at least 1 tip rating rated 14.61 tips during the first 49 days (SD 12.39, minimum=1, maximum 48, median=10). Table 4 portrays the average ratings for the 6 highest-rated and the 6 lowest-rated tips. Tips were rated on a scale of 1 to 5, with 5 being the highest rating of likability. As illustrated in Table 4, the lowest-rated tip had a mean rating of 4.00 out of 5, suggesting that, overall, all tips were rated highly by the youth. Notably, the highest rated tips acknowledged challenges and provided motivational messages about overcoming and moving past struggles.

**Table 4.** Tip rating descriptive statistics (in order of preference).

| Tip | n[a] | Mean (SD) | 95% CI |
|---|---|---|---|
| **Highest-rated tips** | | | |
| Don't put off until tomorrow what you can get done today. | 34 | 4.71 (0.62) | 4.51-4.92 |
| "It's not whether you get knocked down, it's whether you get up." [Vince Lombardi] | 24 | 4.71 (0.55) | 4.49-4.93 |
| We all have setbacks. It's okay to be disappointed, but don't let them break you. | 29 | 4.62 (0.68) | 4.37-4.87 |
| No one can predict the future. Sometimes we have to wait and see what happens. Try not to spend too much time in the future. Stay in the present moment. | 28 | 4.57 (0.92) | 4.23-4.91 |
| Progress requires patience. Few things that are very important to us can be achieved in one day, but if you stick to the plan you'll get there. | 27 | 4.57 (0.88) | 4.25-4.90 |
| Motivation can be contagious. Surround yourself with people who are working hard towards their goals, and hold each other accountable. | 23 | 4.57 (0.79) | 4.24-4.89 |
| **Lowest-rated tips** | | | |
| Checking something off your to-do list every day can help you feel accomplished, even if it's small. Pick one task to achieve for the day. | 29 | 4.17 (0.91) | 3.84-4.49 |
| Tell someone you appreciate them. Showing gratitude to the people who are important to us can make YOU feel great! | 24 | 4.17 (1.05) | 3.75-4.59 |
| Just because you think something doesn't make it true. If it's not helping you, see if you can find another way of looking at it, or let it go. | 30 | 4.15 (1.23) | 3.73-4.57 |
| It's always hard to establish a new skill. Remember that it takes practice when you try something new. Try it out for a week and then decide if it helps. | 24 | 4.13 (1.33) | 3.59-4.66 |
| How's your day going today? Check in with yourself and see how you're feeling. What are you feeling in your body? How's your mood? Whether you're feeling happy, sad, or anywhere in between, I'm sending you a pick-me-up! | 32 | 4.00 (1.27) | 3.56-4.44 |
| Don't struggle with what you can't change, but don't think you have no control at all over your environment. Focus on what IS in your control. | 29 | 4.00 (1.33) | 3.51-4.49 |

[a]n indicates the number of participants that rated the tip upon its first presentation (within the first 49 days).

## Discussion

### Principal Findings

Overall, our findings suggest that an automated mobile phone–based intervention can be a promising way of engaging homeless youth around mental health. We were able to successfully recruit 100 homeless youth into the study, including many youth who were accessing emergency overnight shelters and drop-in centers (34% of current sample, 34/100) that traditionally serve more transient youth with less access to mental health services than their shelter-based peers. Overall, 77% of the study sample appeared to keep and maintain their cellphones in good condition over the 6-month study period. Throughout the entire study, only 20 of the 100 distributed cell phones were reported to be lost, stolen, or damaged, and an

additional 3 phones had technical issues. Collectively, these data support the feasibility of a fully automated intervention over an extended period in a population of homeless youth.

Overall, 63% of participants at 3 months and 68% of participants at 6 months reported that they received at least moderate benefit from the intervention. Thus, the intervention appeared to be well-liked by those who maintained participation. Though participants who stayed engaged through the midpoint or end point reported that they benefited from the study, the actual retention rates from baseline to end point were lower than predicted. Overall, 48% of the total sample (48/100) completed the 3-month assessment, and only 19% of the total sample (19/100) completed the 6-month assessment. As previously noted, the youth in this study experienced greater housing instability than those from the interim housing programs recruited into the pilot study discussed above [19]. This pilot study also lasted 1 month compared with 6 months; both of these reasons might explain the much higher rates of retention (33/35) observed in the pilot study compared with the fully automated intervention described in this study. It is also possible that the participants in this study had more competing day-to-day priorities that could have contributed to the attrition rate. Further research is needed to explore what factors may affect engagement with mobile interventions for homeless youth.

Despite the high rate of mental health problems reported in this population, it is important to note that only 38 participants (38%) indicated that they were currently engaged with therapy services at baseline, and many of the youth in this study had access to these services at their shelter locations. By contrast, over 75% of participants who responded to the surveys reported that they used our brief self-help system at the 3-month follow-up. This means that although we were not able to retain as many people as we would have liked, our rate of engagement at the study midpoint was greater than the rate engaged in traditional mental health services at the time participants enrolled in the study. This again suggests that an automated, mobile-based tool kit might be a viable option for engaging a greater number of homeless youths in mental health care. It is important to note that the Pocket Helper 2.0 app was specifically designed for homeless youth based on initial input from these youth [40] and was refined based on feedback received during a previous pilot trial [19]. Involving the target end users in the design process from the start is a standard practice in the co-design process. Co-design may be especially important for underserved or marginalized populations such as homeless youth to ensure that tools are truly developed to meet their needs [41]. Co-design has been used successfully in other populations to develop tools tailored to their needs and challenges [42]. Therefore, it is possible that engagement was relatively high because the app was tailored to the needs of these youth and that not all mobile interventions would be equally acceptable to homeless youth.

One goal of this study was to evaluate how youth used the various feature modalities of the intervention. The features reported to be of the greatest benefit were the daily tips and daily surveys, which all youth received as a push notification to their phones. In fact, at both 3 and 6 months, participants overwhelmingly rated these 2 features of the Pocket Helper 2.0 app most favorably, with 69% to 85% reporting at least moderate benefit from these features across both follow-up time points. Previous studies have shown that the very act of self-reflection and self-monitoring can be therapeutic in a treatment context [12,43,44]. It is important to note that the surveys were incentivized with small payments, which may have affected the acceptability ratings for this intervention feature. However, the tips were also rated very favorably without any incentive, suggesting that participants may be responding positively to the interactive style of engagement with these features. The tip ratings also seem to suggest that participants particularly liked receiving tips that were motivational and encouraged them to overcome struggles and work toward progress. Given that homeless youth are often isolated with limited social support [45], having this type of motivational feature may be important for engaging the youth. Future directions of this project should more carefully evaluate specific reasons why participants enjoyed these features of the Pocket Helper 2.0 app so much more than other apps provided to them in this study.

The StreetLight app, Pocket Helper 2.0 Support System, IntelliCare apps, and Crisis Text Line were used by the majority of participants; however, it is clear that the perceived benefit from these features did not match the perceived benefit from the daily tips and surveys. These features all involved minimal-to-no direct human interaction but still required participants to be proactive in engaging with them, unlike the tips and surveys that were sent as a daily push notification. Out of the 4 aforementioned features, the StreetLight app and Pocket Helper 2.0 Support System were the most used features (74%-79% usage over the study), though not all those who used these features found them to be beneficial (37%-56% reported at least moderate benefit). Notably, both the StreetLight app and Pocket Helper 2.0 Support System were specifically designed for homeless individuals, whereas the IntelliCare apps and Crisis Text Line were designed without a specific subpopulation in mind. It is also noteworthy that the brief cognitive behavioral self-help tool was as engaging and appealing to participants as an app that provided real-time information about local resources such as food and shelter. This suggests that homeless youth in this study placed equal value on both basic needs and mental wellness, and further suggests that by removing logistical barriers to care, youth are able to and want to prioritize mental health.

With respect to the IntelliCare apps and Crisis Text Line, a minority of participants (16%-33%) found these features to be at least moderately beneficial. Both the Crisis Text Line and the IntelliCare apps require repeat engagement for maximum benefit, whereas the StreetLight app and Pocket Helper 2.0 Support System are able to provide support in a single interaction. Moreover, the daily tips and surveys were pushed to participants' phones automatically and did not require the youth to initiate engagement with the app. Overall, these findings suggest that participants preferred tools that required minimal investment.

Koko and the Illinois Warm Line were consistently among the least used features, with 48% and 42% of responders indicating usage of these features at 3 months, respectively. The usage of Koko dropped to 32% at 6 months, whereas the usage of the Illinois Warm Line stayed consistent at 42%. The reported

benefits of the Illinois Warm Line and Koko were also low compared with other features. Less than 15% of youth reported at least a moderate benefit for each feature at the midpoint. By the end point, only 3 of 19 (15%) participants reported at least a moderate benefit from the Illinois Warm Line and 2 of 19 (11%) participants reported at least a moderate benefit from Koko. Youth may prefer the features such as the Crisis Text Line over the Warm Line because it allows them to engage via text messaging rather than over the phone, consistent with previous studies that have shown that texting is the preferred method of communication in this age group [46,47]. It is also possible that the youth disliked the features that required more social interaction (ie, Illinois Warm Line and Koko) because of poor experiences with the mental health system in the past and a general sense of mistrust of telling *strangers* about their problems [48,49]. Trust difficulties coupled with these adverse treatment experiences in the past may increase youth's skepticism toward apps requiring social interaction with others.

It is important to note that the usage and likability of the features varied between participants and between time points. For example, at 3 months, the daily survey was rated as the second most liked feature and was also tied as the second least liked feature. This may indicate some degree of dichotomization of participant preferences and should give pause in developing a *one-size-fits-all* approach. Although an option is to provide all possible tools with the hopes that it might provide something desirable to the maximum number of individuals, it is unclear whether there are any adverse impacts associated with providing youth with tools they do not like or do not find beneficial. One of the advantages of technology-based interventions is the option for customization or digital precision approaches. Future studies should also seek to evaluate adaptive iterations of this intervention, such that these apps can be tailored to the specific mental health needs of the youth using them or that specific features may be more relevant at certain times of a youth's life. Future research should also explore the extent to which the inclusion of less favorable features may or may not detract from the usage of more favorable ones.

The results of our study suggest that participants were actively engaged in our intervention. At the same time, approximately one-third of the participants at the midpoint and end point reported that simply having access to a working phone was one of the most important benefits of study participation. Not surprisingly, addressing digital poverty in this population not only increases access to mental health care services but also allows for greater independence in other areas of youth's lives (eg, being able to contact a potential employer), which could also positively impact mental health. This possibility should be explored in greater detail in future follow-up studies with homeless youth.

Although a thorough discussion of the ethics of providing interventions using a technology platform is well beyond the scope of this paper, it is important to highlight the need to weigh the pros and cons of utilizing this intervention in lieu of formal therapy. The authors do not assert that this intervention should replace traditional care, but rather see it as a bridge to future treatment. When the alternative is no mental health care, providing youth with the tools they need to address their mental health concerns in *real time* is an ethical and clinically sound strategy.

Finally, the low retention rates in this study warrant further exploration. Although some recent research studies have demonstrated that automated interventions without a human component can yield high levels of engagement and do not necessarily increase the risk of attrition [24,26], many studies have found that human support leads to higher rates of engagement [50]. Thus, although our participants reported liking these automated features, this does not mean the features were sufficient to keep them engaged. Of course, there is also the possibility of *happy abandonment* insofar as youth might have felt they got everything they could expect from these features and saw no incremental benefit of continuing to use them. It is important to note that previous work has not been done in homeless youth, and it is not known which variables unique to this population may maximize the likelihood of engagement with a fully automated intervention. It is possible that sustained engagement with an intervention that does not yield immediately measurable results is difficult, particularly when there are so many competing priorities. Future research should explore ways to increase engagement of homeless youth in a mobile phone–based mental health intervention over a longer time or evaluate whether a brief, more targeted intervention may be more efficacious and sustainable in this population.

## Limitations

One major limitation of this study is selection bias. The youth in this study were all connected to mental health and/or case management support through the shelter networks in the Chicago area. Future iterations of this work should also try to reach youth living on the streets without access to interim housing or drop-in shelters. Related to this point is that feedback about the intervention was only obtained from youth who demonstrated some level of continued engagement, and it is unknown why youth lost at follow-up assessment time points discontinued study participation. A better understanding of the variables that contribute to retention among homeless youth would allow us to more successfully tailor future iterations of technology-based interventions for this population.

As the data collected in this study were primarily quantitative, less is known about the specific reasons why youth preferred certain tools (eg, why the daily tips and surveys emerged as the most highly rated components of the intervention). In particular, because the surveys were incentivized, we were unable to determine whether the payment affected the youths' acceptability ratings and whether this feature would have been rated less favorably without the incentive. Conducting focus groups or individual interviews with homeless youth in the future would allow for a more careful assessment of app preferences, a better understanding of the perceived benefits of study participation, and participant-driven suggestions for future iterations of fully automated interventions in this population.

## Conclusions and Future Directions

The fully automated, mobile phone–based mental health intervention evaluated in this study demonstrates both feasibility and acceptability in providing mental wellness tools to

underserved homeless youth with limited access to traditional care. Overall, it appears that participants tended to prefer both automated and self-help features, as compared with ones involving more direct human interaction. This may result from this work being done in homeless youth as youth, especially digital natives who have been raised in the digital age, may be more comfortable connecting to people and receiving information and support through digital means. Most youth have used the internet to find health information or download a health app, and many of them use it to connect to other people regarding health concerns [51]. The fact that tips and surveys were clearly favored suggests that these youth prefer both brief and passive interactions with technology. In fact, youth reported continued usage of the Pocket Helper 2.0 Support System over the course of the study, and even preferred it over the StreetLight app, which provides citywide resources related to basic needs for homeless youth. Collectively, these results suggest that youth prefer digital tools that engage with them and that require only brief interactions for benefit. A critical next step is to evaluate the perceived clinical benefits of this intervention. As previously mentioned, mental health data were collected at each time point of the study, and future research should evaluate whether participation in this fully automated intervention yields reduction in self-reported mental health difficulties and improvements in overall mental wellness.

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## Conflicts of Interest

None declared.

Multimedia Appendix 1
Guide to apps provided to participants in study.
[PDF File (Adobe PDF File), 128 KB - mental_v6i10e15144_app1.pdf ]

Multimedia Appendix 2
Tip rating descriptive statistics (in order of preference; greatest to least).
[PDF File (Adobe PDF File), 166 KB - mental_v6i10e15144_app2.pdf ]

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## Abbreviations

**IRB:** institutional review board
**PROMIS:** Patient-Reported Outcomes Measurement Information System

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