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Contents

Original Papers

Original Paper

Characterizing Participation and Perceived Engagement Benefits in an Integrated Digital Behavioral Health Recovery Community for Women: A Cross-Sectional Survey

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Abstract

Background: Research suggests that digital recovery support services (D-RSSs) may help support individual recovery and augment the availability of in-person supports. Previous studies highlight the use of D-RSSs in supporting individuals in recovery from substance use but have yet to examine the use of D-RSSs in supporting a combination of behavioral health disorders, including substance use, mental health, and trauma. Similarly, few studies on D-RSSs have evaluated gender-specific supports or integrated communities, which may be helpful to women and individuals recovering from behavioral health disorders.

Objective: The goal of this study was to evaluate the SHE RECOVERS (SR) recovery community, with the following 3 aims: (1) to characterize the women who engage in SR (including demographics and recovery-related characteristics), (2) describe the ways and frequency in which participants engage with SR, and (3) examine the perception of benefit derived from engagement with SR.

Methods: This study used a cross-sectional survey to examine the characteristics of SR participants. Analysis of variance and chi-square tests, as well as univariate logistic regressions, were used to explore each aim.

Results: Participants (N=729, mean age 46.83 years; 685/729, 94% Caucasian) reported being in recovery from a variety of conditions, although the most frequent nonexclusive disorder was substance use (86.40%, n=630). Participants had an average length in recovery (LIR) of 6.14 years (SD 7.87), with most having between 1 and 5 years (n=300). The most frequently reported recovery pathway was abstinence-based 12-step mutual aid (38.40%). Participants reported positive perceptions of benefit from SR participation, which did not vary by LIR or recovery pathway. Participants also had high rates of agreement, with SR having a positive impact on their lives, although this too did vary by recovery length and recovery pathway. Participants with 1 to 5 years of recovery used SR to connect with other women in recovery at higher rates, whereas those with less than 1 year used SR to ask for resources at higher rates, and those with 5 or more years used SR to provide support at higher rates. Lifetime engagement with specific supports of SR was also associated with LIR and recovery pathway.

Conclusions: Gender-specific and integrated D-RSSs are feasible and beneficial from the perspective of participants. D-RSSs also appear to provide support to a range of recovery typologies and pathways in an effective manner and may be a vital tool for expanding recovery supports for those lacking in access and availability because of geography, social determinants, or other barriers.

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KEYWORDS

substance use disorder; mHealth; mental health; substance addiction; rehabilitation

Introduction

Substance use disorders (SUDs) affect over 20 million individuals aged 12 years and older in the United States [1]. In addition, over 22 million individuals aged 18 years and above have resolved an SUD, with nearly half of those identifying as a person in recovery [2]. The etiology, mortality, and progression of SUDs differ between men and women [3], and research suggests that women are more likely to have social networks with a greater prevalence of SUD, which can be a major barrier to maintaining recovery [4,5]. Resolving an SUD and initiating recovery are associated with engagement in formal treatment services (eg, inpatient SUD treatment, pharmacotherapies), engagement in mutual aid organizations (eg, SMART recovery, Alcoholics Anonymous), participation in recovery support institutions (eg, recovery community organizations, collegiate recovery programs), and receipt of recovery support services (eg, peer recovery coaching) [2,6]. Although the use of technology to support and deliver SUD intervention and treatment services has been well studied [7-11], the exploration of digital recovery support services (D-RSSs) would benefit from additional research [12,13], especially as it relates to gender-specific support for women. Studies examining D-RSSs have primarily focused on exploratory utilization and perception outcomes and the characterization of the populations engaging in such supports, including adolescents [14-17] and adults [18-24]. Among these studies, there have also been the characterization of ethnic and racial minorities [25], as well as international citizens [26-28]. A limited number of studies have examined recovery-related outcomes (eg, recurrence of substance use and quality of life) in relation to D-RSSs. Of those, preliminary evidence suggests that D-RSSs are comparable in efficacy to face-to-face (F2F) recovery supports [15,20], and, in some cases, D-RSSs perform better than groups receiving F2F supports [14,16]. However, the few studies where digital supports outperformed care as usual (ie, F2F support) are limited to adolescent populations. In addition, an experimental study showed that combining digital recovery support with care as usual improved outcomes (in this instance, number of risky drinking days) compared with the control of care as usual only [29]. D-RSSs may take on several distinct forms, including recovery social networking sites (R-SNS) [19,20,22-24,26,30], which include mutual aid forums and websites and may be private or public; smartphone apps [15,25,27,29]; Web-based apps [19,31]; short message service text messaging [14,16,32]; combinations of smartphone apps and external sensors (eg, breathalyzers; [28]). Despite these different forms, several consistent support mechanisms appear across each type of D-RSS, including peer-to-peer support, information dissemination, and resource sharing. Exploration of D-RSSs for specific populations, such as women and those utilizing recovery pathways other than the traditional abstinence-based 12-step mutual aid, is even more limited. In fact, to our knowledge, only 1 D-RSS specific to women has been examined to date (eg, *Soberistas*) [22,33], and no such examination of D-RSSs for alternative recovery pathways has been undertaken. Women in recovery and with SUDs face unique challenges [34-36], as do those who elect to use recovery pathways other than 12-step mutual aid [37]. Particularly, incidence of cooccurrence for mental health (MH), trauma, and sexual trauma is high for women [38,39], whereas those using alternative recovery pathways often face a lack of availability and access [22,40,41], as well as systemic barriers to elect an alternate pathway [42-44]—despite evidence that alternative pathways operate via similar mechanisms and produce similar effects to 12-step mutual aid [37]. D-RSSs present an opportunity to ease each of these barriers through low-cost expansion [13] and creation of specialized communities for particular populations with distinct characteristics, be it gender, substance of preference, or chosen recovery pathway. To further the research on both D-RSS broadly and D-RSS specifically for women, this study evaluates the SHE RECOVERS (SR) recovery community, with the following 3 aims: (1) to characterize the women who engage in SR (including demographics and recovery-related characteristics), (2) describe the ways and frequency in which participants engage with SR, and (3) examine the perception of benefit derived from engagement with SR. For all aims, we also examined whether participant outcomes and characteristics differed as a function of length in recovery (LIR) and primary recovery pathway (eg, 12-step mutual aid and SMART recovery). Although no previous research on variance among recovery pathways and a female-specific population exists to our knowledge, a recent study on D-RSSs found significant differences between participants with less than 1 year in recovery compared with those with more than 1 year [23]. The analyses found that participants with more time in recovery had higher levels of positive recovery indicators (eg, recovery capital), less D-RSS engagement, and similar perceptions of benefit. To add to our understand of this possible relationship between LIR and D-RSS, we defined *a priori* hypotheses as (1) participants with the longest LIR (5+ years) would have higher recovery-related outcomes (eg, recovery capital and self-esteem) compared with those with shorter LIR (<1 year or between 1 and 5 years), (2) participant engagement outcomes would vary as a factor of LIR, and (3) participants' perceptions of benefit would not vary as a factor of LIR. Hypothesis 2 and 3 were not generated with subgroup comparisons, given that only 1 D-RSS was examined

in this study (hypothesis 2) and because of the fact we did not expect variability among perceptions of benefits (hypothesis 3), as compared with multiple D-RSS and a lack of difference in perceptions of benefit in Bergman and colleagues' recent work [23].

Methods

Description of Digital Recovery Support Service

SR, founded in Canada in 2011, is now an international movement of women in or seeking recovery from a wide variety of issues, including SUDs and other behavioral health issues, such as trauma, emotional and physical abuse, MH disorders, and cooccurring disorders. Historically, SR has been available only as a D-RSS, but more recently, it has begun to offer both F2F and digital supports. The digital community comprises a public Facebook page, 2 private Facebook groups, digital training events, digital recovery coaching, a website, and an email listserv. In total, the digital recovery community provides D-RSSs to an estimated 200,000 female, transgender, and nonbinary identifying individuals. F2F supports include in-person, multiday recovery retreats (held at varying locations several times a year), local SR chapter meetings, in-person trainings, and yoga classes. SR estimates that 10,000 individuals participated in F2F supports as of December 2018. Currently, the prevalence of SR usage in specific countries and localities is unknown.

Design and Recruitment

A digital, cross-sectional design was used in this study. Following International Review Board approval from the University of the Sciences, participants were recruited from the SR private Facebook groups, public Facebook page, and email listserv. Recruitment information, which read, "We are working with a team of researchers to learn more about our community and about the larger digital recovery community as a whole. As women who have engaged with the SR community, we hope that you will take the 15 min that it takes to complete this survey. You should plan to complete the survey in 1 sitting. The back button will not be available, so please read questions and answers carefully," was posted at each location in the Fall of 2018. Participants electing to click on the study link provided in the recruitment post were taken to a *Qualtrics* (Provo, Utah) digital survey. All participants were first provided with the informed consent, then they took a brief informed consent survey to ensure understanding, and then they either provided consent or declined to participate. For all participants, the survey questions collected demographics, recovery-related characteristics, and novel perception and agreement of benefit questions. Participants were not compensated for their participation, and results were anonymous—neither Internet Protocol addresses and names nor protected health information were collected. Recruitment was completed in the span of 2 weeks, and a final sample of 729 was included in the study. Only 6 of the participants clicking on the study link declined to participate, and no consenting participants were excluded.

Measures

Participation and Engagement Frequency

A total of 2 novel measures were used to collect SR participation and engagement frequency. The first used a dichotomous scale (*yes* or *no*) to assess participant lifetime engagement (ie, any use in their lifetime) in SR supports, including public Facebook page, private Facebook group, in-person retreats, workshops, conferences, in-person local chapter meetings, digital SR coach training or other trainings, or SR recovery coaching. The second used an ordinal scale (0=never, 5=multiple times a day) to assess frequency of participant engagement in the D-RSSs of the community (eg, *How often do you post in the SR digital community? How often do you comment on others' posts in the SR digital community?*). Several additional questions were included as part of engagement-related outcomes, including *How many digital friendships have you made as a result of your SR involvement?* (which was scored on an ordinal scale; 1=1 to 10 friendships, 5=50 or more friendships) and *What do you primarily use the SR digital community for?* (which participants could select from the following options: to reach out for assistance, to reach out for resources, to foster connection with other women in recovery, to receive support, and to give support). Participants also reported how they first became engaged with SR from a mutually exclusive list of options, as well as the length of time they had been engaged over their lifetime. F2F engagement questions were also asked of participants, including if they had connected with other SR participants in person and the number of in-person SR events they had previously attended.

Recovery-Related Characteristics

The survey included the Brief Assessment of Recovery Capital [45], a 10-item measure of individual recovery capital (alpha=.90; scores range from 10-60, with higher scores indicating greater recovery capital), the Rosenberg Self-Esteem Scale [46], a 10-item measure of global self-esteem (alpha=.88; scores range from 8-40, with higher scores indicating greater self-esteem), the Perceived Stigma of Addiction Scale [47], an 8-item measure of public stigma of SUDs (alpha=.73; scores range from 8-32, with higher scores indicating greater perceived stigma), and the Generalized Self-efficacy Scale [48], a 10-item measure of self-efficacy (alpha=.76-.90; scores range from 10-40, with higher scores indicating more self-efficacy). Participants also reported their LIR at the time of the survey (in years and months), what they were recovering from, from a list of nonmutually exclusive options (eg, SUD, MH disorder, trauma, and disordered eating), their primary recovery pathway from a list of mutually exclusive options (eg, abstinence-based 12-step, abstinence-based non-12-step, and medication), and their history of recurrence of substance use for those participants reporting an abstinence-based recovery pathway. For participants reporting a primary recovery pathway of 12-step mutual aid, they also reported which 12-step group they most often engaged with.

Behavioral Health History

Participants reported their primary substance of use from a list of options (eg, alcohol, opioids, and marijuana), as well as any

MH diagnoses given to them by a licensed professional in their lifetime (eg, generalized anxiety disorder and posttraumatic stress). History of engagement with SUD and MH treatment, as well as recovery residences, was also collected for each participant. Finally, participants reported lifetime incidence of physical health problems related to their behavioral health (ie, SUD or MH disorder), as well as lifetime involvement in the criminal justice system.

Benefit Agreement and Perception

A total of 2 Likert-type novel measures were used to collect participants' benefit perception of SR D-RSSs and F2F services and overall participant agreement with the benefits of SR in the participants' life. Benefit perception questions required participants to rank their perceived level of benefit from various SR supports (eg, peer-to-peer digital connection, recovery coaching, and yoga classes), with scores ranging from 1 to 4 (1=extremely beneficial, 4=not very beneficial); participants were instructed to estimate the perceived benefit of a particular support if they had not participated in it. Agreement questions asked participants to rank their level of agreement, with several statements relating to the impact SR had on their life (eg, SR provides me support for things I am dealing with in my personal life, SR provides me support for things I am dealing with in my recovery life, and SR helps me to feel less stigmatized by others because of my recovery in my personal life), with scores ranging from 1 to 5 (1=strongly agree, 5=strongly disagree). Participants also reported which services, both D-RSS and F2F, they would like SR to offer more of by responding with either "yes" or "no" to a list of options that were not mutually exclusive (eg, an SR podcast, in-person retreats, and advocacy activities).

Data Analysis

We used descriptive statistics for each study aim (1-3). To examine the relationship of LIR for each aim, we recoded the LIR self-reported by each participant in years and months into a trichotomous variable (1=Less than 1-year LIR; 2=1 year or more but less than 5-year LIR; 3=5 years or greater LIR). These ordinal values map onto both the *Diagnostic and Statistical Manual of Mental Disorders* (5th edition) [49] and the clinical literature suggesting 5+ years of sustained recovery is related to significantly reduced recurrence of substance use risk and improved outcomes, such as quality of life and recovery capital [50]. Recovery status, including length of recovery, was self-reported by participants and not cross validated for verification; it was rather taken as face valid. In the current sample, 17 participants did not identify as a person in recovery, and 3 participants identifying as in recovery did not report a time length associated with that recovery. These participants were included in the final sample descriptive statistics but not in the analyses requiring LIR or an affirmed recovery status. These participants did not significantly differ from participants who were in recovery or reported a recovery length, on all measured demographic characteristics, confirmed via chi-square tests of independence. To examine the relationship of the primary recovery pathway for each aim, we collapsed recovery pathways into abstinence-based 12-step mutual aid, abstinence-based non-12-step mutual aid, harm reduction and medication, professional therapy, yoga and meditation, SR community, other D-RSSs, or a combination of multiple pathways. Our reasons for grouping pathways into these categories were both substantive—to maximize clinical similarity among the pathways—and statistical—to ensure similar sample sizes for completed analyses. We used analysis of variance (ANOVA) tests to examine group differences for continuous variables and a combination of chi-square tests (Pearson chi-square tests for nominal variables and linear-by-linear association tests for the LIR ordinal variable) and univariate logistic regressions to examine differences on categorical variables. For the significant chi-square tests, we used adjusted residual post hoc tests [51], with residuals greater or less than 2 evaluated as significant contributors to the overall chi-square statistic. Logistic regressions were completed in 2 steps (see Textbox 1), with the first containing demographic controls (age, marital status, household income, and education) and the second step including LIR groups (automatically dummy coded with SPSS V24 (IBM, Inc), reference group less than 1 year) and primary recovery pathway (automatically coded, reference group abstinence-based 12-step mutual aid). The Sidak method was used to correct for multiple comparisons to avoid statistical significance by chance. Demographically, participants using different primary recovery pathways did not significantly vary, confirmed via chi-square tests of independence.

Textbox 1. Logistic regression model for examination of each dichotomous categorical outcome.

Step 1

Age

Marital status

Household income

Education status

Step 2

Age

Marital status

Household income

Education status

Length in recovery

- Less than one year (reference)
- 1-5 years
- 5+ years

Recovery pathway

- Abstinence-based 12-step mutual aid (reference)
- Abstinence-based non-12-step mutual aid
- Harm reduction and medication
- Professional therapy
- Yoga and meditation
- She Recovers community
- Other digital recovery support services
- Combination of multiple pathways

Results

Participants

Participants (N=729) had a mean age of 46.83 years (SD 9.54), and were predominantly Caucasian (94%), married or in a domestic partnership (56.8%), heterosexual (87.1%), had either a 4-year (36.8%) or graduate degree (31%), were employed full time (50.6%), had a past-year household income over US $90,000 (56%), and owned their home (67.1%). The majority of participants reporting being in recovery (98.4%). Full participant demographics are available in Table 1. Participants with less than 1 year, 1 to 5 years, and 5+ years were similar on all measured demographic characteristics. The recovery typology (ie, complete or nonabstinence and nonsubstance related recovery) of each participant is available in Table 2, and all lengths in recovery reported are among all typologies reported by participants.

Recovery-Related Characteristics

Participants reporting a length of time associated with their recovery (n=709) had a mean LIR of 6.14 years (SD 7.87), with most reporting between 1 to 5 years (n=300), followed by 5+ years (n=253) and less than 1 year (n=156). Among all recovering participants (n=712), individuals had mean recovery capital scores of 50.57 (SD 6.53), self-esteem scores of 30.44 (SD 5.59), self-efficacy scores of 32.24 (SD 4.45), and perceived stigma scores of 21.71 (SD 3.50). Most participants in recovery reported a primary recovery pathway of abstinence-based 12-step mutual aid (38.4%, n=275), followed by professional therapy (10.6%, n=76), abstinence-based non-12-step mutual aid (10.2%, n=73), and involvement in the SR community (9.2%, n=66). Of those reporting a 12-step mutual aid recovery pathway, Alcoholics Anonymous was engaged with most often (75.6%, n=208). Of those identifying any abstinence-based recovery pathway, most had not experienced a recurrence of use since initiating recovery (78.4%, n=302,). Of those who had history of recurrence (n=83), most had experienced 5 or more recurrences (39.7%, n=33), followed by 2 to 4 recurrences (32.6%, n=27), and 1 recurrence (27.7%, n=23). Full recovery-related characteristics are available in Table 2.

Table 1. Participant demographic characteristics (N=729).

Variable	Value
Age (years), mean (SD)	46.83 (9.54)
Generation[a], n (%)	
Millennial	84 (11.5)
Generation X	400 (54.9)
Baby Boomer	245 (33.6)
Gender, n (%)	
Female	725 (99.5)
Other[b]	4 (0.5)
Race, n (%)	
White	685 (94.0)
Multiracial	14 (1.9)
Black	8 (1.1)
Other[c]	22 (3.0)
Ethnicity, n (%)	
Latino descent	31 (4.3)
Relationship status, n (%)	
Married/domestic partnership	414 (56.8)
Divorced	147 (20.2)
Single, never married	93 (12.8)
Other[d]	75 (10.2)
Sexual orientation[e], n (%)	
Heterosexual	635 (87.1)
Bisexual	58 (8.0)
Homosexual	21 (2.9)
Educational status, n (%)	
Did not complete high school	11 (1.5)
High school graduate/General Education Diploma	110 (15.1)
2-year college degree	114 (15.6)
4-year college degree	268 (36.8)
Postgraduate/professional degree	226 (31.0)
Employment status, n (%)	
Employed (full-time)	369 (50.6)
Self-employed	146 (20.0)
Employed (part-time)	94 (12.9)
Homemaker	47 (6.4)
Retired	37 (5.1)
Other	36 (5.0)
Income level (personal), n (%)	
US $0-$10,000	81 (11.1)
US $10-$29,999	88 (12.1)
US $30-$49,999	143 (19.6)

Variable	Value
US $50-$69,999	134 (18.4)
US $70-$89,999	97 (13.3)
US $90,000 or more	186 (25.5)
Income level (household), n (%)	
US $0-$10,000	26 (3.6)
US $10-$29,999	45 (6.2)
US $30-$49,999	78 (10.7)
US $50-$69,999	79 (10.8)
US $70-$89,999	93 (12.8)
US $90,000 or more	408 (56.0)
Housing status, n (%)	
Own home	489 (67.1)
Live in rental alone	144 (19.8)
Other[f]	96 (13.1)

[a]Generation cutoff ranges used are Millennial (18 to 35 years), Generation X (36 to 51 years), or Baby Boomer or older (52 or more years).

[b]Gender: other includes nonbinary, fluid, and intersex.

[c]Race: other includes Asian/Pacific Islander, American Indian or Native American, and Canadian Indigenous.

[d]Relationship status: other includes in a relationship/dating, separated, widowed, and polyamorous relationship.

[e]Valid percentage provided, as not all participants chose to respond to this question.

[f]Housing status: other includes live with parents or caregivers, live in a rental with roommates in recovery, live in a rental with roommates not in recovery, and no permanent housing.

Table 2. Participant recovery characteristics (N=729).

Variable	Value
Recovery length (years), mean (SD)	6.14 (7.87)
Recovery capital total, mean (SD)	50.57 (6.53)
Perceived stigma total, mean (SD)	21.71 (3.50)
Self-esteem total, mean (SD)	30.44 (5.59)
Self-efficacy total, mean (SD)	32.24 (4.45)
Recovery type[a], n (%)	
Substance use disorder	630 (86.4)
Mental health disorder	402 (55.1)
Codependency	311 (42.7)
Disordered eating	176 (24.1)
Process disorder	65 (8.9)
Trauma	284 (39.0)
Emotional, sexual, or physical abuse	273 (37.4)
Grief	210 (28.8)
Burnout	139 (19.1)
Medical condition	49 (6.7)
Not in recovery	12 (1.6)
Primary recovery pathway (n=717), n (%)	
Abstinence (12-step)	275 (38.4)
Professional therapy	76 (10.6)
Abstinence (non-12-Step)	73 (10.2)
Involvement in SHE RECOVERS	66 (9.2)
Yoga or other movement modality	48 (6.7)
Combination of multiple pathways	43 (6.0)
Other digital recovery program	33 (4.6)
Abstinence (spiritual)	30 (4.2)
Meditation	28 (3.9)
Harm reduction	19 (2.6)
Medication-assisted recovery	18 (2.5)
Abstinence (religious)	8 (1.1)
12-step group engaged with most often (n=275), n (%)	
Alcoholics anonymous	208 (75.6)
Narcotics anonymous	48 (17.5)
Other	19 (6.9)
Experienced recurrence of use (n=385)[b], n (%)	
Yes	83 (21.6)
No	302 (78.4)
Recurrences (n=83), n (%)	
1	23 (27.7)
2-4	27 (32.6)
5 or more	33 (39.7)

[a]Total percentage greater than 100%, as participants could provide more than 1 affirmative answer.

[b]Only asked of those identifying an abstinent-based recovery pathway.

Differences Among Participant Groups

Results from the ANOVAs found that all recovery-related characteristics varied significantly by participant LIR—recovery capital: $F_{2,706}$=28.99, P<.001; perceived stigma: $F_{2,706}$=3.82, P=.02; self-esteem: $F_{2,706}$=11.45, P<.001); self-efficacy: $F_{2,706}$=6.808, P<.001)—and most varied significantly by primary recovery pathway—recovery capital: $F_{7,709}$=9.05, P<.001; self-esteem: $F_{7,709}$=3.24, P<.001; self-efficacy: $F_{2,709}$=4.54, P<.001; perceived stigma was not significant P=.67). Post hoc testing revealed significantly lower recovery capital, self-esteem, and self-efficacy scores on average for participants with less than 1 year of recovery compared with both participants with 1 to 5 years and 5 or more years (P<.001). Participants with 1 to 5 years in recovery had significantly higher perceived stigma scores than participants with 5 or more years (P=.01. Post hoc testing for recovery pathways found that the harm reduction and medication pathway had lower recovery capital scores than all other pathways except for professional therapy (P<.001), lower self-esteem compared with abstinence-based 12-step and other D-RSSs (P<.001), and lower self-efficacy compared with all groups except professional therapy and SR (P=.001 to .03). Pearson chi-square tests found participant primary recovery pathway was significantly associated with LIR—X^2_1=29.5, P<.001. Post hoc chi-square tests found that participants with less than 1 year in recovery reported pathways of abstinence-based 12-step mutual aid at lower rates (adjusted residual (adj res)=–5.1), but the SR community (adj res=2.7) and other D-RSSs (adj res=2.0) reported pathways of abstinence-based 12-step mutual aid at higher rates. In addition, post hoc chi-square tests found that participants with 1 to 5 years in recovery reported pathways of abstinence-based 12-step mutual aid at lower rates (adj res=–2.5) and that participants with 5 or more years in recovery reported abstinence-based non-12-step mutual aid (adj res=–2.5), yoga and meditation (adj res=–2.2), the SR community (adj res=–3.0), and other D-RSSs (adj res=–3.3) at lower rates, but reported pathways of abstinence-based 12-step mutual aid at higher rates (adj res=7.0).

Behavioral Health Characteristics

A majority of participants (n=630, 86.4%) reported being in recovery from a SUD, followed by MH disorder (55.1%, n=402), codependency (42.7%, n=311), and trauma (39%, n=284). A majority of participants in recovery from SUDs reported alcohol (76.3%, n=511) as a primary substance of use. Of those reporting an MH disorder diagnosis, depressive disorder was the most common (29.9%, n=218). Less than half of the participants (37.3%, n=272) had either been to SUD treatment or stayed in a recovery residence (11%, n=80), although more had been to MH disorder treatment (44.3%, n=323). Less than a third of participants reported lifetime incidence of a physical health complication related to their SUD or MH disorder (28%, n=204) or lifetime involvement in the criminal justice system (26.2%, n=191). Participant behavioral health characteristics did not vary by LIR or primary recovery pathway, confirmed via chi-square tests. Full behavioral health characteristics are available in Table 3.

Table 3. Participant behavioral health characteristics (N=729).

Variable	Value
Primary substance of preference (n=670), n (%)	
Alcohol	511 (76.3)
Multiple substances	64 (9.6)
Prescription opioids	24 (3.6)
Cocaine	18 (2.7)
Heroin	13 (1.9)
Amphetamines	12 (1.8)
Marijuana	9 (1.3)
Benzodiazepines	4 (0.6)
Other	15 (2.2)
Mental health diagnoses (lifetime), n (%)	
Depression	218 (29.9)
Anxiety	182 (25.0)
Multiple diagnoses	101 (13.9)
Bipolar disorder	25 (3.4)
Attention hyper deficit disorder	19 (2.6)
Other	28 (3.8)
Not applicable	156 (21.4)
Completed SUD[a] treatment, n (%)	
Yes	272 (37.3)
Completed MHD[b] treatment, n (%)	
Yes	323 (44.3)
Recovery residence stay (lifetime), n (%)	
Yes	80 (11.0)
Physical complications because of SUD/MHD (lifetime), n (%)	
Yes	204 (28.0)
Criminal justice system involvement (lifetime), n (%)	
Yes	191 (26.2)

[a]SUD: substance use disorder.

[b]MHD: mental health disorder.

Participation and Engagement

A majority of participants first became involved with SR through the public Facebook page (52.1%, n=380), and they had been involved for 2 years or less (75.7%, n=552). Engagement with SR on Facebook was most common with 81.9% of the participants reporting lifetime engagement with the public Facebook page and 52.9% reporting engagement with the private Facebook group. Slightly over a third of participants had participated in the in-person SR supports (34%, n=248), with less reporting lifetime engagement with in-person local SR meet ups (8.9%, n=65), digital training (8.5%, n=62), or recovery coaching (2.5%, n=18). Of those who had participated in F2F SR supports (n=259), most had participated in only 1 (n=135, 52.1%). The most common reason for engaging in SR D-RSSs was to foster connection with other women in recovery (45.4%, n=331) and receive support (32.9%, n=240). Few participants posted or commented daily on SR (4.6% and 6.5%, respectively), with participants posting at least on a monthly basis 46.3% of the time and commenting at least on a monthly basis 57.6% of the time. Most participants (56.9%, n=415) had not connected with others in SR F2F, but they would like to do so in the future. Conversely, most participants had made between 1 and 10 digital friendships since engaging in SR (83.5%, n=609). Complete participant and engagement descriptive results are available in Table 4.

Table 4. Participant SHE RECOVERS engagement and activity (N=729).

Variable	Value
First contact with SHE RECOVERS, n (%)	
SHE RECOVERS public Facebook page	380 (52.1)
Other	157 (21.5)
SHE RECOVERS private Facebook group	85 (11.6)
In-person SHE RECOVERS retreat	44 (6.0)
In-person SHE RECOVERS conference	36 (4.9)
In-person SHE RECOVERS workshop	9 (1.2)
Attending SHE RECOVERS recovery coach training	7 (1.0)
Receiving coaching from a SHE RECOVERS recovery coach	5 (0.7)
In-person SHE RECOVERS local meet up	4 (0.5)
SHE RECOVERS yoga	2 (0.3)
Length of engagement with SHE RECOVERS, n (%)	
0-3 months	148 (20.3)
4-6 months	95 (13.0)
6-11 months	104 (14.3)
1-2 years	205 (28.1)
2-3 years	85 (11.7)
3-4 years	38 (5.2)
4-5 years	27 (3.7)
5-6 years	12 (1.6)
6-7 years	15 (2.1)
Lifetime engagement, n (%)	
Public Facebook page	597 (81.9)
Private Facebook group	386 (52.9)
In-person retreats, conferences, and workshops	248 (34.0)
In-person local chapter meet ups	65 (8.9)
Digital training event	62 (8.5)
Recovery coach service	18 (2.5)
In-person events attended (n=259), n (%)	
1	135 (52.1)
2	60 (23.2)
3	28 (10.8)
4	11 (4.2)
5 or more	25 (9.7)
Primary reason for engagement, n (%)	
Foster connection with other women in recovery	331 (45.4)
Receive support	240 (32.9)
Give support	76 (10.4)
Reach out to ask for resources	42 (5.8)
Reach out to ask for help or advice	40 (5.5)
Frequency of posting in SHE RECOVERS digital, n (%)	
Monthly	201 (27.6)

Variable	Value
Weekly	103 (14.1)
Daily	33 (4.6)
Never	392 (53.7)
Frequency of comments in SHE RECOVERS digital, n (%)	
Monthly	193 (26.5)
Weekly	179 (24.6)
Daily	47 (6.5)
Never	310 (42.4)
Connected In-person with others outside of official SHE RECOVERS events, n (%)	
No, but would like to	415 (56.9)
Yes	191 (26.2)
No, and do not want to	123 (16.9)
Digital friendships made, n (%)	
1-10	609 (83.5)
11-30	82 (11.4)
31 or more	37 (5.1)

Differences Among Participant Groups

Pearson chi-square tests found participants' primary reason for participating in SR D-RSSs was significantly associated with LIR—X^2_1=3.9, *P*=.04). Post hoc chi-square tests found that participants with 1 to 5 years in recovery use SR D-RSSs to reach out for resources less than other groups (adj res=–2.9), but use SR D-RSSs to foster connection with other women in recovery at higher rates (adj res=2.1); the tests also found that those with 5+ years use SR D-RSSs to give support or positive encouragement more than other groups (adj res=2.4).

Participants' primary reasons for participating in SR D-RSSs were also significantly associated with primary recovery pathway—X^2_{28}=54.8, *P*=.002). Post hoc tests also found participants with a harm reduction or medication primary pathway use SR D-RSSs to reach out for resources more than other groups (adj res=3.0), but use SR D-RSSs to foster connection with other women in recovery at lower rates (adj res=–3.3); the tests also found that those using the SR community as a primary pathway use SR D-RSSs to connect with other women in recovery more (adj res=3.9), but use SR D-RSSs to receive support less (adj res=3.2). Omnibus tests for logistic regression models predicting lifetime engagement with SR supports were significant for engagement with the SR public Facebook page (*P*=.002; r^2=0.12; Hosmer and Lemeshow (H and L) *P*=.69), SR private Facebook group (*P*<.001; r^2=0.20; H and L *P*=.24), in-person SR retreats (*P*<.001; r^2=0.17; H and L *P*=.94), in-person SR local meet ups (*P*<.02; r^2=0.13; H and L *P*=.07), SR digital trainings (*P*<.001; r^2=0.17; H and L *P*=.82), and SR recovery coaching (*P*<.001; r^2=0.33; H and L *P*=.86). Complete statistical results are available in Tables 5 and 6.

Notably, LIR was significantly associated with engagement outcomes in each logistic regression except for engagement in SR recovery coaching. LIR of 5 or more years had greater odds of SR public Facebook page engagement; LIR of 1 to 5 years and 5 or more years had greater odds of SR private Facebook group engagement; LIR of 1 to 5 years and 5 or more years had greater odds of in-person SR retreats engagement; LIR of 1 to 5 years had greater odds of in-person local SR local meet ups; LIR of 1 to 5 years and 5 or more years had greater odds of SR digital trainings.

Table 5. Logistic regression factors associated with lifetime engagement with SHE RECOVERS supports. Regressions contained demographic controls (age, marital status, household income, and education). None were significant predictors in any model (*P*>.05).

Variable	Public Facebook page, OR[a] (95% CI)	Private Facebook group, OR (95% CI)	In-person SHE RECOVERS retreats, OR (95% CI)
Length in recovery			
1-5 years	1.36 (.83-2.21)	2.37 (1.52-3.68)[b]	1.99 (1.25-3.18)[c]
5+ years	1.77 (1.01-3.12)[c]	2.11 (1.32-3.38)[c]	2.35 (1.42-3.89)[c]
Recovery pathway			
Abstinence-based non-12-Step	.42 (.22-.78)[c]	1.79 (1.11-2.89)[c]	1.15 (.69-1.91)
Harm reduction and medication	.35 (.14-.87)[c]	1.92 (.91-4.05)	.70 (.28-1.73)
Professional therapy	.53 (.25-1.12)	1.24 (.71-2.15)	.75 (.40-1.39)
Yoga and meditation	.37 (.18-.76)[c]	1.31 (.75-2.28)	1.25 (.69-2.27)
SHE RECOVERS community	.25 (.13-.50)[b]	16.48 (6.45-42.07)[b]	5.49 (2.91-10.36)[b]
Other digital supports	.56 (.21-1.46)	1.36 (.63-2.95)	1.16 (.51-2.61)
Multiple recovery pathways	.29 (.13-.65)[c]	3.21 (1.52-6.78)[c]	1.73 (.86-3.49)

[a]OR: odds ratio.

[b]*P*<.001.

[c]*P*<.05.

Table 6. Logistic regression factors associated with lifetime engagement with SHE RECOVERS supports. Regressions contained demographic controls (age, marital status, household income, and education). None were significant predictors in any model (*P*>.05).

Variable	In-person SR local meet ups, OR[a] (95% CI)	SR digital trainings, OR (95% CI)	SR recovery coaching, OR (95% CI)
Length in recovery (years)			
1-5	2.65 (1.20-5.84)[b]	2.44 (1.01-5.88)[b]	1.43 (.38-5.30)
5+	1.97 (.81-4.75)	3.93 (1.59-10.0)[b]	.56 (.10-3.27)
Recovery pathway			
Abstinence-based non-12-Step	2.55 (1.16-5.61)[b]	4.73 (2.04-10.96)[c]	3.32 (.43-25.44)
Harm reduction and medication	1.08 (.23-5.12)	.66 (.65-6.09)	0 (0-0)
Professional therapy	1.17 (.36-3.45)	2.00 (.65-6.10)	6.68 (.71-62.96)
Yoga and meditation	1.48 (.50-4.40)	4.65 (1.73-12.49)[b]	8.21 (.83-81.51)
SHE RECOVERS community	5.66 (2.42-13.22)[c]	5.80 (2.29-14.74)[c]	19.82 (2.84-138.21)[b]
Other digital supports	1.97 (.51-7.59)	1.11 (.13-9.19)	5.41 (.37-79.94)
Multiple recovery pathways	2.50 (.82-7.57)	3.93 (1.30-11.89)[b]	1.93 (.09-42.68)

[a]OR: odds ratio.

[b]*P*<.05.

[c]*P*<.001.

Benefit Perception and Agreement

Overall, participants had strong perceptions of the benefit of SR support (mean 13.30, SD 5.77), and they were in agreement with the impact SR has in their lives (mean 15.38, SD 5.48). Benefit perception was ranked highest among peer-to-peer digital connection, peer-to-peer in-person connection, and in-person prosocial events (mean 2.09). Participant agreement was ranked highest among helping participants feel less stigmatized about their recovery (mean 1.70), providing support for participants' recovery life (mean 1.84), and helping participants feel better about their personal life (mean 1.88). Participants reported a desire to have SR offer more in-person prosocial events (44.9%), an SR podcast (43.3%), and an SR smartphone app (34.2%) most often. Full benefit perception and agreement descriptive results are available in Table 7.

Table 7. Participant benefit perception, support function agreement, and desire for additional services (N=729).

Variable	Value
SHE RECOVERS benefit perception (all), mean (SD)	13.30 (5.77)
Peer-to-peer digital connection, mean (SD)	2.09 (1.07)
Extremely or very beneficial, n (%)	506 (69.4)
Moderately or not very beneficial, n (%)	223 (30.6)
Peer-to-peer in-person connection, mean (SD)	2.09 (1.20)
Extremely or very beneficial, n (%)	487 (66.8)
Moderately or not very beneficial, n (%)	242 (33.2)
In-person prosocial events, mean (SD)	2.09 (1.07)
Extremely or very beneficial, n (%)	484 (66.4)
Moderately or not very beneficial, n (%)	245 (33.6)
SHE RECOVERS yoga, mean (SD)	2.35 (1.23)
Extremely or very beneficial, n (%)	422 (57.9)
Moderately or not very beneficial, n (%)	307 (42.1)
Educational events and activities, mean (SD)	2.20 (1.20)
Extremely or very beneficial, n (%)	462 (63.4)
Moderately or not very beneficial, n (%)	267 (36.6)
Recovery coaching, mean (SD)	2.45 (1.23)
Extremely or very beneficial, n (%)	392 (53.8)
Moderately or not very beneficial, n (%)	337 (46.2)
SHE RECOVERS support benefit agreement (all), mean (SD)	15.38 (5.48)
Provides support for personal life, mean (SD)	2.04 (0.90)
Strongly or moderately agree, n (%)	499 (68.4)
Neither agree nor disagree, n (%)	197 (27.1)
Moderately or strongly disagree, n (%)	33 (4.5)
Provides support for recovery life, mean (SD)	1.84 (0.90)
Strongly or moderately agree, n (%)	566 (77.6)
Neither agree nor disagree, n (%)	139 (19.1)
Moderately or strongly disagree, n (%)	24 (3.3)
Provides support for professional life, mean (SD)	2.57 (1.04)
Strongly or moderately agree, n (%)	311 (42.7)
Neither agree nor disagree, n (%)	322 (44.2)
Moderately or strongly disagree, n (%)	96 (13.1)
Helps me feel better, mean (SD)	1.88 (0.90)
Strongly or moderately agree, n (%)	554 (76.0)
Neither agree nor disagree, n (%)	151 (20.7)
Moderately or strongly disagree	24 (3.3)
Helps me feel less stigmatized, mean (SD)	1.70 (0.88)
Strongly or moderately agree, n (%)	586 (80.4)
Neither agree nor disagree, n (%)	124 (17.0)
Moderately or strongly disagree, n (%)	19 (2.6)
Have made lasting friendships, mean (SD)	2.76 (1.28)
Strongly or moderately agree, n (%)	271 (37.2)

Variable	Value
Neither agree nor disagree, n (%)	299 (41.0)
Moderately or strongly disagree, n (%)	159 (21.8)
Important part of everyday life, mean (SD)	2.59 (1.11)
Strongly or moderately agree, n (%)	327 (44.9)
Neither agree nor disagree, n (%)	283 (38.8)
Moderately or strongly disagree, n (%)	119 (16.3)
Services desired more of, n (%)	
Peer-to-peer digital recovery meetings	197 (27.0)
In-person prosocial events	327 (44.9)
Advocacy events and activities	165 (22.6)
Educational events and activities	226 (31.0)
Podcast	316 (43.3)
Life skills training and supports	145 (19.9)
Community smartphone app	249 (34.2)

Differences Among Participant Groups

Results from the ANOVAs found that participant agreement of SR impact varied significantly by LIR—$F_{2,706}$=9.62, P<.001)—but participant benefit perceptions did not (P=.76). Post hoc tests for LIR revealed participants with 1 to 5 years had greater rates of agreement (ie, lower mean score but greater rate of agreement) than those with less than 1 year or more than 5 years of recovery. On average, this agreement rate was 1.56 greater on the novel agreement scale compared with those with 1 year or less (P=.01) and 1.91 greater compared with those with 5+ years (P<.001). Similarly, results found that participant agreement varied significantly by primary recovery pathway—$F_{2,709}$=7.14, P<.001), but participant benefit perceptions did not (P=.06). Post hoc tests revealed participants identifying the SR community as their primary pathway had, on average, higher agreement scores than all other recovery modalities, including 4.82 higher than abstinence-based (12-step; P<.001), 4.31 higher than abstinence-based (non-12-step; P<.001), 4.88 higher than harm reduction and medication (P<.001), 5.29 higher than yoga and meditation (P<.001), 3.76 higher than other digital recovery supports (P=.26), and 4.86 higher than a combination of recovery modalities (P<.001).

Discussion

Principal Findings

Expansion of gender-specific, integrated recovery supports is needed to ease the impact of barriers and obstacles to long-term recovery facing women [4,5,36]. D-RSSs are a potential way to expand these targeted supports. D-RSSs can be delivered through a variety of platforms, including R-SNS [23]. SR is a distinct form of D-RSS, leveraging a public social networking site (eg, Facebook) to create an R-SNS community, along with a Web portal, digital trainings, and digital activities, to create a robust support structure. To our knowledge, this is the first study to characterize the use of Facebook pages and groups as a D-RSS, and this is the second study on women-centric D-RSSs [22]. Interestingly, the only other D-RSSs that appear to use a public platform as a primary means of communication are those available on Reddit [52,53]. As Reddit is completely anonymous, it may not be able to foster targeted population support, for example, women in recovery, in the same way as a nonanonymous platform, such as Facebook.

The SR community offers a unique opportunity to evaluate supportive spaces that are specific to women and for those seeking support from myriad types of recovery—not only SUDs. Although a majority of participants reported SUD recovery, there was also a high degree of cooccurrence, including MH disorders and trauma, among others. SR is not only home to women reporting diverse primary recovery pathways, including the most prevalent, 12-step mutual aid, but also to non-12-step mutual aid, harm reduction, professional therapy, yoga and meditation, and other D-RSSs. Many of these so called "alternative pathways" [54] are reported by the participants in this study, suggesting that D-RSSs can successfully create supportive capacity for individuals who use different pathways and may not have access to regular in-person supports [41]. Our second and third *a priori* hypotheses were supported in this study, whereas the first was only partially supported. LIR was associated with recovery-related and engagement outcomes but not participant perception of benefit; however, the only recovery-related outcome that was most positive for those with 5+ years of recovery was perceived stigma. For all other recovery-related outcomes, there was no significant difference between participants with 5+ years of recovery and those with 1 to 5 years, although both groups had significantly more positive outcomes compared with those with less than 1 year in recovery. Though not part of any *a priori* hypotheses, it is also worth noting that participant level of agreement with SR having a positive life impact was associated with LIR and recovery pathway, and recovery pathway was associated with recovery-related and engagement outcomes but not participant perception of benefit. Participants in this study had a high degree

of perceived benefit of SR participation related to D-RSSs and F2F supports. This suggests that SR is helpful or can be helpful across a spectrum of needs for women in recovery and that such benefit is perceived across a range of recovery pathways and lengths in recovery. Although agreement with SR impact in participants' personal, professional, and recovery lives was associated with recovery pathway, it is not surprising that participants reporting SR involvement as their primary pathway tended to have greater agreement. Descriptively, participants with non-SR primary recovery pathways also had high levels of agreement with the impact of SR on their lives. We believe this finding speaks to the potential ability of SR participation to mobilize enhanced functioning across multiple life domains for individuals with a variety of primary recovery pathways (ie, 12-step and non-12-step and abstinence and harm reduction), with the greatest impact likely for those who use it as a primary support rather than an adjunct. Interestingly, those participants with 1 to 5 years in recovery had the highest rates of agreement with SR impact, different from both those with less than 1 year and 5 or more years. This may speak to the way in which the 1 to 5 years in recovery group engages with SR—results suggest they use SR to primarily connect with other women in recovery more than other groups—helping them derive more personal benefit in their personal, professional, and recovery lives. This relationship with SR may serve as a mechanism of social connection. In fact, previous research suggests this type of social connection is critical to the recovery progress in person, as well as digitally [55-57]. When compared with those with less than 1 year, who use SR primarily to receive resources, and those with 5 or more years, who use it primarily to provide support, perhaps it is this focus on fostering connection that may be the driver of perceived positive life impact. Findings also suggest recovery-related characteristics differ as a function of both LIR and recovery pathway. Although this may seem intuitive—indeed, previous research has shown that as recovery progresses over time, recovery-related outcomes tend to improve [58]—the SR data demonstrate that the mechanisms explaining improvements in recovery-related outcomes, other than time, are not generally well understood across various recovery trajectories and pathways. For example, in this study, as might be expected, recovery capital, self-esteem, and self-efficacy were generally lower for those in earlier recovery, whereas perceived stigma was lowest for those with 5 or more years. At the same time, recovery capital, self-esteem, and self-efficacy also tended to be lower, on average, for participants reporting pathways that were not abstinence-based 12-step mutual aid. However, LIR and reported pathway were related to those with longer time in recovery more likely to report a 12-step mutual aid pathway. As such, we cannot know from the present findings if differences between recovery pathway and recovery-related outcomes are because of LIR or choice of recovery pathway. It is logical that those with longer recovery lengths are more likely to be engaged in 12-step mutual aid, as it has been the most popular and available pathway for decades [22,40,41]. Thus, the differences in recovery-related outcomes found among recovery pathways may not be because of the choice of pathway, but the differences may rather be an artifact of LIR. In fact, recent research suggests that outcomes among popular mutual aid pathways are similar after controlling for participants' recovery goals [59], lending credence to this possibility. However, further research is needed to elucidate this relationship. Overall, participant engagement was highest (>80%) with the SR D-RSSs that were available on Facebook. Digital trainings, events, and recovery coaching were used less frequently. This may be because of the cost associated with supports not on Facebook or another factor that was not examined in the current sample. Participants' primary reasons for using SR were associated with LIR and recovery pathway. Findings suggest that participants with less time were more likely to use SR to ask for resources and support, perhaps as they are new in recovery and in greater need of supportive resources to sustain progress. Participants with a median length of recovery (1-5 years) were less likely to use SR to seek resources, but they were more likely to use SR to foster connection with other women in recovery. This may be because of the fact that these participants are more stable in their recovery, needing less resources but still have a desire to grow their recovery network as a primary source of support and connection. Those participants with the longest time (5 or more years) were most likely to use SR to give support and resources, which may be in a sense "service work"—a reciprocal helping model. This would line up with previous research into mutual aid recovery programs and service to others in sobriety [60]. As would be expected, participants who reported SR as their primary recovery pathway were more likely to engage in most SR supports and also use SR D-RSSs to connect with other women in recovery at higher rates. However, that this group did not use SR to receive support more frequently was surprising, as we would expect participants to use their primary recovery pathway to seek out support most often. Results also found participants reporting primary harm reduction or medication recovery pathways used SR D-RSSs to reach out for resources at higher rates but used SR D-RSSs to connect with other women in recovery at lower rates than other groups. This may speak to the high rates of stigma and discrimination associated with this pathway [61,62] and perhaps the low availability of resources available to them, both of which are interrelated. However, as perceived stigma was not significantly different among pathways, this explanation may be less likely—although it is possible the perceived stigma measure used is not sensitive to more nuanced forms of stigma across recovery pathways. LIR was also associated with lifetime engagement of certain SR supports (both F2F and digital). As compared with participants with less than 1 year, participants with 1 to 5 years and 5 or more years in recovery were both more likely to have engaged in all of these supports except for SR recovery coaching. This may be because of participant desire to augment their recovery supports or programs with additional supports as their recovery evolves over time. It is also plausible that for a participant to have found the SR community, a certain threshold of exposure to recovery and different recovery communities may have been necessary. Such exposure would logically increase in proportion to the amount of time spent in recovery, suggesting that those with longer recovery lengths are more likely to find D-RSSs than those new in recovery. Interestingly, engagement with the SR public Facebook page was significantly associated only with the 5 or more years group, which may suggest, in combination with the lower perceived

stigma scores of this group, that these participants are more willing to be public and visible with their recovery.

Limitations

These findings from this study should be interpreted in light of a few notable limitations. Although the sample was large, it may not generalize to all SR participants, especially those who are individuals of color, identify as transgender male to female or gender nonconforming, or are of a lower socioeconomic status. Several novel measures were created for this study, and interpretations of these instruments and interpreted results should be approached with conservatism. As a cross-sectional study, findings are limited to a single point in time and cannot explain the temporal relationship among variables.

Future Directions

A systematic review of D-RSSs has not yet been completed to our knowledge, although one is needed to thoroughly review the current state of the emergent field. With several observational surveys completed on R-SNS D-RSSs, future research should use prospective, experimental designs or other causal inference methods (eg, propensity scoring) to examine the effects of participation in R-SNS and other types of D-RSSs. Continued research evaluating the efficacy of D-RSSs to support targeted populations, such as women, individuals with cooccurring disorders, or using alternative recovery pathways, should be a priority, given the dearth of resources available to these populations, the increased barriers faced in accessing recovery supports, and the ways in which recovery benefits differ in nature, especially between men and women [63]. Particularly of interest is the cohesion of these integrated communities and whether they maintain cohesion over extended periods of time. Also of interest is the direct comparison of different types of D-RSSs to each other, as there may be benefits (ie, costs and availability) to leveraging existing free public platforms, such as Facebook, over creation of proprietary smartphone apps. Research examining D-RSSs uptake, attrition, and secondary uptake (ie, leaving the platform but returning at a later date) is also of interest. From this study, we are also interested in identifying the subset of D-RSS users who may never post, comment, or otherwise engage apart from logging on. There may exist a parallel in F2F recovery support research, where active involvement in mutual aid (eg, having a sponsor and sharing at meetings) was shown to be a stronger predictor of abstinence than attendance [64,65]. However, this type of "recovery voyeurism" in digital spaces is still an undefined and unexplored phenomenon that may have important implications for clinical and translational research.

Conclusions

In correspondence with previous literature, D-RSSs are positioned to be a vital tool in increasing support and access for those who utilize nontraditional recovery pathways, as well as those groups that may face other barriers to recovery support access. D-RSSs, such as SR, provide support to marginalized, disenfranchised, and specialized communities in response to the unique and varied needs of such targeted populations—women in recovery in this instance. A significant obstacle to recovery success for women is social networks with a higher prevalence of SUDs, an obstacle that SR helps to remove, especially for women with 1 to 5 years of recovery. This category of individuals, those with 1 to 5 years in recovery, may benefit the most from D-RSSs that are similar to SR (ie, those involving the use of public and private social networking platforms to connect with other peers in recovery), although more research is needed. Existing public digital infrastructure, such as popular social media platforms, may be leveraged to facilitate low-cost D-RSSs creation, which may carry a smaller financial burden than the creation of proprietary platforms or technology. One of the strengths of D-RSSs, such as SR, is the ability to diversify and tailor offerings of support for a variety of disorders, concerns, and illnesses. Intentional diversification of recovery supports may help populations initiating and sustaining recovery engage with a range of recovery supports that are challenging to access in person.

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Conflicts of Interest

None declared.

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Abbreviations

adj res: adjusted residual
ANOVA: analysis of variance
D-RSS: digital recovery support service
F2F: face-to-face
H and L: Hosmer and Lemeshow
LIR: length in recovery
MH: mental health
R-SNS: recovery social networking sites
SR: SHE RECOVERS
SUD: substance use disorders

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Original Paper

Exploring Mediators of a Guided Web-Based Self-Help Intervention for People With HIV and Depressive Symptoms: Randomized Controlled Trial

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Abstract

Background: Cognitive behavioral therapy (CBT) is frequently used to treat depressive symptoms in people living with HIV. We developed an internet-based cognitive behavioral intervention for people with HIV and depressive symptoms, which was based on an effective self-help booklet. The Web-based intervention was previously found to be effective.

Objective: The objective of this study was to investigate potential mediators of the Web-based intervention.

Methods: This study was part of a randomized controlled trial, in which the intervention was compared with an attention-only waiting list control condition. Participants were 188 (97 in intervention group and 91 in control group) people with HIV and mild to moderate depressive symptoms recruited in HIV treatment centers in the Netherlands. A total of 22 participants (22/188, 11.7%) in the study were female and 166 (166/188, 88.3%) were male. The average age of the participants was 46.30 years (SD 10.63). The intervention comprised Web-based self-help CBT for 8 weeks, 1 to 2 hours a week, including minimal telephone support from a coach. The participants received Web-based questionnaires at pretest, 3 times during the intervention/or waiting period, and post intervention. The outcome was depressive symptoms. Factors tested as potential mediators were changes in behavioral activation, relaxation, the cognitive coping strategies catastrophizing and positive refocusing, goal re-engagement, and coping self-efficacy.

Results: Using multilevel structural equation modeling, changes in behavioral activation (P=.006) and goal re-engagement (P=.009) were found to be significant mediators of the intervention effect. The mediation effect seemed to occur between weeks 3 and 5 for behavioral activation and weeks 1 and 3 for goal re-engagement. Using (bivariate) autoregressive latent trajectory analysis, we found a return effect (from the dependent variable to the mediator) for goal re-engagement but not for behavioral activation, which suggested that the mediation effect of changes in behavioral activation was stronger than that in goal re-engagement.

Conclusions: The results suggest that changes in behavioral activation and goal re-engagement may mediate the effect of the Web-based intervention for people with HIV and depressive symptoms. The results may lead to possible mechanisms of change of the intervention and improvement of therapy outcomes.

Clinical Trial: Netherlands Trial Register NTR5407; https://www.trialregister.nl/trial/5298

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KEYWORDS

HIV; depression; internet; cognitive behavioral therapy; coaching; randomized controlled trial; mediators

Introduction

Psychological Treatment for People Living With HIV and Depressive Symptoms

Depressive symptoms are quite common among people living with HIV (PLWH). This may be related to psychosocial factors, such as the stigma that is associated with having HIV [1], concerns about disclosing the illness to others [2], and difficulties with coping with HIV [3]. Symptoms of depression in PLWH may be treated with psychological interventions. Cognitive behavioral therapy (CBT) is frequently used to treat depressive symptoms in PLWH, and numerous studies have found it to be effective [4-8]. In CBT, the focus is on identifying and changing maladaptive cognitions and behaviors to improve one's mood [9]. CBT provided through the internet is increasingly being used and investigated, and it was found to be equally successful as face-to-face CBT for people with depressive symptoms [10,11]. Internet-based treatments have some advantages over face-to-face treatments, such as their larger reach, lower costs, and increased accessibility. We developed an internet-based intervention with coaching for PLWH and depressive symptoms, which was based on an effective self-help booklet: *Living Positive With HIV* [12]. It has been found that this Web-based intervention was effective in treating depressive symptoms in PLWH, compared with a control group that received minimal coaching [13].

However, we do not know which factors are mediators of the intervention effect. Mediators are factors that (partially) explain the relation between an independent and a dependent variable. In this case, we look for treatment factors that may explain the relationship between receiving the Web-based intervention and the decrease in depressive symptoms [14]. When a mediator of intervention effect is found, it may provide us indications for possible mechanisms of change [15]. A mechanism of change is defined as a process that leads to change, which may answer the important question: how does the intervention work? It is important to have more knowledge about the mechanisms of change to be able to adapt and improve the intervention to optimize the outcome [15]. To investigate mediators of treatment outcome, at least 3 measurement moments are needed to establish a timeline of mediators and outcomes.

Previous Research

Research on Web-based CBT to treat depressive symptoms in PLWH is scarce. As far as we know, no studies were conducted on mediators of Web-based CBT for depressive symptoms in PLWH, although potential mediators of CBT (face-to-face and Web-based) for people with depressive symptoms in general have been investigated in the last decade. First of all, when we look at face-to-face CBT for depressive symptoms, the literature regarding changes in cognitions as a mediator is mixed. A total of 3 reviews have found that a change in cognitions was an important mediator [16-18], whereas another review has concluded that there is little evidence for cognitive mediation in CBT for depression [19]. Therefore, the role of changing cognitions as a mediator in CBT for depressive symptoms is still unclear. Furthermore, the mediating role of behavioral factors such as changes in activation level in CBT for depression was investigated in a review [18]. Changes in behavioral factors were found to be a significant mediator in 3 out of 6 studies.

Next to mediation studies of face-to-face CBT for depressive symptoms, mediators were also investigated in Web-based CBT for depressive symptoms. It has been found that changes in dysfunctional attitudes, a negative problem orientation [20], repetitive negative thinking [20,21], use of cognitive skills [22], and perceived control over things in life [20,23] were mediators in the relation between Web-based CBT and (a decrease in) depressive symptoms. Increasing activity levels was not found to be a mediator in Web-based CBT for depression [22]. Concluding, the results regarding mediators of change of (Web-based) CBT are mixed and should be investigated further. In addition, many previous mediation studies correlated across subjects changes over time—using only 2 measurement moments (ie, pretest and posttest)—in 2 variables, which does not allow to establish a timeline of mediators and outcomes [15,18]. More research with at least 3 measurement moments is needed to establish this timeline.

This Study

In this study, potential mediators of the effect of the Web-based intervention *Living Positive With HIV* on depressive symptoms were investigated. The intervention is based on CBT and contains 4 main components: behavioral activation, relaxation, changing negative thoughts into more balanced thoughts, and goal attainment. We statistically explored mediators for the decrease in depressive symptoms, which might refer to causal mechanisms of change that might have been activated by the intervention components. The following potential mediators were investigated in this study: changes in behavioral activation, relaxation, the cognitive coping strategies catastrophizing and positive refocusing, goal re-engagement, and coping self-efficacy. These mediators were investigated because they correspond with the components of the intervention. For example, learning to use adaptive cognitive coping strategies (potential mediator) was expected to be related to changes in cognitions (intervention component). We attempted to determine a temporal pattern of change: the mediators and the outcome (depressive symptoms) were investigated at pretest, 3 times during the intervention, and post intervention.

Methods

Participants and Procedure

This study is part of a randomized controlled trial (RCT; Netherlands Trial Register NTR5407) investigating the effectiveness of the self-help intervention *Living Positive With HIV*. More information about the procedure of the RCT can be

found elsewhere [12]. Nursing consultants and doctors in 23 of 26 HIV treatment centers in the Netherlands recruited participants during regular checkups. Patients were screened with the Patient Health Questionnaire–2 (PHQ-2 [24]), and when their score was higher than 0, they were informed about the study and referred to the researchers when they were interested. Researchers called the patients and screened them on the inclusion criteria: being HIV positive for at least 6 months, aged >17 years, mastery of the Dutch or English language, available for the next 8 weeks, having internet and an email address, no current use of antidepressants or current use for >3 months without change of type or dose of antidepressants in the past 3 months, absence of severe cognitive impairments, not currently treated by a psychologist or psychiatrist, presence of mild to moderate depressive symptoms (determined by a PHQ-9 [25] score >4 and <20), and absence of severe suicide ideation (determined by a score <2 on question 9 of the PHQ-9).

When patients were eligible and agreed to participate, Web-based informed consent was signed. Thereafter, participants completed the pretest and were randomly allocated to the intervention or control condition (waiting list and attention-only from a coach). Stratified randomization by sex and HIV treatment center was performed. A random number table was used to create the sequence, which was done by an independent researcher and concealed from the main researcher. There were multiple measurement moments after randomization: 3 times during the intervention (lessons 1, 3, and 5) or waiting period (weeks 1, 3, and 5), a posttest when participants were finished with the intervention (experimental group) or 8 weeks after pretest (control group), and a follow-up at 3 and 6 months (the last follow-up was only completed in the intervention group). In this study, the follow-up measurements were not used in the analyses. Participants received €25 when they completed all questionnaires. The study was approved by the medical ethics committee of the Leiden University Medical Center (nr. P14.091).

Study Conditions

Guided Web-Based Self-Help Intervention

The intervention comprises CBT and contains 4 main components. The first component is behavioral activation: participants are asked to think of a small positive activity that they can perform in the coming weeks (eg, taking a short walk, week 1). They are encouraged to engage in this activity and expand this to other activities. The second component is relaxation exercises that are available on the Web and take about 20 min (week 2). The third component is changing negative cognitions into more balanced cognitions (by challenging negative thoughts) and eliciting strong and positive feelings when negative feelings are experienced (counterconditioning, weeks 3-5). The last component is goal attainment: setting important, realistic, concrete personal goals (eg, quit smoking) and working on attaining them by increasing self-efficacy (weeks 6-7). The participants received log-in details for the secured website of the intervention. No changes to the intervention were made during the RCT. The intervention comprises 8 lessons with psychoeducation, exercises, and assignments. The participants were engaged with the intervention for approximately 8 weeks. On the basis of a pilot study, it was expected that they spent 1 to 2 hours a week on the intervention.

In addition, they were called by a personal coach each week for about 15 min. The coach checked the well-being of the participant and discussed the progress of the intervention. The coaches used motivational interviewing to motivate the participants to continue with the intervention to minimize attrition. Coaching was provided until the participant had finished the intervention, for a maximum of 10 weeks. When participants had not finished by then, they could complete the intervention on their own. The coaches were master's degree students in clinical psychology or graduates with a master's degree in the field of psychology. They received a training and followed a coaching manual. In the coaching manual, the questions that the coaches were supposed to ask were listed in the form of an example conversation to ensure that all coaches provided the same type of support. Furthermore, each coach was asked to record 2 calls in the beginning of the study, which were examined by the main researcher on adherence to the coaching manual. Weekly supervision sessions of 1 hour with coaches and a researcher to discuss issues encountered during coaching were scheduled in the beginning of the study. There were less issues at the end of the study; therefore, they were handled via email or phone. More information about the study conditions and procedures can be found elsewhere [12].

Control Condition

Participants that were allocated to the control condition were put on a waiting list and received attention only from a personal coach. Telephone coaching was provided for 8 weeks, approximately 5 min per week. The coach addressed the well-being of the participant, monitored depressive symptoms, and motivated the participant to keep waiting and complete questionnaires. The participant was referred to the HIV treatment center or general practitioner when the depressive symptoms worsened and became severe. After the 3-month follow-up, participants were invited to start with the intervention.

Assessments

All assessments were completed on the Web and administered at pretest, weeks 1, 3, and 5 during the intervention and waiting period, and at posttest. The questions asked during the intervention and waiting period concerned the symptoms experienced during the last week. It is important to note that the measurements of weeks 3 and 5 and the posttest also capture the lessons learned in the weeks before, so it was not possible to solely measure pre to post session changes. To reduce the time to complete the questionnaires (it is approximately 10 min), 1 or 2 items were chosen from each questionnaire (with the chosen items being the same across measurement moments). The authors jointly determined the items that represented the concept the best. The decisions were made based on face validity. A confirmatory factor analysis (CFA) in R version 3.6.1 (the R foundation) was conducted to investigate whether the items of each questionnaire belonged to the same factor. A total of 7 factors were specified (1 for each mediator and the outcome measure). The CFA model was considered as fitting

well when (1) the comparative fit index (CFI) and the Tucker–Lewis index (TLI) were >0.95, (2) the root mean square error of approximation (RMSEA) was <0.06, and (3) the 90% confidence interval for RMSEA had an upper bound <0.08 and a lower bound near 0 (not worse than 0.06) [26,27]. The fit indices show that the model was fitting well (CFI=0.98; TLI=0.96; RMSEA=0.05; 90% CI <0.001-0.07). The items load on the factors to which they belong and the correlations between most factors were low. The questionnaires are explained briefly below. More information on the specific questions used and the scoring can be found in Multimedia Appendix 1.

Outcome Measure

The outcome measure for the mediational analysis was the severity of depressive symptoms. This was measured with the PHQ-2 [24] that comprises the first 2 questions of the PHQ-9. The construct and criterion validity of the PHQ-2 are adequate [24], and the Spearman–Brown coefficient ranged from 0.71 to 0.83 throughout the 5 measurement moments in this study. Item-total correlations of the 2 items were 0.42 and 0.55 at pretest.

Potential Mediators

Activation

Behavioral activation was measured by a sum score of 2 items from the subscale activation of the Behavioral Activation for Depression Scale (BADS) [28]. The psychometric properties of the Dutch BADS are adequate [29], and the Spearman–Brown coefficient of the 2 items ranged from 0.79 to 0.84 throughout the 5 measurement moments in this study. Item-total correlations of the 2 items at pretest were 0.64 and 0.69.

Relaxation

Relaxation was measured with 1 self-designed item concerning difficulty to relax. The item-total correlation at pretest was 0.44. The reliability of this instrument could not be calculated because it comprised only 1 item.

Cognitive Coping: Catastrophizing and Positive Refocusing

The subscales catastrophizing and positive refocusing of the Cognitive Emotion Regulation Questionnaire short version (CERQ-short) [30] were adopted to measure the use of these cognitive coping strategies when thinking about having HIV. The subscales comprise 2 items each. The psychometric properties of the CERQ-short are adequate [30]. In this study, the Spearman–Brown coefficient ranged from 0.84 to 0.94 throughout the 5 measurement moments for the catastrophizing subscale and from 0.72 to 0.81 throughout the 5 measurement moments for the positive refocusing subscale. Item-total correlations were 0.72 and 0.82 at pretest for the catastrophizing subscale and 0.70 and 0.80 for the positive refocusing subscale.

Goal Re-Engagement

An item of the Goal Disengagement and Goal Re-engagement Scale (GDGRS) [31] was used to measure goal re-engagement. For this study, the item was specifically reformulated to measure goal re-engagement in relation to having HIV. The reliability of the total instrument was previously found to be satisfactory [31]. Item-total correlation at pretest was 0.80.

Coping Self-Efficacy

A sum score of 2 self-designed items was used to measure self-efficacy to cope with having HIV. The items were based on the Generalized Self-Efficacy Scale, which has good reliability and validity [32]. The Spearman–Brown coefficient of the 2 items in this study ranged from 0.75 to 0.92 throughout the 5 measurement moments. Item-total correlations of the 2 items were 0.73 and 0.79 at pretest.

Statistical Analysis

The mediation analyses were conducted with the PHQ-2 score as dependent variable (Y), group (intervention and control) as independent variable (X), and activation, relaxation, the cognitive coping strategies catastrophizing and positive refocusing, goal re-engagement, and coping self-efficacy as potential mediators (M). Note that the PHQ-2 and all 6 mediator questionnaires were administered at all 5 measurement moments (pretest, weeks 1, 3, and 5, and posttest).

The mediation analyses were performed in 3 steps. In step 1, all potential mediators were entered separately into a multilevel structural equation model (MSEM [33]). An MSEM model was chosen because group (X) does not change over time (level 2: between-subjects level), whereas PHQ-2 (Y) and the mediator (M) scores do change over time (level 1: within-subjects level). As group (X) is constant over time, only mediation at between-subjects level can take place. To test this, MSEM computes the product term $a \times b$ and evaluates its significance, with a being the between effect from X to M and b the between effect from M to Y. Mediation is present when the product term significantly differs from 0. The significant mediators found were, thereafter, all together included in a single model to investigate which mediation effects remained significant after controlling for the other mediators in the model. The analysis in step 1 was repeated for the per protocol sample, as a sensitivity analysis. The per protocol sample included participants in the intervention group that finished at least the first 5 lessons of the intervention and participants in the control group that received at least 5 telephone calls from the coach.

In step 2, an explorative analysis was conducted to investigate when the mediating effect(s) exactly occurred (ie, in between which 2 measurement moments). To this end, for the significant mediators encountered in step 1, the same MSEM model was fitted as in step 1, however, using different combinations of measurement moments. In particular, the timing of the mediation effect(s) was investigated by comparing for each measurement moment an MSEM model including only the measurements up to that moment (including the measurement moment in question) with an MSEM model including only subsequent measurement moments. For example, for week 1, an MSEM model including the pretest and week 1 was compared with an MSEM model including weeks 3 and 5 and the posttest. The first measurement moment for which in both associated MSEM models mediation was present was considered as the moment when the mediation occurred.

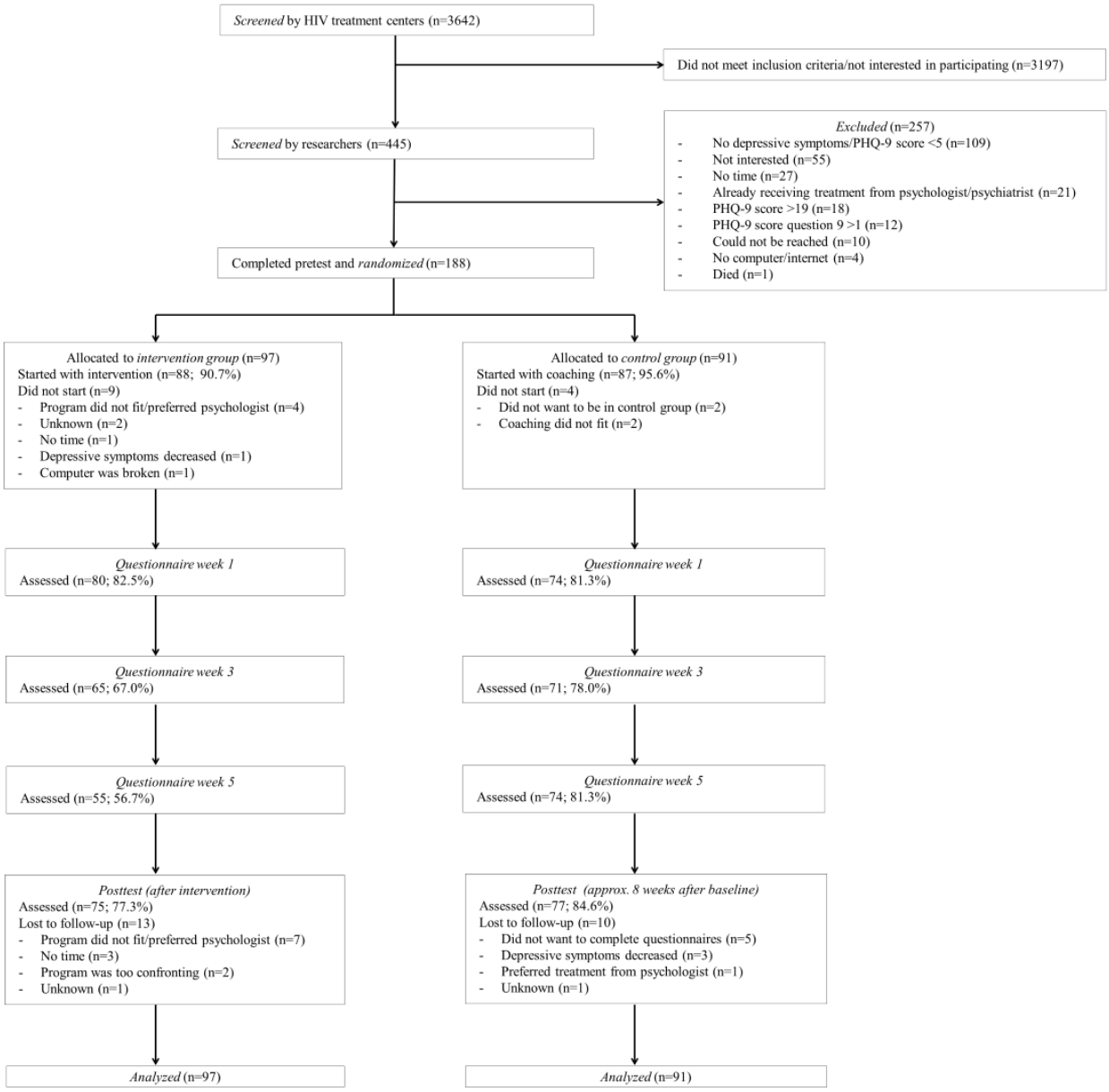
In step 3, return effects from the dependent variable to the significant mediators identified in step 1 (ie, from Y to M) were studied. When return effects are present, this may indicate that the mediation effect is less strong. Return effects were investigated by means of a bivariate autoregressive latent trajectory analysis (ALT [34,35]). To get a good fitting but not too complex ALT model (which generalizes well), some constraints on the parameters were imposed. In particular, for each variable, parameters representing auto-regressive paths were set equal to each other, with the same being true for cross-lagged parameters. Furthermore, for each variable, residual variances for each measurement moment were kept equal (except for the first measurement moment as prescribed by the predetermined model parameterization [34]). Finally, time-specific correlations between residuals were set equal over time. To determine whether the ALT model fitted well to the data, the following model fit indices were evaluated: RMSEA with its 90% CI, CFI, and TLI. The model has a good fit when the RMSEA value is below 0.06, when the 90% CI for RMSEA has an upper bound <0.08 and a lower bound close to 0 and when the CFI and TLI values are higher than 0.95 [26,27]. The analyses were based on full information maximum likelihood techniques, which means that all available data, including participants with partially missing data, were used. Alpha=.05 was used for significance testing. All analyses were conducted in MPlus version 7.31.

Results

Participants

In the HIV treatment centers, 3642 patients were screened on depressive symptoms. Of these, 445 were screened by the researchers and 188 patients were included in the study. Patients were 1:1 randomized to the intervention group (n=97) and the control group (n=91). Note that because of the stratified randomization, the intervention group contains a few more participants than the control group. The posttest was completed by 75 participants (75/97, 77%) of the intervention group and 77 participants (77/91, 84%) of the control group. Figure 1 displays for each group separately the flow of participants through the study in terms of PHQ-2.

Figure 1. Flow of participants through the study. PHQ-9: Patient Health Questionnaire-9.



In total, 22 participants (22/188, 11.7%) in the study were female and 166 (166/188, 88.3%) were male. In the Netherlands, most PLWH are male. The average age of the participants was 46.30 years (SD 10.63). Most participants had a Dutch nationality (158/188, 84.0%), 18 participants (18/188, 9.6%) had another nationality (most common Surinamese), and 12 (12/188, 6.4%) had a Dutch nationality combined with another nationality. A total of 32 participants (32/188, 17.0%) were heterosexual, 144 (144/188, 76.6%) homosexual, and 12 (12/188, 6.4%) bisexual. Most participants had a medium education (77/188; 40.9%) or a high education (69/188, 36.7%), and a minority had a low education (42/188, 22.3%; classification of educational level according to Statistics Netherlands [36]). Participants had HIV for 9.87 years on average (SD 6.58). A total of 23 participants (23/188, 12.2%) had AIDS and 165 (165/188, 87.8%) did not have AIDS, and 184 participants (184/188, 97.9%) used antiretroviral therapy (ART) and 4 (4/188, 2.1%) did not use ART. More information on the baseline characteristics of the sample can be found elsewhere [13]. Mean scores on the questionnaires at different time points can be found in Table 1.

Table 1. Mean scores on the questionnaires at different time points.

Characteristic	Intervention group, mean (SD)	Control group, mean (SD)	Mean difference	*P* value
Depressive symptoms (PHQ-2[a]) pretest	3.10 (1.47)	2.78 (1.26)	0.32	.11
Week 1	2.13 (1.41)	2.27 (1.55)	−0.15	.54
Week 3	1.66 (1.20)	2.24 (1.56)	−0.58	.02
Week 5	1.24 (1.25)	2.05 (1.59)	−0.82	.002
Posttest	1.53 (1.41)	2.38 (1.59)	−0.84	.001
Behavioral activation (BADS[b]) pretest	4.78 (3.15)	4.58 (3.05)	0.20	.66
Week 1	5.90 (2.74)	5.30 (2.88)	0.60	.19
Week 3	6.52 (2.88)	5.35 (2.82)	1.17	.02
Week 5	7.35 (2.31)	5.78 (2.74)	1.56	.001
Posttest	7.57 (2.99)	5.46 (3.07)	2.11	<.001
Relaxation pretest	1.62 (0.60)	1.69 (0.68)	−0.07	.43
Week 1	1.66 (0.57)	1.74 (0.62)	−0.08	.40
Week 3	1.97 (0.59)	1.80 (0.65)	0.17	.12
Week 5	2.13 (0.70)	1.81 (0.61)	0.32	.01
Posttest	2.05 (0.66)	1.86 (0.70)	0.20	.08
Catastrophizing (CERQ-short[c]) pretest	3.80 (2.36)	3.37 (1.74)	0.43	.15
Week 1	3.44 (1.77)	3.61 (2.10)	−0.17	.60
Week 3	3.05 (1.58)	3.38 (2.04)	−0.33	.29
Week 5	2.75 (1.21)	3.24 (1.68)	−0.50	.05
Posttest	2.92 (1.75)	3.16 (1.69)	−0.24	.39
Positive refocusing (CERQ-short) pretest	6.39 (2.23)	6.37 (2.03)	0.02	.95
Week 1	6.13 (1.89)	5.96 (1.85)	0.17	.58
Week 3	6.32 (1.96)	5.90 (1.97)	0.42	.21
Week 5	6.91 (1.96)	6.39 (2.05)	0.52	.15
Posttest	7.04 (2.17)	6.07 (2.19)	0.97	.01
Goal re-engagement (GDGRS[d]) pretest	3.15 (0.86)	2.97 (0.82)	0.19	.13
Week 1	3.42 (0.79)	3.12 (0.81)	0.30	.02
Week 3	3.55 (0.75)	3.10 (0.94)	0.46	.002
Week 5	3.71 (0.79)	3.26 (0.97)	0.45	.01
Posttest	3.55 (0.79)	3.08 (0.99)	0.47	.002
Coping self-efficacy pretest	7.08 (1.78)	7.24 (1.66)	−0.16	.53
Week 1	7.51 (1.59)	7.15 (1.78)	0.36	.19
Week 3	8.03 (1.60)	7.14 (1.83)	0.89	.003
Week 5	8.11 (1.40)	7.53 (1.69)	0.58	.03
Posttest	7.93 (1.65)	7.20 (1.72)	0.73	.02

[a]PHQ-2: Patient Health Questionnaire–2.

[b]BADS: Behavioral Activation for Depression Scale.

[c]CERQ-short: Cognitive Emotion Regulation Questionnaire short version.

[d]GDGRS: Goal Disengagement and Goal Re-engagement Scale.

Mediation Analysis Step 1

Table 2 shows the results of the mediation analysis based on MSEM in which all mediators are investigated separately. Changes in BADS and GDGRS were found to be significant mediators. Subsequently, these 2 mediators were together included in a single model. Changes in BADS remained a significant mediator when changes in GDGRS were controlled for ($a \times b$=0.25; SE 0.10; P=.01), whereas changes in GDGRS were not a significant mediator anymore when changes in BADS were controlled for ($a \times b$=0.15; SE 0.09; P=.10). Correlations between BADS and GDGRS varied across measurement moments (range from r=0.07; P=.39 to r=0.54; P<.001). The mediation analysis was repeated on the per protocol sample and the results were similar as for the whole sample. For illustrative purposes, Figure 2 displays the course of PHQ-2, BADS, and GDGRS scores over time in both groups. The intervention group shows a stronger reduction in PHQ-2 score over time than the control group, and at the same time BADS scores and GDGRS scores increase more over time in the intervention group than in the control group.

Figure 2. Course of the mean Patient Health Questionnaire–2 (PHQ-2) score, Behavioral Activation for Depression Scale (BADS) score, and Goal Disengagement and Goal Re-engagement Scale (GDGRS) score over time for both groups (per protocol sample).

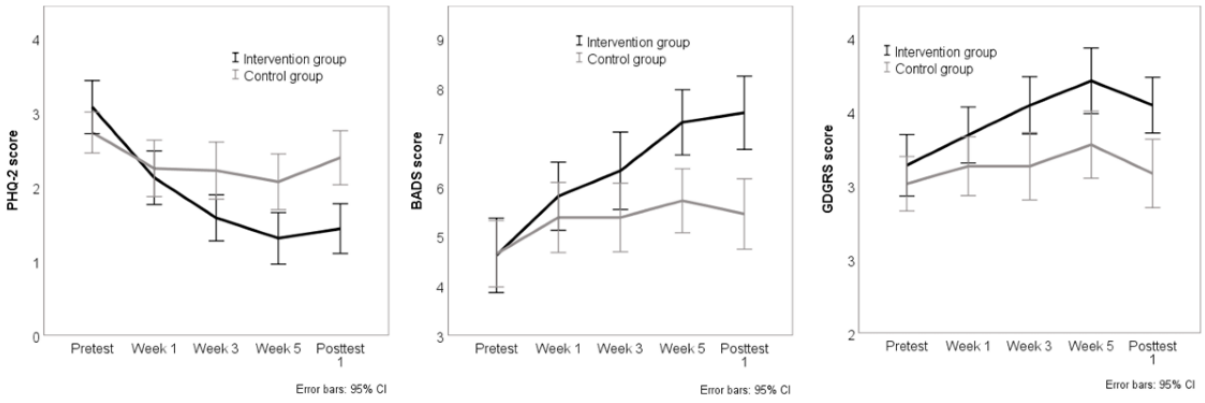


Table 2. Mediation effects of 6 potential mediators (tested separately) with group as independent variable and Patient Health Questionnaire-2 score as dependent variable, based on multilevel structural equation model analysis on data containing all 5 measurement moments.

Potential mediator	$a \times b$[a]	SE	P value
Behavioral activation (BADS[b])	0.31	0.11	.006[c]
Relaxation	0.05	0.08	.55
Catastrophizing (CERQ-short[d])	−0.005	0.06	.92
Positive refocusing (CERQ-short)	0.10	0.08	.17
Goal re-engagement (GDGRS[e])	0.29	0.11	.009[c]
Coping self-efficacy	0.12	0.08	.13

[a]Coefficient for the product term testing the mediation effect.

[b]BADS: Behavioral Activation for Depression Scale.

[c]P<.05.

[d]CERQ-short: Cognitive Emotion Regulation Questionnaire short version.

[e]GDGRS: Goal Disengagement and Goal Re-engagement Scale.

Mediation Analysis Step 2: Timing of Mediation Effects

Table 3 shows the timing of the mediation effects of the significant mediators in step 1. The results show that for changes in BADS, the mediation effect is not significant when the pretest and weeks 1 and 3 measurements are combined. However, the mediation effect is significant when the week 5 and posttest measurements are combined. Therefore, it seems likely that the BADS mediation effect occurs between weeks 3 and 5. For changes in GDGRS, the results are almost similar. The mediation effect is not significant when the pretest and week 1 measurements are combined and is significant when the weeks 3 and 5 and posttest measurements are combined. Hence, it seems likely that the GDGRS mediation effect occurs between weeks 1 and 3.

Table 3. Timing of mediation effects—comparison of the mediation effect in multilevel structural equation models fitted to data containing different sets of measurement moments to investigate when the mediation effect occurs.

Combination of measurement moments	BADS[a]			GDGRS[b]		
	$a \times b$[c]	SE	*P* value	$a \times b$	SE	*P* value
Combination 1						
Pretest	0.03	0.06	.66	0.06	0.04	.17
Week 1–posttest	0.44	0.13	.001[d]	0.43	0.14	.003[d]
Combination 2						
Pretest–week 1	0.10	0.10	.30	0.20	0.12	.09
Week 3–posttest	0.59	0.16	<.001[d]	0.50	0.18	.005[d]
Combination 3						
Pretest–week 3	0.20	0.11	.08	0.19	0.10	.04[d]
Week 5–posttest	0.69	0.20	<.001[d]	0.60	0.27	.03[d]
Combination 4						
Pretest–week 5	0.23	0.11	.04[d]	0.22	0.10	.02[d]
Posttest	0.52	0.15	<.001[d]	0.24	0.10	.02[d]

[a]BADS: Behavioral Activation for Depression Scale.

[b]GDGRS: Goal Disengagement and Goal Re-engagement Scale.

[c]Coefficient for the product term testing the mediation effect.

[d]*P*<.05.

Mediation Analysis Step 3: Return Effects

Table 4 presents the results of the analysis on return effects from the dependent variable to the significant mediators. The values of the fit indices (RMSEA, CFI, and TLI) indicate that the model has an acceptable to good fit. The results show that there is no return effect from the PHQ-2 to the BADS, but there is a return effect from the PHQ-2 to the GDGRS. However, the standardized coefficient (beta) for the effect of the GDGRS on the PHQ-2 (beta=−.20) is higher, in absolute value, than the beta for the effect of the PHQ-2 to the GDGRS (beta=−.13). This suggests that the mediation effect is larger than the return effect.

Table 4. Results of the analysis on return effects from the dependent variable (Patient Health Questionnaire–2) to the mediators.

Mediator	Dependent variable → Mediator		*P* value	RMSEA[a] (90% CI)	CFI[b]	TLI[c]
	Unstandardized coefficient (SE)	Standardized[d] coefficient (SE)				
BADS[e]	−0.12 (0.10)	−0.06 (0.05)	.24	0.06 (0.04-0.09)	0.94	0.94
GDGRS[f]	−0.08 (0.03)	−0.13 (0.06)	.02[g]	0.06 (0.03-0.08)	0.95	0.94

[a]RMSEA: root mean square error of approximation.

[b]CFI: comparative fit index.

[c]TLI: Tucker–Lewis Index.Using STDYX standardization.

[d]Using STDYX standardization.

[e]BADS: Behavioral Activation for Depression Scale.

[f]GDGRS: Goal Disengagement and Goal Re-engagement Scale.

[g]*P*<.05.

Discussion

Principal Findings

This study investigated potential mediators of a guided internet-based intervention for PLWH with depressive symptoms, compared with a control group that received attention only. Changes in behavioral activation and goal re-engagement were found to be significant mediators of the intervention effect. For changes in behavioral activation, the mediation effect seemed to occur between weeks 3 and 5 of the intervention and for changes in goal re-engagement, between weeks 1 and 3. The mediation effect of changes in behavioral activation seemed to be stronger than the effect of changes in goal re-engagement because goal re-engagement was not a significant mediator anymore when the model was controlled for behavioral

activation. Moreover, a return effect (from the dependent variable to the mediator) was found for goal re-engagement and not for behavioral activation.

In a review about CBT for depression, changes in behavioral activation were found to be a significant mediator in 3 out of 6 studies [18]. More specifically, when only high-quality studies were examined, 3 out of 4 studies concluded that changes in behavioral factors were a significant mediator. This is in line with our findings. However, a previous study into internet CBT for depression investigated changes in behavioral activation as a mediator and found that it was not a significant mediator of the intervention effect [22]. An explanation for the difference in results between our study and this previous study may be the difference in timing of the intervention components and measurement moments, that is, the component behavioral activation was offered early in our intervention and late in the other intervention. We included 3 measurement moments during the intervention period in our study and there was only 1 measurement moment during the intervention in the previous study, and at that moment behavioral activation was not offered yet. Therefore, it is not surprising that no mediation effect of behavioral activation was found in the previous study. It is important to include multiple measurement moments of the dependent variable and possible mediators during the intervention period to determine a timeline of the effects of mediators and outcome. As far as we know, changes in goal re-engagement as a mediator of intervention effect for (Web-based) CBT for depression was not investigated previously. More research is needed regarding the mediating role of changes in behavioral activation and goal re-engagement in Web-based CBT for depressive symptoms.

This study was conducted to find mediators of the intervention effect, which may provide us with suggestions for possible mechanisms of change underlying the intervention. As changes in behavioral activation and goal re-engagement were found to be mediators of the intervention, they might suggest possible mechanisms of change. It was previously found that reward processing and avoidance might be possible mechanisms of change of behavioral activation [37-39], that is, specific components of the intervention might activate these mechanisms, for example, by activating participants, avoidance of (positive) activities might be reduced. In turn, this may lead to a reduction in depressive symptoms. However, it was previously found that there is no 1-to-1 relation between offering certain components of the intervention and the change in corresponding mediators [19,40]. For example, it was found that negative thinking decreased after CBT but also after behavioral activation. So, even when the focus was not on changing negative thoughts in the behavioral activation treatment, they did decrease [40]. Though, the results of this study may suggest that behavioral activation and goal re-engagement may be important components of the intervention. More research should be conducted into the relation between offering certain components of the intervention and the change in corresponding mediators.

Goal re-engagement and behavioral activation as components of the intervention are related, as both are trying to increase the amount of (positive) activities to improve one's mood. In addition, in interventions that include behavioral activation, goal setting is often included as a first step of activation [41,42]. As behavioral activation and goal re-engagement are related, it may not be surprising that the timing of the mediation effects did not correspond to the timing of the related intervention components. The mediation effect of changes in behavioral activation occurred approximately 3 weeks after the component was introduced, and in goal re-engagement occurred approximately 4 weeks before the component was introduced. This is also in line with previous findings regarding the weak relation between offering a certain intervention component and a change in the corresponding mediator [19,40]. No other significant mediators of intervention effect were found. This means that changes in relaxation, coping self-efficacy, and the cognitive coping strategies catastrophizing and positive refocusing were no significant mediators. In most previous reviews [16-18], changes in cognitions were found to be mediators of CBT for depression, but 1 review found no evidence for changes in cognitions as a mediator [19]. In this study, changes in cognitions were not measured, but changes in the use of cognitive coping strategies was included. This may be comparable with a change in cognitions, but changes in the use of cognitive coping strategies were not found to be mediators. These cognitive coping strategies were addressed in the intervention and also did improve in the intervention group. However, the use of these strategies also improved in the control group. Future studies may investigate changes in cognitions as a mediator of intervention effect. Many PLWH suffer from depressive symptoms which are related to, among others, the stigma that is associated with having HIV [1] and coping difficulties [3]. The intervention that was investigated in this study was able to decrease depressive symptoms in PLWH. This may also have a positive effect on their quality of life and medication adherence. The findings from this study and future research may be used to optimize the intervention and improve the mental health of PLWH even more.

Strengths and Limitations

Some strengths and weaknesses of this study may be identified. An important strength was that a temporal pattern of change was investigated because multiple measurement moments were included during the intervention period. Many previous mediation studies only included a pretest and a posttest, which is not sufficient to demonstrate a timeline and *real* mediation effects [15]. In addition, multiple mediators were investigated that corresponded to components of the intervention. Another strength was that advanced state-of-the-art statistical analyses were used: MSEM and ALT. Furthermore, all available data were used in the analyses, so participants with some missing measurement moments were not totally excluded from the analyses. Finally, return effects from the dependent variable to the mediators were investigated to study the strength of the mediation effects.

A weakness of this study is that the measurement of some mediators included the use of self-designed questionnaires with only a few items. The reliability and construct validity (established with factor analysis) of these questionnaires was mostly adequate, but the validity of the short scales needed to be more thoroughly investigated. Only a few items were used

because multiple concepts were measured multiple times and it should not have taken too much time to complete them. Another weakness was that there was much dropout during the study. However, the dropout rate was comparable with other studies regarding the effectiveness of internet interventions [43,44]. No differences in demographic and HIV specific characteristics (eg, duration of HIV) were found between dropouts and completers in this study [13], so probably attrition bias was not a problem. Furthermore, the measurements of weeks 3 and 5 and the posttest also capture the lessons learned in the weeks before, so it was not possible to solely measure pre to post session changes. Finally, a selection of mediators was investigated in this study. Other mediators may also have an effect and may be assessed in future studies.

Future Research

In future studies, mediators may be more elaborately assessed with validated questionnaires with more items. Attrition may be prevented by using techniques that were previously suggested, such as inducing hope for benefits of the intervention and reducing time barriers by using habit-forming strategies [45]. Other potential mediators may be investigated, such as changes in worrying. In addition, it is important to study what the mechanisms of change of the intervention are. This is a challenge to investigate, as the relation between intervention components, mediators, and mechanisms of change is weak. As a first step, dismantling studies may be conducted, where each component of the intervention is provided to a different group of participants and will be compared with a group that receives the complete intervention [15]. In this way, it can be investigated which components may be related to changes in specific mediators. Furthermore, manipulation of a proposed mechanism of change may be conducted to study the effects on the outcome [15]. Finally, it may be useful to conduct studies in minority groups in the Netherlands, such as females and heterosexual males with HIV, to investigate their specific needs. In addition, the gender distribution may be different in other countries, which has to be taken into account in future studies.

Conclusions

To conclude, potential mediators of a guided internet-based intervention for PLWH with depressive symptoms were studied. The intervention was previously found to be effective in decreasing depressive symptoms, compared with a control group receiving attention only. We found that changes in behavioral activation and goal re-engagement were significant mediators of the intervention effect. The mediation effect of changes in behavioral activation seemed to be stronger than that in goal re-engagement. The mediators that were found in this study may suggest possible mechanisms of change of the intervention. More research into these mechanisms of change is needed to find out how the intervention works. The outcomes of these studies may be used to optimize the intervention and help decrease depressive symptoms among PLWH even more effectively.

Acknowledgments

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Conflicts of Interest

Multimedia Appendix 1
Items and scoring of the questionnaires.
[PDF File (Adobe PDF File), 32KB - mental_v6i8e12711_app1.pdf]

Multimedia Appendix 2
CONSORT-EHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 2MB - mental_v6i8e12711_app2.pdf]

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Abbreviations

ART: antiretroviral therapy
BADS: Behavioral Activation for Depression Scale
CBT: cognitive behavioral therapy
CERQ-short: Cognitive Emotion Regulation Questionnaire short version
CFA: confirmatory factor analysis
CFI: comparative fit index
GDGRS: Goal Disengagement and Goal Re-engagement Scale

MSEM: multilevel structural equation model
PHQ: Patient Health Questionnaire
PLWH: people living with HIV
RMSEA: root mean square error of approximation
TLI: Tucker–Lewis index

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Original Paper

Reimbursement of Apps for Mental Health: Findings From Interviews

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Abstract

Background: Although apps and other digital and mobile health tools are helping improve the mental health of Americans, they are currently being reimbursed through a varied range of means, and most are not being reimbursed by payers at all.

Objective: The aim of this study was to shed light on the state of app reimbursement. We documented ways in which apps can be reimbursed and surveyed stakeholders to understand current reimbursement practices.

Methods: Individuals from over a dozen stakeholder organizations in the domains of digital behavioral and mental health, care delivery, and managed care were interviewed. A review of Current Procedural Terminology (CPT) and Healthcare Common Procedure Coding System (HCSPCS) codes was conducted to determine potential means for reimbursement.

Results: Interviews and the review of codes revealed that potential channels for app reimbursement include direct payments by employers, providers, patients, and insurers. Insurers are additionally paying for apps using channels originally designed for devices, drugs, and laboratory tests, as well as via value-based payments and CPT and HCSPCS codes. In many cases, it is only possible to meet the requirements of a CPT or HCSPCS code if an app is used in conjunction with human time and services.

Conclusions: Currently, many apps face significant barriers to reimbursement. CPT codes are not a viable means of providing compensation for the use of all apps, particularly those involving little physician work. In some cases, apps have sought clearance from the US Food and Drug Administration for prescription use as digital therapeutics, a reimbursement mechanism with as yet unproven sustainability. There is a need for simpler, more robust reimbursement mechanisms to cover stand-alone app-based treatments.

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KEYWORDS

mental health; psychiatry; compensation; mobile health; clinical coding; administrative claims, healthcare

Introduction

Diversity of Apps

Numerous patient-facing and provider-facing smartphone apps are available to potentially improve the mental health of Americans. Apps are being used for screening, diagnosis, treatment, ongoing monitoring, decision making, and administrative purposes. As a result of the broad variety of apps in use, there are diverse means of reimbursement being used to compensate for app utilization.

Some mental health apps are being paid for by employers, insurers (public and private), health care providers, and patients. In general, insurers and employers are paying for apps in 2 ways: paying for them directly and paying for them indirectly by paying for services that are facilitated by app-based interventions. When insurers pay for apps directly, they are using multiple means to do so: reimbursing them through paying Current Procedural Terminology (CPT) or Healthcare Common Procedure Coding System (HCSPCS) codes, through paying for them as if they were pharmaceuticals or medical devices, and by making direct payments for them, which are not tied to

any codes or defined payment mechanisms. To summarize the present state of app reimbursement, this paper provides an overview of how apps are being reimbursed today, documents potential pathways to reimbursement, and reviews the limitations of these pathways. Apps, like all medical products, warrant reimbursement only if they are effective. There are a number of methods by which app effectiveness can be evaluated. We do not address those methods here.

Overview of How Apps Can Be Reimbursed Today

App reimbursement is occurring through multiple channels, and some major categories of apps are not receiving reimbursement from payers at all. As is shown in Figure 1, there are at least 6 different pathways to reimbursement that exist. The diversity in potential reimbursement mechanisms is an outgrowth of both the wide set of actors paying for apps (insurers, employers, health care providers, and patients) and the variation in functionality of the apps themselves. Adding to the confusion, interviews with industry stakeholders revealed that in some situations, a single app is being reimbursed through multiple means, depending on the context. Thus, the means for reimbursement is neither universal across apps nor even always within a given app. A common means of funding apps is direct payment. When direct payments are made, employers, insurers, or health care providers can compensate the app vendor by paying a one-time fee for a general license to the app, paying a subscription for a general license to the app, paying a one-time fee per user, paying a per user-per month fee, paying a per employee/member per month fee, or paying a fee tied to the level of app utilization. Similarly, patients may directly buy access to apps for themselves on a one-time basis, via subscription or on the basis of utilization (eg, in-app purchases). When apps are not purchased directly, insurers may pay for them as if they were prescription drugs or devices and as if they were laboratory tests, or they may pay for them via payments made for CPT codes. Finally, money paid through value-based payment arrangements can be used by health care providers to purchase apps. Although this mode of payment is rather indirect, it does enable health care providers to purchase apps if they believe that doing so will decrease costs or enhance the value of care that they deliver.

When CPT codes are used to facilitate payment for apps, there are 2 ways in which they may be implemented. First, some CPT codes are directly applicable to an app-delivered health care service. For instance, app-based screening can fulfill the requirements of a screening CPT code. Second, some CPT codes are applicable to broad services that can be facilitated by apps. For example, an app-based platform might facilitate collaborative care and enable a health care provider to bill for the CPT code associated with collaborative care. Some of the revenue from the CPT code could be used to cover the app's costs, whereas the remainder would likely need to be spent on associated services (eg, staffing) necessary to perform the services associated with the billed CPT code. One of the factors that drive the need for multiple reimbursement methods to be used to cover apps is that apps vary in their level of physician and nonphysician involvement. As is shown in Figure 2, there is a spectrum of levels of physician and nonphysician (eg, nurse, psychologist, technician) involvement in the use of apps. Some apps involve absolutely no human involvement, for instance, self-help tools that a family physician might wish to recommend to a patient expressing a minor health issue. From there, progressively greater levels of human involvement can occur, ranging from the periodic review of data captured in an app by a nonphysician (eg, a brief screening) to live interaction with a physician (eg, telemental health). Stand-alone interventions lend themselves to being reimbursed as if they were devices, drugs, or laboratory tests, as these analogues were all designed to be services that are reimbursable without physician, nurse, or technician contact.

Figure 1. Channels for app reimbursement. CPT: Current Procedural Terminology.

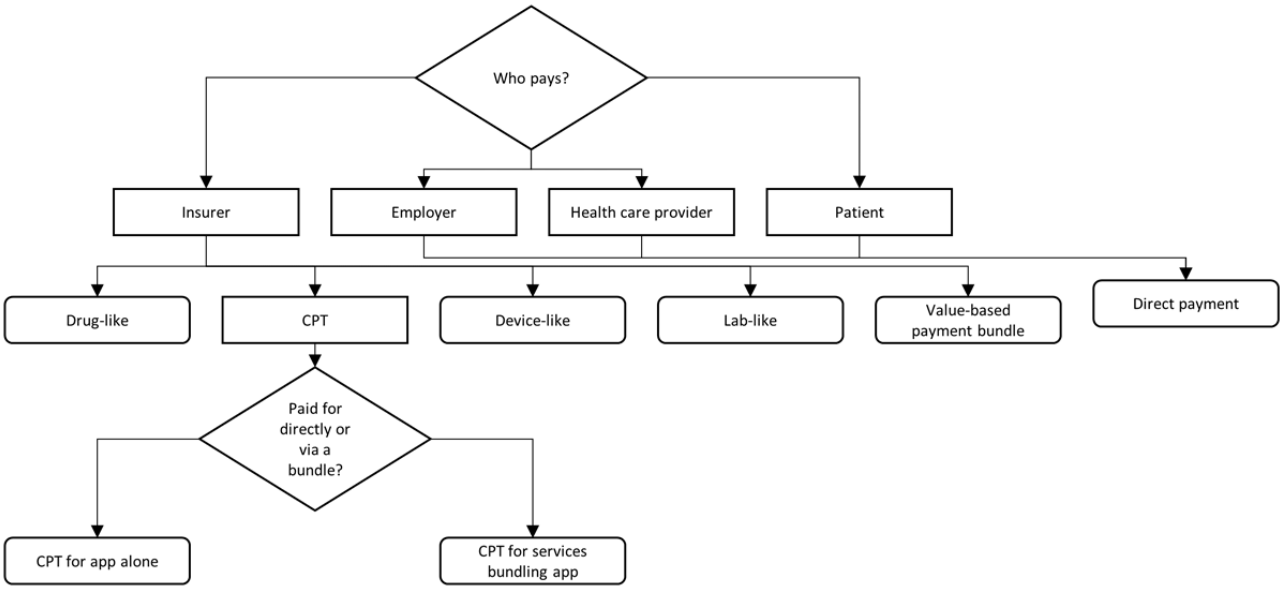
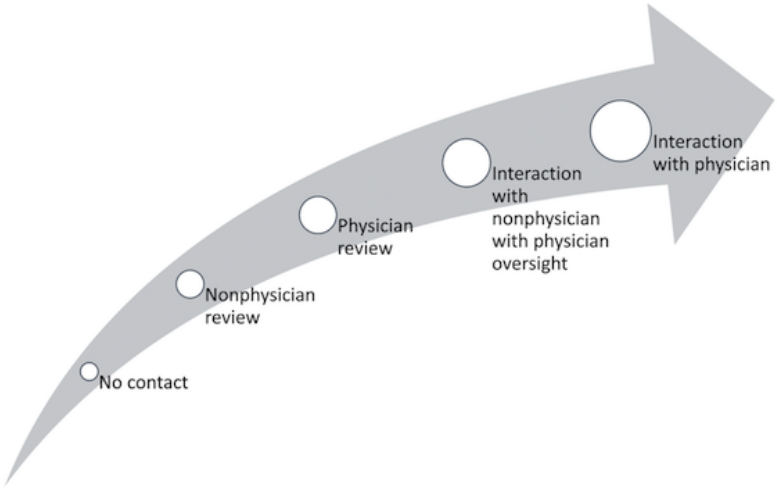


Figure 2. Spectrum of health care provider and technician involvement in app use.



Screening and Repeat Measures for Standardized, Quantitative Clinical Outcomes

A literature review found that virtually all randomized controlled trials have shown that the frequent, timely provision of standardized patient-reported symptoms during psychotherapy encounters is associated with improved outcomes [1]. Apps are a natural tool for screening and repeat measures, as they enable patients to report their state to their health care providers from the comfort of their home. When billing for apps performing screening and repeat measures for standardized, quantitative clinical outcomes, the appropriate CPT code may vary in accordance with the instrument being administered. The American Academy of Pediatrics has produced a table (reproduced below as Table 1), which indicates the correspondence between instruments and CPT codes [2].

Table 1. Current Procedural Terminology codes appropriate for assorted instruments.

Instrument	Codes			
	96110	96127	96160	96161
Acute Concussion Evaluation (ACE)	__[a]	—	X	—
Ages and Stages Questionnaire—Third Edition	X	—	—	—
Ages and Stages Questionnaire—Social Emotional	—	X	—	—
Australian Scale for Asperger Syndrome (ASAS)	—	X	—	—
Beck Youth Inventory— Second Edition BYI-II	—	X	—	—
Behavior Assessment Scale for Children—2nd Edition	—	X	—	—
Behavior Rating Inventory of Executive Function	—	X	—	—
Conners Rating Scale	—	X	—	—
CRAFFT Screening Interview	—	—	X	—
Edinburgh Postnatal Depression Scale[b] (EPDS)	—	—	—	X
Edinburgh Postnatal Depression Scale (EPDS)	—	X	—	—
Kutcher Adolescent Depression Scale (KADS)	—	X	—	—
Modified Checklist for Autism in Toddlers (MCHAT)	X	—	—	—
Patient Health Questionnaire (PHQ-2 or PHQ-9)	—	X	—	—
Parents' Evaluation of Developmental Status (PEDS)	X	—	—	—
Pediatric Symptom Checklist (PSC)	—	X	—	—
Screen for Child Anxiety Related Disorders (SCARED)	—	X	—	—
Vanderbilt rating scales	—	X	—	—

[a]Not applicable.

[b]When billed under the infant and not the mother.

The most common CPT code deemed appropriate is 96127, which is defined as "Brief emotional/behavioral assessment, (eg, depression inventory, attention-deficit/hyperactivity disorder [ADHD] scale), with scoring and documentation, per standardized instrument." In the case of pediatrics, a different code that relates to developmental screening may be more appropriate: 96110, "Developmental screening (eg, developmental milestone survey, speech and language delay screen), with scoring and documentation, per standardized instrument." Finally, if a health risk assessment is used to assess for mental health issues, either 96160, "Administration of patient-focused health risk assessment instrument (eg, health hazard appraisal), with scoring and documentation, per standardized instrument," or 96161, "Administration of caregiver-focused health risk assessment instrument (eg, depression inventory) for the benefit of the patient, with scoring and documentation, per standardized instrument," should be billed, depending on whether the focus of the assessment is the patient or the caregiver [3].

Collaborative Care Codes

Information technology has the potential to play a key role in supporting collaboration, information exchange, and planning. Codes to support the collaborative care model (CoCM) program were introduced by the Centers for Medicare and Medicaid Services in 2018. Although these codes cannot be billed for the use of a freestanding app, as collaborative care inherently involves human effort, apps can play a role in facilitating collaborative care and documenting that the necessary resources have been provided to fulfill the requirements of the codes being billed. The collaborative care codes provide funding for both less intensive and more intensive versions of collaborative care. The code 99484 was created to fund Behavioral Health Integration models of care other than CoCM, and the codes 99492, 99493, and 99494 were created to cover the activities of true CoCM programs. Eligibility for 99484 differs from the CoCM codes, making it suitable for environments with fewer staff resources [4]. Although 99484 only requires at least 20 min of clinical staff time, overseen by a physician or qualified health professional, the CoCM codes require a psychiatric consultant and behavioral health care manager to be a part of the care team, which provides 70 min of services in the first month and 60 min of services in subsequent months.

Methods

Individuals from over a dozen stakeholders in digital behavioral and mental health domain were interviewed, representing organizations offering solutions, including a digital device (app as a medical device), an app intended to take the place of a drug, app-facilitated telemedicine, app-facilitated care coordination and case management, app- and device-facilitated sobriety testing, a peer therapy app, a patient remote monitoring service, and a suite of app-based care tools. Other stakeholders interviewed included individuals associated with a commercial payer, a Medicaid payer, an employee assistance program, a health care provider organization, and a medical professional society. In total, 22 interviews were conducted, of which 10 were with for-profits offering digital tools, 4 were with nonprofits related to mental health, 3 were with health care provider organizations, 3 were with academics, and 2 were with government entities. During each of the interviews, the stakeholders were asked about the pathways their organizations had used to achieve reimbursement, as well as the pathways through which they had seen other organizations achieve reimbursement. Payer and provider stakeholders were asked about how app-based care was financed by their organizations.

Results

The list of codes in Table 2 summarizes the codes (1) that were found to be in active use or were attempted to be placed in active use during the interview process, or (2) that could theoretically be put into use in the judgment of the authors (these are noted as "not observed"). It contains HCSPCS codes, as defined by the Centers for Medicare and Medicaid Services; CPT codes are a subset of the HCSPCS codes. The types of providers (eg, psychiatrists, psychologists, social workers, and technicians) who may bill the codes vary from code to code. For instance, 96138 may be billed for work performed by a technician, whereas 96116 may only be billed for work performed by a "physician or other qualified health care professional." To keep the list at a manageable length, the list of codes only contains those for initial encounters or for the lowest duration of a service. In some cases, there are related codes for subsequent encounters or longer durations of service. These codes were identified by reviewing the 2019 edition of the American Medical Association's *CPT Professional* book, the definitive source on CPT codes [5].

It should be noted that some organizations reported using different codes with different payers and different codes in different clinical settings. For instance, a provider of a digital behavioral health integration and remote patient monitoring solution used the code 99489 in settings lacking a behavioral health specialist, leading to lower reimbursements, and 99492 in settings with a behavioral health specialist, leading to higher reimbursements. As was the case with the digital behavioral health integration tool, in many instances, some degree of health care provider involvement is necessary to bill a code. Thus, there were many cases in which digital tools played a key role in a solution, but they could not be reimbursed if used on an entirely stand-alone basis by a patient. Finally, many organizations are not using codes at all; instead, they are relying on other mechanisms, such as (1) direct billing via a "one-off" contract with an employer or insurer or (2) patient self-pay. These 2 approaches, used because of the absence of a code intended for apps per se, are cumbersome and difficult to implement on a large scale. They are an indication of the barrier to widespread adoption of apps that exists today.

Table 2. List of potential Healthcare Common Procedure Coding System (Current Procedural Terminology) codes that may potentially be used to reimburse for app-related services.

Code	Definition [3]	Context in which use of code was observed
90832	Psychotherapy, 30 min with patient (using 95 or GT modifier to indicate telemental health)	Teletherapy service
90885	Psychiatric evaluation of hospital records, other psychiatric reports, psychometric and/or projective tests, and other accumulated data for medical diagnostic purposes	Not observed
90887	Interpretation or explanation of results of psychiatric, other medical examinations and procedures, or other accumulated data to family or other responsible persons, or advising them how to assist patient	Not observed
90889	Preparation of report of patient's psychiatric status, history, treatment, or progress (other than for legal or consultative purposes) for other individuals, agencies, or insurance carriers	Not observed
96105	Assessment of aphasia (includes assessment of expressive and receptive speech and language function, language comprehension, speech production ability, reading, spelling, and writing, eg, by Boston Diagnostic Aphasia Examination), with interpretation and report per hour	Cognitive and psychological screening app
96110	Developmental screening (eg, developmental milestone survey, speech, and language delay screen), with scoring and documentation, per standardized instrument	Not observed
96116	Neurobehavioral status exam (clinical assessment of thinking, reasoning and judgment, eg, acquired knowledge, attention, language, memory, planning and problem solving, and visual spatial abilities) by physician or other qualified health care professional, both face-to-face time with the patient and time interpreting test results and preparing the report; first hour	Not observed
96127	Brief emotional/behavioral assessment (eg, depression inventory, attention-deficit/hyperactivity disorder scale), with scoring and documentation, per standardized instrument	Screening component (eg, Patient Health Questionnaire-9, General Anxiety Disorder-7) within various self-service, patient-facing apps
96130	Psychological testing evaluation services by a physician or other qualified health care professional, including integration of patient data, interpretation of standardized test results and clinical data, clinical decision making, treatment planning and report, and interactive feedback to the patient, family member(s) or caregiver(s), when performed; first hour	Tech-enabled care management and case management service
96138	Psychological or neuropsychological test administration and scoring by a technician, 2 or more tests, any method; first 30 min	Tech-enabled care management and case management service
96146	Psychological or neuropsychological test administration, with single automated, standardized instrument via electronic platform, with automated result only	Tech-enabled care management and case management service
96160	Administration of a patient-focused health risk assessment instrument (eg, health hazard appraisal), with scoring and documentation, per standardized instrument	Not observed
96161	Administration of a caregiver-focused health risk assessment instrument (eg, depression inventory) for the benefit of the patient, with scoring and documentation, per standardized instrument	Medicaid depression initiative
99091	Collection and interpretation of physiologic data (eg, electrocardiogram, blood pressure, and glucose monitoring) digitally stored and/or transmitted by the patient and/or caregiver to the physician or other qualified health care professional, qualified by education, training, and licensure/regulation (when applicable), requiring a minimum of 30 min of time, every 30 days	Physiologically based sobriety monitoring program (exploring but not using code)
99358	Prolonged evaluation and management service before and/or after direct patient care; first hour	Not observed
99367	Medical team conference with interdisciplinary team of health care professionals, patient, and/or family not present, 30 min or more; participation by physician	Not observed
99401	Preventive medicine counseling and/or risk factor reduction intervention(s) provided to an individual (separate procedure); approximately 15 min	Health coaching
99406	Smoking and tobacco use cessation counseling visit; intermediate, greater than 3 min, up to 10 min	Between-visit patient remote monitoring and behavioral health integration app
99408	Alcohol and/or substance (other than tobacco) abuse structured screening (eg, Alcohol Use Disorders Identification Test, Drug Abuse Screening Test) and brief intervention services; 15 to 30 min	Not observed
99429	Unlisted preventive medicine service	Not observed

Code	Definition [3]	Context in which use of code was observed
99446	Interprofessional telephone/internet/electronic health record assessment and management service provided by a consultative physician, including a verbal and written report to the patient's treating/requesting physician or other qualified health care professional; 5-10 min of medical consultative discussion and review	Not observed
99453	Remote monitoring of physiologic parameter(s), for example, weight, blood pressure, pulse oximetry, and respiratory flow rate, initial; setup and patient education on use of equipment	Not observed
99457	Remote physiologic monitoring treatment management services, 20 min or more of clinical staff/physician/other qualified health care professional time in a calendar month, requiring interactive communication with the patient/caregiver during the month	Not observed
99483	Assessment of and care planning for a patient with cognitive impairment, requiring an independent historian, in the office or other outpatient, home or domiciliary or rest home, with all of the following required elements: cognition-focused evaluation, including a pertinent history and examination; medical decision making of moderate or high complexity; functional assessment (eg, basic and instrumental activities of daily living), including decision-making capacity; use of standardized instruments for staging of dementia (eg, functional assessment staging test, clinical dementia rating); medication reconciliation and review for high-risk medications; evaluation for neuropsychiatric and behavioral symptoms, including depression, including use of standardized screening instrument(s); evaluation of safety (eg, home), including motor vehicle operation; identification of caregiver(s), caregiver knowledge, caregiver needs, social supports, and the willingness of caregiver to take on caregiving tasks; development, updating or revision, or review of an Advance Care Plan; creation of a written care plan, including initial plans to address any neuropsychiatric symptoms, neurocognitive symptoms, functional limitations, and referral to community resources as needed (eg, rehabilitation services, adult day programs, and support groups) shared with the patient and/or caregiver with initial education and support. Typically, 50 min are spent face to face with the patient and/or family or caregiver	Not observed
99484	Care management services for behavioral health conditions, at least 20 min of clinical staff time, directed by a physician or other qualified health care professional, per calendar month, with the following required elements: initial assessment or follow-up monitoring, including the use of applicable validated rating scales; behavioral health care planning in relation to behavioral/psychiatric health problems, including revision for patients who are not progressing or whose status changes; facilitating and coordinating treatment, such as psychotherapy, pharmacotherapy, counseling and/or psychiatric consultation; continuity of care with a designated member of the care team	Between-visit patient remote monitoring and behavioral health integration app facilitating collaborative care; used in contexts where there is no behavioral health specialist
99487	Complex chronic care management services, with the following required elements: multiple (2 or more) chronic conditions expected to last at least 12 months or until the death of the patient, chronic conditions place the patient at significant risk of death, acute exacerbation/decompensation, or functional decline, establishment or substantial revision of a comprehensive care plan, moderate- or high-complexity medical decision making; 60 min of clinical staff time directed by a physician or other qualified health care professional, per calendar month	Tech-enabled care management and case management service
99490	Chronic care management services, at least 20 min of clinical staff time directed by a physician or other qualified health care professional, per calendar month, with the following required elements: multiple (2 or more) chronic conditions expected to last at least 12 months or until the death of the patient; chronic conditions place the patient at significant risk of death, acute exacerbation/decompensation, or functional decline; comprehensive care plan established, implemented, revised, or monitored	Tech-enabled chronic care management service
99492	Initial psychiatric collaborative care management, first 70 min in the first calendar month of behavioral health care manager activities, in consultation with a psychiatric consultant, and directed by the treating physician or other qualified health care professional, with the following required elements: outreach to and engagement in treatment of a patient, directed by the treating physician or other qualified health care professional; initial assessment of the patient, including administration of validated rating scales, with the development of an individualized treatment plan; review by the psychiatric consultant, with modifications of the plan if recommended; entering patient in a registry and tracking patient follow-up and progress using the registry, with appropriate documentation, and participation in weekly caseload consultation with the psychiatric consultant; provision of brief interventions, using evidence-based techniques, such as behavioral activation, motivational interviewing, and other focused-treatment strategies	Between-visit patient remote monitoring and behavioral health integration app facilitating collaborative care; used in contexts where there is a behavioral health specialist
99494	Initial or subsequent psychiatric collaborative care management, every additional 30 min in a calendar month of behavioral health care manager activities, in consultation with a psychiatric consultant, and directed by the treating physician or other qualified health care professional (listed separately, in addition to code for primary procedure)	Not observed

Code	Definition [3]	Context in which use of code was observed
99495	Transitional Care Management Services, with the following required elements: communication (direct contact, telephone, and electronic) with the patient and/or caregiver within 2 business days of discharge. Medical decision making of at least moderate complexity during the service period. Face-to-face visit, within 14 calendar days of discharge	Not observed
99499	Unlisted evaluation and management service	Not observed
A9999	Miscellaneous Durable Medical Equipment (DME) supply or accessory, not otherwise specified	Treatment for substance use disorder (unclear if in active use)
E1399	Durable medical equipment, miscellaneous	Treatment for substance use disorder
G0444	Annual depression screening, 15 min	Medicaid depression initiative
G8431	Screening for depression is documented as being positive, and a follow-up plan is documented	Medicaid depression initiative
G8510	Screening for depression is documented as negative, a follow-up plan is not required	Medicaid depression initiative
H0047	Alcohol and/or other drug abuse services, not otherwise specified	Treatment for substance use disorder (vendor had difficulty obtaining payment from payers using this code)
T1505	Electronic medication compliance management device, includes all components and accessories, not otherwise classified	Treatment for substance use disorder

Discussion

Potential List of Codes That Could Be Used for Reimbursement

Given that a number of apps and digital tools for behavioral health are components of broader solutions involving clinicians or technicians and are only able to achieve reimbursement because of some level of clinician or technician involvement, every code for behavioral health could potentially be used to help cover the costs of a digital intervention. Furthermore, 96127, brief emotional/behavioral assessment, appears to be the main code used for app-based patient assessments in which there is no active clinician involvement while the assessment is being administered.

Limitations of the Existing Reimbursement Pathways

In theory, almost any intervention could be shoehorned into one of the pathways depicted in Figure 1, especially if paired with physician, nonphysician health care provider, or technician time. Furthermore, shoehorning interventions into the "Direct Payment" pathway is problematic, as it requires negotiations to occur 1 payer, provider, or employer at a time. As such, it is not an efficient way for the adoption of an intervention to rapidly occur. Meanwhile, CPT and HCSPCS codes, offer a smoother pathway to reimbursement, but they do so only when payers are willing to honor them and provide sufficient reimbursements.

Apps as Procedures

CPT codes are reimbursed by payers in accordance with the total number of Relative Value Units (RVUs) that they have been assigned. RVUs are a standardized unit, used across procedures to determine the amount of effort and expenditure involved in delivering a given procedure. There are 3 components to the total RVUs assigned to a CPT code: the work RVUs, malpractice RVUs, and practice-expense RVUs. Work RVUs capture the effort of the clinician before, during, and after the procedure. Practice-expense RVUs capture the supplies used to perform the procedure, as well as the associated costs of staff and the facility in which the procedure is performed. Malpractice RVUs are based on the degree of liability that the clinician incurs by performing the procedure, and these are calculated by using malpractice premium data [6]. To determine the total RVUs for a procedure, the 3 components are adjusted by a Geographic Practice Cost Index to account for geographic cost variation, and these are then combined. As the majority of the total RVU value ascribed to most CPT codes comes from the work RVU component, apps that do not involve physician work inherently lead to lower total RVUs. CPT codes for services performed without physician intervention, such as 96127, brief emotional/behavioral assessment, are primarily paying for the brief physician time involved in assimilating the information from assessment into the overall care plan. The total RVUs assigned to 96127, brief emotional/behavioral assessment, when performed in a nonfacility setting are low, as the procedure is worth 0.00 work RVUs, 0.01 malpractice RVUs, and 0.14 practice-expense RVUs. Given that Medicare paid in 2019 is US $36.04 per RVU, a brief emotional/behavioral assessment worth 0.15 RVUs would yield a payment of US $5.41. Although this payment may be adequate if a provider can efficiently assign the assessment, document its completion, assimilate the findings, and bill the appropriate CPT code, providers without efficient systems in place may have difficulty billing this code profitably.

The focus of using CPT codes to tie reimbursement largely to physician effort has resulted in there being a dearth of codes for services performed without physician intervention. Although there are a handful of codes for services provided without physician effort, such as those for transcranial magnetic stimulation or the administration of a health risk assessment, a vast majority of CPT codes involve a level of physician involvement. Although a code exists for a *stand-alone screening tool*, no such code exists to cover the costs associated with a *stand-alone treatment tool*, such as app-based cognitive behavioral therapy (CBT). As such, a CBT tool would need to be reimbursed (1) on the basis of the brief screenings that it may contain to assess patient progress, (2) on the basis of the human services that are wrapped around it, or (3) through a

noncode payment channel. The first case is problematic, as it undervalues the curative effects of the app, beyond mere screening. The second case is problematic, as it requires human intervention and limits the ability of mental health to scale via technology. Similarly, the third case is problematic, as it requires the app developer to negotiate a direct payment or obtain US Food and Drug Administration (FDA) approval for classification as a prescription device or drug. When apps are used in conjunction with physician or technician effort to achieve the requirements of a CPT code, there are typically time requirements that are used to determine the extent to which a CPT code is paid. More is paid when greater quantities of physician or technician time are required. As such, *these time requirements hamper the introduction of technology-based efficiency into mental health*, as if certain time thresholds are not met, some codes become unbillable. A relaxation of these time requirements or the introduction of more codes requiring 0 min of clinician or technician time would create new avenues for the introduction of efficiency through technology. Given the shortage of mental health providers, yoking payment to the direct involvement of humans (physicians or nonphysicians) is a barrier to efficiency and increased provider capacity.

Apps as Devices and Drugs

To overcome the linkage between CPT-based reimbursement and physician work, malpractice, and practice expenses, some organizations have chosen to pursue other paths of reimbursement. Namely, as the existing mechanisms for reimbursing devices and drugs do not consider the degree of physician effort when determining reimbursements, these mechanisms are being pursued by several app companies. When apps are treated as prescription devices or drugs, they may only be billed by individuals with prescribing authority. States vary in their willingness to grant various nonphysician health care providers, from nurse practitioners to psychologists, the ability to prescribe, and in some cases, grant only partial prescribing authority. As a result of the limitations on prescribing authority, a majority of psychologists are unable to prescribe apps, as most of them lack prescribing authority [7]. Nonetheless, organizations pursuing this route may see the rigor of FDA approval as a stamp of quality and a potential barrier to entry for competitors. Furthermore, as FDA approval is generally required for apps acting as medical devices or as accessories to them, in some cases, FDA approval is pursued out of necessity [8]. There are a number of organizations pursuing the device and drug approach. Working with Sandoz, a pharmaceutical company, Pear Therapeutics obtained FDA clearance for its app for patients with substance use disorder as the first prescription digital therapeutic [9]. Meanwhile, Click Therapeutics partnered with Otsuka to bring to market an app for major depressive disorder, which it intends to have classified as software as a medical device for the purposes of regulation by the FDA [10]. Akili Interactive Labs has sought FDA approval for its attention-deficit/hyperactivity disorder intervention, which it deems a “digital medicine,” and has worked with the pharmaceutical manufacturer Shionogi to commercialize it in Asia [11]. In all 3 cases, partnerships with external pharmaceutical companies were forged.

Gaps in Existing Reimbursement Pathways Limiting the Reimbursement of Some Apps

Although there are multiple potential ways in which apps can be fit into the existing reimbursement system, there is no guarantee of payment for most codes; time from a health care provider or a technician may be necessary to achieve reimbursement, and the app, in some situations, may need to undergo a regulatory review process for it to be reimbursed if used by patients on a stand-alone basis. When apps can only be reimbursed when these various accommodations are made, it adds friction to their development and utilization. Furthermore, time-based requirements for human participation limit the degree to which technology can drive efficiency in mental health.

Limited Support for Self-Directed Treatment

As was mentioned during the discussion of how RVUs are assigned to CPT codes, when an app does not involve clinician or technician activity, it is not likely to receive substantial reimbursement. Thus, some developers have sought to have their apps covered as drugs or devices. HCSPCS codes, such as T1505, electronic medication compliance management device, include all components and accessories, not otherwise classified; A9999, miscellaneous durable medical equipment supply or accessory, not otherwise specified; and E1399, durable medical equipment, miscellaneous, provide the sorts of catchall pathways necessary for apps seeking a durable medical equipment approach to reimbursement. There may be 2 pathways toward creating simpler reimbursement mechanisms for app-related treatments. First, the existing durable medical equipment codes could be clarified to include apps. Although they are already being used in some cases for this purpose, they are at the discretion of the insurer. Second, there may be a need for a treatment-related equivalent to the brief emotional/behavioral assessment code 96127. Such a code could be used to cover automated app-based treatment conducted in a standardized fashion rather than automated app-based screening.

Limitations on Administration of Measures and Patient Cost Exposure

Screenings for conditions, such as depression (eg, Patient Health Questionnaire-9) and anxiety (eg, General Anxiety Disorder-7), are the laboratory tests of mental health. Screenings can be performed repeatedly on the same patients to facilitate measurement-based care. There is substantial evidence to show that the frequent use of such screenings to implement measurement-based care is beneficial to patient welfare, as they enable mental health care providers to better understand the trajectory of an illness [12]. Although the CPT code 96127 does provide a potential means of covering the cost of measurement-based care, there are sometimes limitations on its frequency of use and on the number of screening exams that may billed during a given visit. These limitations vary by payer. For instance, Amerigroup allows a maximum of 2 units of 96127 per visit [13]. PerformCare allows 96127 to be billed up to 4 units per day, every day [14]. In 2018, Aetna removed a restriction that had been placed on the code, which had only allowed it to be billed once per year [15]. These limitations are in direct conflict with multiple research studies that document

that these standardized measures need to be administered frequently to properly guide treatment decisions and improve outcomes [12]. The lack of uniformity in reimbursement policies for this code across payers may impact app developers, as patients with some health plans may yield substantially more revenue as a result of this code than patients with other health plans.

Although there are benefits to screening for patients, the use of app-based screening has the potential to result in frequent and, perhaps, unanticipated copayments. Although the code 96127 was originally implemented and created to support the Affordable Care Act's mandate to include mental health services as a component of required Essential Health Benefits, the use of the code only qualifies for the Affordable Care Act's no-cost sharing provision if it is billed as a screening for an asymptomatic patient (patient with the International Classification of Diseases, version 10 code Z13.89) [16]. Patients who are symptomatic and are using screening tools as a component of ongoing measurement-based care are potentially subject to copayments. To avoid surprising patients with bills related to screenings that they self-administered, it is necessary for health care providers to carefully explain the financial consequences of the use of this code or consider avoiding billing it. As self-administered, reimbursable tools for mental health become more prevalent, there will inevitably need to be substantial patient education regarding the costs associated with the tools. If repeated screening leads to substantially improved outcomes and cost savings, payers may wish to eliminate copayment requirements for screening apps to improve adherence.

Conclusions

There is no standard pathway through which mental health apps can all be reimbursed. The appropriate pathway is dependent on the nature of the app and its degree of clinician and technician involvement. The costs associated with a number of apps are actively being reimbursed today, both directly and indirectly. Nonetheless, substantial friction to reimbursement remains, and many apps are funded through out-of-pocket payments by patients. As apps are being used to support various activities within mental health care, including therapy sessions, care management, case management, and collaborative care, in many cases, reimbursement is occurring for a bundle of services, which is app facilitated, rather than for the app itself. Going forward, there are a number of changes to the reimbursement system, which could facilitate the adoption of digital tools for mental health. Namely, the FDA's approval process for apps could be simplified and standardized, and CPT codes could be created or modified to facilitate payments for additional services where there are 0 min of clinician or technician time involved in service delivery.

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Conflicts of Interest

ACP reports employment by Payer+Provider Syndicate and stock ownership of Berkshire Hathaway, Community Health Systems, CVS Health Corp, HCA Healthcare, Payer+Provider Syndicate, Quorum Health Corp, and Tenet Healthcare Corp. ACP additionally reports paid positions on the Scientific Advisory Board of PsyberGuide and on the Expert's Council of the Mary Christie Foundation. MBB reports ownership interests in Ignition Interfaces, Inc and RCT Logic, LLC, as well as other companies through portfolios managed by third parties. HTH reports serving as an advisor to Happify, 7 Cups, and MYnd Analytics, and HTH reports an investment in Pear Therapeutics.

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Abbreviations

CBT: cognitive behavioral therapy
CoCM: collaborative care model
CPT: Current Procedural Terminology
FDA: US Food and Drug Administration
HCSPCS: Healthcare Common Procedure Coding System
RVU: Relative Value Unit

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Original Paper

A Test of Feasibility and Acceptability of Online Mindfulness-Based Stress Reduction for Lesbian, Gay, and Bisexual Women and Men at Risk for High Stress: Pilot Study

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Abstract

Background: In conservative and rural areas, where antidiscrimination laws do not exist, lesbian, gay, and bisexual (LGB) people are at risk for excess stress arising from discrimination. Stress-reducing interventions delivered via innovative channels to overcome access barriers are needed.

Objective: This study aimed to investigate the feasibility and acceptability of online mindfulness-based stress reduction (OMBSR) with LGB people in Appalachian Tennessee at high risk for stress.

Methods: In 2 pilot studies involving pre-post test designs, participants completed 8 weeks of OMBSR, weekly activity logs, semistructured interviews, and surveys of perceived and minority stress.

Results: Overall, 24 LGB people enrolled in the study and 17 completed OMBSR. In addition, 94% completed some form of mindfulness activities daily, including meditation. Participants enjoyed the program and found it easy to use. Perceived stress (Cohen, perceived stress scale-10) decreased by 23% in women (mean 22.73 vs mean 17.45; $t10=3.12$; $P=.01$) and by 40% in men (mean 19.83 vs mean 12.00; $t5=3.90$; $P=.01$) between baseline and postprogram. Women demonstrated a 12% reduction in overall minority stress (Balsam, Daily Experiences with Heterosexism Questionnaire) from baseline to 12-week follow-up (mean 1.87 vs mean 1.57; $t10=4.12$; $P=.002$). Subscale analyses indicated that women's stress due to vigilance and vicarious trauma decreased by 21% and 20%, respectively.

Conclusions: OMBSR may be a useful tool to help LGB people reduce general and minority-specific stress in socially conservative regions lacking antidiscrimination policies.

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KEYWORDS

sexual minority; lesbian; gay; bisexual; psychological stress

Introduction

Background

Lesbian, gay, and bisexual (LGB) people in Appalachian Tennessee hold intersecting identities that make them different from non-Appalachian heterosexual people and LGB people in urban areas. Specifically, intersecting Appalachian and minority sexual orientation identities magnify discrimination, stigma, and stress caused by living outside the heterosexual norm.

Appalachia is a diverse rural geographic region made up of 420 counties located in 13 states, including 50 counties in East Tennessee. Appalachia is a medically underserved region, and

residents earn very low income, with many residing in economically distressed counties where the median income is 80% of the average US income. Over 16% of Appalachian residents live below the poverty level and, in many counties, up to 20% of Appalachian households are living in poverty [1]. A larger proportion of residents in Appalachia (42%) live in rural areas compared with the rest of the United States (20%) [2].

Like many rural regions, Appalachia is socially a conservative region that upholds traditional values that preserve social traditions and morality that condemns LGB people. People with sexual orientations other than heterosexuality are regarded as perverted abnormalities and are systematically stigmatized, ostracized, and socially isolated [3]. It is also a region that lacks state and local antidiscrimination policies and laws [4], and this reinforces the interpersonal and structural stigmatization of sexual minorities [5]. Yet, Appalachian and sexual minority identities are both extremely important for this group [3,6] and rejecting either would be damaging to their self-concept and well-being.

Relatively little empirical evidence exists about the health of LGB people who live in Appalachian Tennessee. However, it is possible that the risks experienced by Appalachian and LGB people may magnify stress, health risks, and poor health for individuals who are both LGB and reside in Appalachia. For example, in our research, lesbian women in Appalachia experienced 40% higher perceived stress than the published norms and high-risk health behaviors, including tobacco use, physical inactivity, and obesity [7].

Behavioral interventions are needed for reducing stress and improving health in high-risk subgroups, including Appalachian LGB people. Mindfulness-based stress reduction (MBSR) is one promising behavioral intervention to reduce stress. Mindfulness is cognitive training [8-11] in self-regulation of attention and orientation to experience [11]. MBSR programs involve 8 weeks of weekly face-to-face, 2.5-hour group sessions, with a trained facilitator in a clinical setting, in addition to daily at-home formal and informal mindfulness-based activities. MBSR interventions produce clinically meaningful reductions in stress in clinical and nonclinical samples and show twice the stress reduction as other behavioral and cognitive interventions [12].

Owing to the risk for being outed and exposed to discrimination and stigma, Appalachian LGB people's intersecting identities reduce the likelihood of attending traditional, clinic-based, face-to-face interventions [13]. In addition, LGB people in Appalachia experience numerous logistical barriers including cost of attendance, travel, and time away from work. Therefore, innovative delivery channels and adaptation may be needed to reach and deliver MBSR to this high-need group.

Online mindfulness-based stress reduction (OMBSR) may be a solution to the logistical barriers that may limit Appalachian LGB people's participation in MBSR. OMBSR interventions can be, and have effects, similar to those delivered by trained facilitators. Participants completing OMBSR have shown a clinically meaningful, greater than or equal to 10%, stress reduction from baseline [14,15]. Reducing stress by 10% or more among LGB people in Appalachia could be enormously beneficial for reducing the risk for stress-related health issues [16].

To date, there is no published evidence concerning the feasibility or acceptability of OMBSR with Appalachian LGB people. As with other vulnerable subgroups, it is possible that LGB people in Appalachia have unique needs and experiences that could impact program enrollment, retention, and completion. It is not known if LGB people in Appalachia will enroll in OMBSR, find it useful, enjoy or complete activities, or require substantive or other adaptations for maximum uptake. If LGB people in Appalachia have unique needs and experiences that impact program enrollment, retention, and completion, determining feasibility and acceptability will provide necessary information to guide how we move forward with randomized efficacy trials and program tailoring.

Including LGB women and men in a single behavioral intervention could be beneficial for stretching limited time and financial resources for interventions and broad intervention dissemination. LGB men and women experience similar sexual orientation–related minority stressors in the form of interpersonal and structural stigma and discrimination; however, these groups may differ in terms of health risks and health-related experiences by gender [17-20]. In addition, there may be gender-based differences in the effectiveness of MBSR in the general population wherein women are more likely to engage in MBSR activities than men [21]. Therefore, investigating gender differences in OMBSR use is important for developing MBSR interventions that maximize program efficacy while minimizing expense.

Objective

This project investigated the feasibility and acceptability of an 8-week OMBSR program delivered to LGB women and men in Appalachia. Our main objectives were to determine the (1) acceptability and amount and aspects of OMBSR that could be delivered to and completed by LGB people residing in Appalachian Tennessee, (2) differences by gender, and (3) preliminary associations between the OMBSR program and perceived and minority stress. To fulfill these objectives, we conducted 2 pilot studies, each using a pre-post test design.

Methods

Participant Recruitment

The participants were recruited into an 8-week OMBSR program through a mix of convenience and snowball sampling, an effective strategy for difficult-to-locate populations [5,22]. The inclusion criteria were living in Appalachian east Tennessee; identifying as lesbian, gay, or bisexual; being able to read English; aged 18 years or older; and having internet access. The eligible participants were invited to participate and then each provided informed consent. The informed consent process involved providing participants with detailed project protocol description, including description of the 8-week OMBSR program and data collection activities. LGB people were ineligible if they were diagnosed with thyroid or pituitary gland disorders. The enrolled participants received compensation for

survey completion and interviews. All participants provided informed consent before participation. This project was approved by the University of Tennessee Institutional Review Board (UTK IRB-16-02769-FB).

Online Mindfulness-Based Stress Reduction Procedure

The OMBSR intervention was a free, 8-week OMBSR program [23]. The program content paralleled Kabat-Zinn's in-person MBSR [11]. The participants logged on to the OMBSR website weekly to receive intervention content and activities. The content included videos and readings about how mindfulness impacts the body and brain and how to apply mindfulness to difficult emotional experiences (Table 1). Formal activities included 10- to 30-min guided meditations. Informal activities involved applying mindfulness principles to daily living (ie, bringing awareness to the moment, nonjudgment, and breathing exercises).

Table 1. Weekly content in the 8-week online mindfulness-based stress reduction intervention.

Week	Intervention content		
	Main topic	Formal practice	Informal practice
1	Simple awareness	Body scan	Simple awareness and/or mindful eating
2	Attention and the brain	Introduction to sitting meditation	Pleasant events calendar
3	Introduction to yoga	Mindful Yoga (Yoga 1), body scan, sitting	Unpleasant events calendar
4	Stress: responding versus reacting and 1-min breathing space	Mindful Yoga (Yoga 2) and sitting	STOP: the 1-min breathing space
5	Dealing with difficult emotions and sensations	Various *(soften-soothe-allow meditation on 1st day)*	The soften, soothe, allow process
6	Mindfulness and communication	Body scan, sitting, Yoga *(+ mountain or lake meditation)*	Communication calendar
7	Mindfulness and compassion	Body scan, sitting, Yoga *(+ loving kindness)*	Any (simple awareness, mindful eating, STOP, soften)
8	Conclusion: developing a practice of your own	None	None

Measures

Feasibility and Acceptability

Acceptability was measured with semistructured, qualitative interviews conducted at week 8 after completing the OMBSR program. The questions assessed the participants' preferred OMBSR activities, skipped and disliked activities, program challenges and successes, requested improvements and changes, and qualitative changes in health and stress.

Amount and Aspects of Online Mindfulness-Based Stress Reduction Completed

Self-reported online weekly activity logs measured the amount and aspects of OMBSR completed weekly by participants. Activity logs were specific to weekly intervention content (available upon request). The first 4 questions of the activity log were set to a 4-point Likert scale (3=every day, 0=never) and included questions about activities completed and frequency of practice. Participants rated the usefulness of OMBSR videos, readings, and formal (meditation) and informal (mindful awareness to a routine activity) mindfulness activities on a 5-point Likert scale (5=very useful, 1=not at all useful). The participants scored a zero for activities they did not complete.

Perceived Stress

Perceived stress was measured with Cohen's 10-item perceived stress scale (PSS) [24]. Items were set to a 5-point Likert scale (0=never, 4=very often). Items were summed to generate a PSS score; low scores indicated less perceived stress.

Minority Stress

Self-reported experiences with minority stress were measured with the Daily Experiences with Heterosexism Questionnaire (DEHQ) [25]. Items were on a 6-point Likert scale (0=did not happen, 5=it happened and bothered me extremely). Items were averaged across all items and for each subscale; lower scores indicated lower minority stress.

Demographic Characteristics

Age, race/ethnicity, education, income, and relationship status were collected using standard questions from the Behavioral Risk Factor Surveillance System [26]. Participants self-reported their sexual orientation with one question asked during eligibility screening.

Analyses

Descriptive and summary statistics described and compared participants' demographic characteristics, program completion, and aspects of program completed, stratified by gender.

Qualitative content analyses were conducted on professionally transcribed semistructured interviews [27]. This process involved reading and re-reading the transcripts to achieve immersion. Then, transcripts were re-read for content analysis. Overall, 7 deductive codes were identified before conducting content analyses: device preferences, activity preferences, positive and negative feelings about the program, struggles with the program, positive consequences of the program, and recommendations for program improvements.

Summary and descriptive statistics were calculated on perceived and minority stress measures. Per-protocol and intention-to-treat (ITT) analyses were conducted on perceived and minority stress variables. For ITT analyses, baseline stress values were carried forward for participants lost to follow-up. Paired samples *t* tests tested changes in stress from baseline to postprogram and baseline to follow-up. Repeated-measures analysis of variance tested mean values for each measure of stress against one another at the 3 time points.

Results

Participant Demographic Characteristics

A total of 16 lesbian women and 8 gay and bisexual men enrolled in the study; 11 women and 6 men completed the full program and assessments and 5 women and 2 men were lost to follow-up (Multimedia Appendix 1). Multimedia Appendix 1 summarizes the participants' demographic characteristics; there were no significant differences in demographic characteristics between those who completed and those who did not complete the OMBSR program. Women and men were similar across all demographic characteristics with only one exception—current relationship status. Of program completers, women were more likely to be in a committed relationship than men.

Feasibility and Acceptability

Most participants reported that the program was easy to use and well organized:

> *Well yeah, I think it's convenient where ever I'm at I don't have to lug around my laptop. I do only have an iPhone 5, so it's not as big. I do like having it right there. Websites and the links are really easy to navigate, so it's not hard.* [OM101, female participant]

> *I was not in town and the website worked just fine. I was out of the country and it worked just fine, and I got to log on.* [OM205, male participant]

OMBSR provided enough variety for participants to acquire the instruction needed to feel successful in their mindfulness practice, although their preferences for activities varied. Some participants reported preference for readings or videos, others preferred guided meditations, and some preferred yoga:

> *I think I'm liking the videos the best, because of the diversity of those, different people, different approaches.* [OM110, female]

> *First, I'll be honest, I did not like the body scan at all, but toward the end of it I found myself doing that more. I guess doing that in the evening sort of prompted that to be one of my favorites because it helps me relax too and settle in for the evening.* [OM207, male]

Others described the specific activities that they did not like:

> *For some reason, it's weird, but I don't particularly like doing the body scan thing.* [OM103, female]

> *Not that I didn't like the readings and videos, but there were a lot of them to sort through, so I didn't feel like I could get to all of them throughout the program... There were days I set precedent, or priority to doing the mindfulness practice over watching the video.* [OM207, male]

Time was the most common barrier to participation; nevertheless, participants reported feeling calmer and less *stressed out*, having greater awareness of the moment and their emotions, and processing experiences differently because of mindfulness activities:

> *Well, so far, I feel my attention has gotten better. I'm slowing down and I'm on the verge of a panic attack 'cause I have so much going on that I'm able to stop and slow myself down and focus on something current and right now and quit worrying about five minutes from now. It allows me to be more present.* [OM105, female]

> *The program made me feel that I'm not the only one struggling with finding a sense of inner peace, and that many people struggle with the same difficulties I struggle with. And, to just take things one step at a time and center myself around breathing, and that meditation isn't about trying to eliminate your issues; it's a way to look deeper into them and cultivate a sense of love for yourself.* [OM209, male]

Overall, participants were happy with OMBSR as it was presented; only 1 participant expressed that they expected the program to be specifically tailored to LGB people:

> *If there's any LGBTQ+ individuals who teach mindfulness courses and have videos and courses on that if those were incorporated in to it, or if there were readings specifically for members of this [LGB] community. Like stress reduction, I feel like that would help a lot because it would be tailored to specific [LGB] experiences and stressors that are in my life right now.* [OM206, male]

However, women and men indicated that they would like the program to include a social component, and this request varied by gender. Women requested a digital social component (eg, private Facebook group) that would support OMBSR participation in 2 ways: (1) as a collaborative resource for asking questions to fellow participants and researchers about specific readings or activities and (2) as a tool to increase social connectedness between LGB women in the region. Men requested that an in-person social component be integrated into OMBSR to support accountability for daily mindfulness activities and program continuation:

> *First, because it is difficult to have a community of lesbians, period. It would be nice to be able to talk about the meditation and things that spur from that.* [M106, female]

> *Something that I would love—so, I guess, to me, it would be an improvement if there was a way to connect with somebody, or a group of people, that were going through the same process. I would love to just even have somebody to just discuss it with...* [OM115, female]

I would've enjoyed an in-person interaction. It would have been difficult depending on location so maybe the next best thing would be a closed FB group. But there's a certain sense of accountability that comes from social interaction so I think I would've benefitted from that. If people could have said… I really liked this video, you should watch X, or Y video or do this reading. [OM207, male]

Amount and Aspects of Online Mindfulness-Based Stress Reduction Completed

Among participants completing the 8-week program, all reported completing some MBSR practice across the program duration. Women reported completing meditation and/or yoga and informal mindfulness between once or twice and most days (mean 1.55, SD 0.52 and mean 1.73, SD 0.79, respectively). Men reported completing meditation and/or yoga and informal mindfulness practices on most days (mean 2.00, SD 0.00 and mean 2.17, SD 0.41, respectively; Table 2).

Table 2. Average type, frequency, and usefulness of participation in online mindfulness-based stress reduction in lesbian, gay, and bisexual women and men, per protocol.

Average characteristics	Women (n=11); mean (SD)	Men (n=6); mean (SD)	*t* (df)	*P* value
Frequency logged on to program website[a]	1.73 (0.47)	2.17 (0.41)	1.93 (15)	.07
Frequency of practicing meditation and/or yoga[a]	1.55 (0.52)	2.00 (0.00)	2.89 (15)	.02
Frequency of informal mindfulness practices[a]	1.73 (0.79)	2.17 (0.41)	1.23 (15)	.23
Usefulness of meditation and/or yoga practice[b]	3.00 (1.26)	4.17 (0.75)	2.05 (15)	.06
Usefulness of informal mindfulness practices[b]	3.09 (2.91)	4.00 (0.63)	2.43 (15)	.03
Usefulness of readings[b]	3.82 (0.75)	4.00 (0.63)	0.50 (15)	.62
Usefulness of videos[b]	3.70 (1.16)	4.17 (0.75)	0.88 (14)	.40

[a]Item measured on 4-point Likert type scale where 0=never, 1=once or twice, 2=most days, and 3=everyday.

[b]Item measured on 5-point Likert-type scale where 1=Not at all useful, 2=somewhat useful, 3=neither useful or not useful, 4=somewhat useful, and 5=very useful.

Significant gender differences were observed. Men reported practicing meditation and/or yoga more than women (mean 2.00, SD 0.00 vs mean 1.55, SD 0.52; t_{15}=2.89; *P*=.02). Men viewed informal mindfulness activities as more useful than women did (mean 4.00, SD 0.63 vs mean 3.09, SD 2.91; t_{15}=1.93; *P*=.03).

Perceived and Minority Stress

Women

Per protocol analysis showed that women's perceived stress average was 22.73 (SD 4.52) at baseline and decreased by 23% (mean 17.45, SD 5.80; t_{10}=3.21; *P*=.01) at postprogram (Table 3). At the 12-week follow-up data collection, on average, women's perceived stress was 20% less than baseline (mean 18.09, SD 6.14; t_{10}=2.49, *P*=.03). As expected, ITT analyses showed similar but less dramatic decreases in perceived stress.

Per protocol, among women, the DEHQ score declined by 12% from baseline to postprogram (mean 1.87, SD 0.37 vs mean 1.65, SD 0.37); this change did not achieve significance (t_{10}=1.90, *P*=.09; Table 3). However, decline in DEHQ score did achieve significance at 12-week follow-up; among women, daily heterosexist experiences declined 16% from baseline to 12-week follow-up (t_{10}=4.12 *;* *P*=.002). As expected, ITT analyses of participants' report of DEHQ showed similar but less dramatic differences.

Reductions were observed in 2 DEHQ subscales: vigilance and vicarious trauma. Vigilance decreased from baseline to postprogram (mean 2.24, SD 1.08 vs mean 2.00, SD 0.86); this change was not significant (t_{10}=0.92, *P*=.38*)*. However, vigilance significantly reduced by 21% from baseline (mean 2.24, SD 1.08) to the 12-week follow-up (mean 1.77, SD 0.91; t_{10}=4.20; *P*=.002). Reductions were also observed in vicarious trauma. Significant reductions occurred from baseline to postprogram (mean 4.21, SD 0.91 vs mean 3.38, SD 1.09; t_{10}=2.69; *P*=.02) and baseline to 12-week follow up (mean 4.21, SD 0.91 vs mean 3.12, SD 1.29; t_{10}=3.67; *P*=.004). ITT analyses showed similar but less dramatic results for both subscales (Table 4).

Men

Per protocol, men's postprogram perceived stress was 19.83 (SD 4.53) at baseline and decreased by almost 40% at postprogram (mean 12.00, SD 3.58, t_5=3.90; *P*=.01). In ITT analyses, perceived stress decreased by 30% from baseline (mean 19.88, SD 1.37) to postprogram (mean 14.00, SD 1.70; t_7=3.01; *P*=.02 *)* (Table 5).

Neither per-protocol nor ITT analyses indicated any differences in men's postprogram or follow-up daily heterosexist experiences from baseline (Table 6).

Table 3. Within-subject differences in perceived and minority stress in lesbian and bisexual women participating in online mindfulness-based stress reduction by per-protocol analysis.

Within-subject differences	Preprogram, mean (SD)	Postprogram, mean (SD)	12-week follow-up, mean (SD)	Per protocol					
				Within-subject effects, *F* (*df*)	*P* value	Postprogram to preprogram difference, *t* (*df*)	*P* value	Follow-up to preprogram difference, *t* (*df*)	*P* value
Perceived stress[a]	22.73 (4.52)	17.45 (5.80)	18.09 (6.14)	5.29 (2,20)	.01	3.12 (10)	.01	2.49 (10)	.03
Estimated daily heterosexist experiences[b]	1.87 (0.37)	1.65 (0.37)	1.57 (0.33)	4.53 (2,20)	.02	1.90 (10)	.09	4.12 (10)	.002
Discrimination and harassment	1.45 (0.43)	1.23 (0.27)	1.32 (0.52)	2.21 (2,20)	.14	2.30 (10)	.04	1.27 (10)	.23
Family of origin	1.81 (0.90)	1.65 (0.89)	1.58 (1.22)	0.32 (2,20)	.73	0.51 (10)	.62	0.76 (10)	.47
Gender expression	1.50 (0.86)	1.48 (0.73)	1.20 (0.55)	1.69 (2,20)	.21	0.07 (10)	.95	1.89 (10)	.09
HIV/AIDS	1.03 (0.08)	1.02 (0.06)	1.02 (0.06)	1.00 (2,20)	.39	1.00 (10)	.34	1.00 (10)	.34
Isolation	2.32 (0.96)	1.84 (0.88)	1.93 (0.98)	2.67 (2,20)	.09	2.01 (10)	.07	2.23 (10)	.05
Parenting	1.26 (0.44)	1.27 (0.41)	1.20 (0.34)	1.46 (2,20)	.26	−0.29 (10)	.78	1.49 (10)	.17
Victimization	1.00 (0.00)	1.00 (0.00)	1.00 (0.00)	—[c]	—	—	—	—	—
Vigilance	2.24 (1.08)	2.00 (0.86)	1.77 (0.91)	2.57 (1.25)[d]	.13	0.92 (10)	.38	4.20 (10)	.002
Vicarious trauma	4.21 (0.91)	3.36 (1.09)	3.12 (1.29)	4.70 (2,20)	.02	2.69 (10)	.02	3.67 (10)	.004

[a]Total measure scaled 1 to 40, with higher scores equaling higher perceived stress.

[b]Grand and subtotal measures scored 1 to 6, with higher scores equaling greater daily experiences of heterosexism.

[c]Test could not be calculated due to lack of variance in data.

[d]Mauchly's assumption of sphericity violated; Greenhouse-Geisser correction reported.

Table 4. Within-subject differences in perceived and minority stress in lesbian and bisexual women participating in online mindfulness-based stress reduction by intention-to-treat analyses.

Within-subject differences	Preprogram, mean (SD)	Postprogram, mean (SD)	Intention to treat						
			12-week follow-up, mean (SD)	Within-subject effects, *F* (*df*)	*P* value	Postprogram to preprogram difference, *t* (*df*)	*P* value	Follow-up to preprogram difference, *t* (*df*)	*P* value
Perceived stress[a]	24.06 (4.78)	20.44 (6.96)	20.88 (6.96)	4.68 (2,30)	.02	2.77 (15)	.01	2.31 (15)	.04
Estimated daily heterosexist experiences[b]	2.01 (0.40)	1.86 (0.47)	1.80 (0.48)	4.09 (2,30)	.03	1.83 (15)	.09	3.39 (15)	.004
Discrimination and harassment	1.62 (0.81)	1.47 (0.80)	1.53 (0.86)	2.13 (2,30)	.14	2.17 (15)	.047	1.26 (15)	.23
Family of origin	1.90 (1.18)	1.86 (1.19)	1.81 (1.38)	0.32 (2,30)	.72	0.52 (15)	.61	0.76 (15)	.46
Gender expression	1.53 (0.79)	1.52 (0.70)	1.53 (0.86)	1.65 (2,30)	.21	0.07 (15)	.95	1.82 (15)	.09
HIV/AIDS	1.09 (0.21)	1.08 (0.20)	1.08 (0.20)	1.00 (2,30)	.38	1.00 (15)	.33	1.00 (15)	.33
Isolation	2.80 (1.24)	2.47 (1.36)	2.53 (1.38)	2.54 (2,30)	.10	1.93 (15)	.07	2.11 (15)	.05
Parenting	1.27 (0.50)	1.28 (0.48)	1.23 (0.45)	1.44 (2,30)	.25	−0.29 (15)	.77	1.46 (15)	.16
Victimization	1.00 (0.00)	1.00 (0.00)	1.00 (0.00)	—[c]	—	—	—	—	—
Vigilance	2.67 (1.13)	2.50 (1.07)	2.34 (1.18)	2.45 (1.41,21.07)[d]	.12	0.92 (15)	.37	3.42 (15)	.004
Vicarious trauma	4.14 (0.97)	3.56 (1.12)	3.40 (1.29)	4.22 (2,30)	.02	2.47 (15)	.03	3.12 (15)	.007

[a]Total measure scaled 1 to 40, with higher scores equaling higher perceived stress.

[b]Grand and subtotal measures scored 1 to 6, with higher scores equaling greater daily experiences of heterosexism.

[c]Test could not be calculated due to lack of variance in data.

[d]Mauchly's assumption of sphericity violated; Greenhouse-Geisser correction reported.

Table 5. Within-subject differences in perceived and minority stress in gay and bisexual men participating in online mindfulness-based stress reduction, by per-protocol analyses.

Within-subject differences	Per protocol								
	Preprogram, mean (SD)	Postprogram, mean (SD)	12-week follow-up, mean (SD)	Within-subject effects, *F* (*df*)	*P* value	Postprogram to preprogram difference, *t* (*df*)	*P* value	Follow-up to preprogram difference, *t* (*df*)	*P* value
Perceived stress[a]	19.83 (4.53)	12.00 (3.58)	13.33 (4.80)	6.70 (2,10)	.01	3.90 (5)	.01	2.15 (5)	.08
Estimated daily heterosexist experiences[b]	2.31 (0.67)	2.08 (0.38)	1.86 (0.50)	1.33 (2,10)	.31	0.86 (5)	.43	1.22 (5)	.28
Discrimination and harassment	1.89 (0.84)	1.64 (0.61)	2.00 (0.85)	0.64 (2,10)	.55	0.86 (5)	.43	−0.26 (5)	.81
Family of origin	2.72 (0.95)	2.42 (0.48)	2.11 (0.51)	1.90 (2,10)	.20	0.84 (5)	.44	1.87 (5)	.12
Gender expression	1.19 (0.40)	1.17 (0.41)	1.00 (0.00)	0.60 (2,10)	.57	0.12 (5)	.91	1.19 (5)	.29
HIV/AIDS	2.73 (1.40)	2.50 (1.11)	1.90 (1.00)	1.11 (2,10)	.37	0.69 (5)	.52	1.06 (5)	.34
Isolation	3.17 (0.49)	2.75 (1.21)	2.54 (1.30)	0.65 (2,10)	.54	0.63 (5)	.56	0.93 (5)	.39
Parenting	1.06 (0.14)	1.00 (0.00)	1.17 (0.33)	1.00 (2,10)	.40	1.00 (5)	.36	−0.76 (5)	.48
Victimization	1.79 (1.60)	1.70 (1.60)	1.21 (0.33)	0.44 (2,10)	.66	0.42 (5)	.70	0.85 (5)	.44
Vigilance	2.64 (1.28)	2.75 (0.90)	2.08 (0.86)	1.14 (2,10)	.36	−0.44 (5)	.68	0.90 (5)	.41
Vicarious trauma	3.64 (1.56)	3.08 (1.12)	2.78 (0.87)	1.86 (2,10)	.20	1.06 (5)	.34	1.73 (5)	.14

[a]Total measure scaled 1 to 40, with higher scores equaling higher perceived stress.

[b]Grand and subtotal measures scored 1 to 6, with higher scores equaling greater daily experiences of heterosexism.

Table 6. Within-subject differences in perceived and minority stress in gay and bisexual men participating in online mindfulness-based stress reduction, by intention-to-treat analyses.

Within-subject differences	Intention to treat								
	Preprogram, mean (SD)	Postprogram, mean (SD)	12-week follow-up, mean (SD)	Within-subject effects, *F* (*df*)	*P* value	Postprogram to preprogram difference, *t* (*df*)	*P* value	Follow-up to preprogram difference, *t* (*df*)	*P* value
Perceived stress[a]	19.88 (3.87)	14.00 (4.81)	15.00 (5.13)	5.27 (2,14)	.02	3.01 (7)	.02	1.99 (7)	.09
Estimated daily heterosexist experiences[b]	2.26 (0.61)	2.09 (0.38)	1.92 (0.48)	1.31 (1.11,2.2)[c]	.29	0.86 (7)	.42	1.20 (7)	.27
Discrimination and harassment	1.81 (0.79)	1.62 (0.60)	1.90 (0.81)	0.65 (2,14)	.54	0.86 (7)	.42	−0.26 (7)	.80
Family of origin	2.85 (1.26)	2.62 (1.17)	2.40 (1.23)	1.82 (2,14)	.20	0.85 (7)	.42	1.77 (7)	.12
Gender expression	1.23 (0.39)	1.21 (0.40)	1.08 (0.24)	0.61 (2,14)	.56	0.12 (7)	.91	1.18 (7)	.28
HIV/AIDS	2.50 (1.26)	2.32 (1.00)	1.88 (0.85)	1.11 (2,14)	.36	0.70 (7)	.50	1.06 (7)	.33
Isolation	3.12 (0.50)	2.81 (1.07)	2.66 (1.15)	0.66 (2,14)	.53	0.64 (7)	.54	0.94 (7)	.38
Parenting	1.10 (0.20)	1.06 (0.18)	1.19 (0.31)	1.00 (2,14)	.39	1.00 (7)	.35	−0.76 (7)	.47
Victimization	1.59 (1.40)	1.34 (0.72)	1.16 (0.30)	0.48 (2,14)	.65	0.42 (7)	.69	0.85 (7)	.42
Vigilance	2.44 (1.16)	2.52 (0.89)	2.02 (0.76)	1.13 (2,14)	.35	−0.45 (7)	.67	0.90 (7)	.40
Vicarious trauma	3.67 (1.44)	3.25 (1.15)	3.02 (1.04)	1.79 (2,14)	.20	1.06 (7)	.32	1.66 (7)	.14

[a]Total measure scaled 1 to 40, with higher scores equaling higher perceived stress.

[b]Grand and subtotal measures scored 1 to 6, with higher scores equaling greater daily experiences of heterosexism.

[c]Mauchly's assumption of sphericity violated; Greenhouse-Geisser correction reported.

Gender-Based Comparisons

Per protocol, average perceived stress did not differ by gender at baseline (t_{15}=−1.26; *P*=.23), postprogram (t_{15}=−2.08; *P*=.06), or follow-up (t_{15}= −1.64; *P*=.12; Multimedia Appendix 2). ITT analyses indicated that compared with men, women had higher perceived stress at baseline (mean 19.88 vs mean 24.06; t_{22}=−2.14; *P*=.04), postprogram (mean 14.00 vs mean 20.44; t_{22}=−2.34; *P*=.03), and follow-up (mean 15.00 vs mean 20.88; t_{22}=−2.11; *P*=.05).

Per protocol, average daily heterosexist experiences differed by gender; postprogram, women's average daily heterosexist experiences (mean 1.65, SD 0.37) were lower than men's (mean 2.08, SD 0.38; t_{15}=2.27; *P*=.04).

Discussion

Principal Findings

OMBSR was feasible and associated with reduced perceived and minority stress among LGB people in Appalachian Tennessee. In terms of feasibility, LGB people logged onto the OMBSR website most days each week to complete readings, videos, and formal and informal mindfulness activities.

Participation in OMBSR was associated with reductions in perceived stress and minority stress for women and in perceived stress among men. In our sample, perceived stress was reduced from baseline by 23% in women and by 40% in men. This is similar to the average clinical and nonclinical presumably heterosexual samples reported by others [14,15]. Participants in Morledge et al's randomized control study reported a 22% reduction in perceived stress from baseline (mean 22.4) to postintervention (17.2) in a clinical sample. Krusche et al showed a 34% reduction in perceived stress from baseline (mean 23.04) to postintervention (mean 15.05) in a convenience sample. Given the associations between chronic stress and poor health [28-30], the substantial reductions in perceived stress evidenced in our study could have very real and clinically meaningful implications for LGB people residing in Appalachian Tennessee [16].

Women in our study also showed a 12% reduction in minority stress from baseline; however, no changes in minority stress were reported for men. According to a prevailing theory, LGB people experience minority stressors in the form of discrimination and stigma related to their nonheterosexual sexual orientation. These minority stressors are cumulative, exist beyond individual control, and are in addition to daily hassles and stressful life events that are experienced by all people [31,32]. The reductions in minority stress reported for women are important, as minority stress is associated with risky health behaviors and poor physical health outcomes [18,33-38]. In particular, women reported that stress arising from experiences of sexual orientation–related vigilance and vicarious trauma was reduced. Vigilance decreased by approximately 21% from baseline to the 12-week follow-up and vicarious trauma was reduced by 20% between baseline and postprogram assessment and by 26% at the 12-week follow-up.

The changes in vigilance and vicarious trauma may be especially meaningful as they relate to OMBSR. Both concepts, vigilance and vicarious trauma, reflect individuals' expectations for

isolation and negative interactions because of their sexual orientation. Vigilance is the higher arousal and attention regarding the risk for potentially heterosexist and homophobic attitudes and behaviors. Vicarious trauma is the perception of threat for negative interactions and harm because of directly or indirectly witnessing these experiences perpetrated against other LGB women. Both vigilance and vicarious trauma center on a person's thinking and perceptions about the world around them. OMBSR is designed to change how people think, including thoughts about risk and anticipation of negative interactions. At an individual level, women may not be able to change the real existence of discrimination and harassment arising from heterosexism and homophobia. However, with the help of OMBSR, they may be able to change the way they think about, or anticipate, these negative experiences, thus, reducing stress and the associated deleterious effects of stress on health.

We are not aware of other empirical tests of OMBSR programs on perceived and minority stress among LGB people. However, others have successfully applied mindfulness principles to weight management for lesbian and bisexual women [39]. Our project was among the first to test this question among LGB men and women and to show preliminary evidence of a mainstream behavioral intervention that could reduce the negative consequences of minority stress among LGB women.

Our gender comparison revealed that women and men in our sample were demographically very similar; however, we found evidence of differences in stress. Regarding perceived stress, women reported higher perceived stress at all assessment points and showed a smaller reduction in stress after completing OMBSR, as did men. This may be evidence that lesbian and bisexual women experience confluent and intersectional gender- and sexual orientation–based biases and oppression [17,19,20]. However, compared with men, on average, women reported lower daily heterosexist experiences; they perceived less and were less bothered by daily experiences with heterosexism than men in this study.

Women and men in our sample reported that they felt socially isolated because of their sexual orientation and that a social component overlaid on the existing OMBSR material could enhance their experience. For women, an online social component should allow facilitators and participants to discuss participants' questions about program activities and increase social connectedness among lesbian and bisexual women. For men, a social component should encourage participants to connect in person to increase accountability to complete daily mindfulness activities and the full 8-week program. This could be facilitated through planned digital or in-person meetings or by encouraging gay and bisexual men to enroll as dyadic pairs, mindfulness teams, with partners or friends. These findings should guide future interventions adaptation and implementation of OMBSR with LGB people in this region.

Limitations

Our study had limitations. These were pilot studies and lacked control groups; therefore, it is unknown if stress reductions were caused by OMBSR or some unknown external factor. However, we carefully considered this in advance and used a pre-post no comparison design to determine the acceptability and feasibility of OMBSR, which could not have been informed by a controlled condition. We did not set out to test the efficacy of OMBSR in this pilot study, which would require a more rigorous, controlled design. Participants qualitatively reported positive changes in health behaviors (eg, decreased substance use) and outcomes (eg, decreased anxiety); however, these were not measured quantitatively. Future studies should measure self-reported health behaviors and outcomes, as well as anthropomorphic measures of stress (eg, allostatic load) to better understand the health benefits of OMBSR for LGB people.

Conclusions

OMBSR is a promising stress-reduction intervention that is acceptable to, and feasible for, LGB people in Appalachian Tennessee. LGB participants engaged in OMBSR frequently—completing readings, videos, and informal and formal mindfulness activities most days of the week and with few external prompts. Surprisingly, almost all participants reported that they would not make any changes to the existing OMBSR program content. However, both women and men did suggest modifying the program to reduce social isolation associated with living in rural areas of Appalachian Tennessee.

Owing to their nonheterosexual sexual orientation, LGB people living in rural areas, including Appalachian East Tennessee, experience discrimination and stigma. These minority stressors add to LGB people's stress in excess of the daily life hassles and stressful events experienced by all people, contributing to poor health. In the absence of comprehensive multilevel interventions that reduce sexual orientation–based discrimination and victimization, individual behavioral–level interventions are necessitated to reduce excess stress among this group. OMBSR is one such solution that is feasible for and acceptable to LGB women and men in Appalachian Tennessee and, as reported qualitatively and via preliminary quantitative data, may improve health in this group.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Demographic characteristics of lesbian, gay, and bisexual women and men participating in an 8-week online mindfulness-based stress reduction program.
[PDF File (Adobe PDF File), 88KB - mental_v6i8e15048_app1.pdf]

Multimedia Appendix 2
Between-subject differences in perceived and minority stress in lesbian, gay, and bisexual women and men participating in online mindfulness-based stress reduction, by per-protocol and intention-to-treat analyses.
[PDF File (Adobe PDF File), 111KB - mental_v6i8e15048_app2.pdf]

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Abbreviations

DEHQ: Daily Experiences with Heterosexism Questionnaire
ITT: intention to treat
LGB: lesbian, gay, and bisexual
MBSR: mindfulness-based stress reduction
OMBSR: online mindfulness-based stress reduction
PSS: perceived stress scale

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Original Paper

Mindful Eating Mobile Health Apps: Review and Appraisal

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Abstract

Background: Mindful eating is an emerging area of research for managing unhealthy eating and weight-related behaviors such as binge eating and emotional eating. Although there are numerous commercial mindful eating apps available, their quality, effectiveness, and whether they are accurately based on mindfulness-based eating awareness are unknown.

Objective: This review aimed to appraise the quality of the mindful eating apps and to appraise the quality of content on mindful eating apps.

Methods: A review of mindful eating apps available on Apple iTunes was undertaken from March to April 2018. Relevant apps meeting the inclusion criteria were subjectively appraised for general app quality using the Mobile App Rating Scale (MARS) guidelines and for the quality of content on mindful eating. A total of 22 apps met the inclusion criteria and were appraised.

Results: Many of the reviewed apps were assessed as functional and had moderate scores in aesthetics based on the criteria in the MARS assessment. However, some received lower scores in the domains of information and engagement. The majority of the apps did not teach users how to eat mindfully using all five senses. Hence, they were scored as incomplete in accurately providing mindfulness-based eating awareness. Instead, most apps were either eating timers, hunger rating apps, or diaries. Areas of potential improvement were in comprehensiveness and diversity of media, in the quantity and quality of information, and in the inclusion of privacy and security policies. To truly teach mindful eating, the apps need to provide guided examples involving the five senses beyond simply timing eating or writing in a diary. They also need to include eating meditations to assist people with their disordered eating such as binge eating, fullness, satiety, and craving meditations that may help them with coping when experiencing difficulties. They should also have engaging and entertaining features delivered through diverse media to ensure sustained use and interest by consumers.

Conclusions: Future mindful eating apps could be improved by accurate adherence to mindful eating. Further improvement could be achieved by ameliorating the domains of information, engagement, and aesthetics and having adequate privacy policies.

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KEYWORDS

feeding behavior; mindfulness; mHealth; diet

Introduction

Background

Research shows that mindful eating may assist with various eating disorders, such as binge eating on excess calories, and with weight management [1,2]. Stress is also reduced when individuals take the time to be mindful while eating by relaxing, being fully present, and not thinking about their problems [3].

Mindfulness is a form of meditation involving a heightened awareness of the present moment [4]. Mindful eating is an informal mindfulness practice and involves tuning into one's 5 senses, including sight, taste, sounds, and smells of the food,

all done while being fully present and eating slowly [4-8]. The key is to follow one's internal bodily cues rather than external eating triggers such as stress or emotional eating and to cease eating when one feels full instead of overeating [5,9]. For example, mindfully eating a blueberry would involve examining the berry with a beginner's fascination, feeling its texture, smelling it, chewing it slowly, rolling the juices between one's teeth, tuning into any sounds such as the mechanical process of chewing, and slowly swallowing it as it moves down the esophagus [6,9]. Mindful eating has been linked with reduced binge-eating behaviors [10].

One convenient medium for delivering mindfulness interventions including mindfulness-based eating awareness (MBEAT) or mindful eating is through mobile health (mHealth). mHealth is a resource for individuals that provides increased accessibility to health information and applications at any time and location using mobile phones, apps, text messages, and iPads or other tablets [11,12].

With the rise in popularity of mindfulness, there are numerous commercial mindfulness and mindful eating apps in the app stores. However, a recent review found that very few are actually based on mindfulness, and their effectiveness is unknown [13].

Objectives

To date, there has been no review of mindful eating apps that aim to teach mindful eating with mindfulness-based eating awareness techniques, in particular, for the management of binge eating and weight management. This review aimed to better understand what types of mindful eating apps are available in the app store and to appraise their overall effectiveness. Appraising the quality of these apps includes assessing the extent to which they teach the accepted principles of mindfulness. This will provide a better understanding of whether app users who suffer from eating problems are accessing a legitimate mindful eating resource. It is also helpful for future app development and app interventions as there has not been an mHealth mindful eating app trial to date [14].

This review aimed to appraise the quality of the mindful eating apps and to appraise the quality of content on mindful eating apps.

Methods

Search Strategy

A review of mindful eating apps for iPhone was undertaken from March to April 2018. We searched iTunes Australia for relevant mindful eating apps using the search words, *mindful eating*.

As iTunes does not allow for string searches that may generate precise narrow search results such as in scholarly databases for literature reviews, we tested the search of *mindful eating* by first reviewing whether relevant hits came up with these terms. Once it was confirmed that these terms generated mindful eating apps and met the inclusion criteria and that other search terms did not make the search more precise or manageable, such as general *diet*, *eating*, or *mindfulness*, the final search was based on these terms. The search was carried out in English. However, mindful eating apps that were generated from the search were not excluded if they were in a different language because of the language fluency of the reviewers.

The search was limited to iTunes and thus limited to iOS to ensure budgetary compliance and manageability as we budgeted to include apps that were free up to the price of Aus $5. However, many apps in the iTunes store overlap with apps in Google Play; hence, this review has general applicability for Android users as well beside iPhone and iPad users.

Inclusion and Exclusion Criteria

The inclusion criteria were all mindful eating apps that aimed to teach mindful eating and assist with binge eating/eating disorders with a central mindful eating–based approach or were weight loss apps whose central component focused on mindful eating. Mindful eating apps were broadly defined as apps that had any one of the following elements that are essential to mindful eating: slowing one's eating, recording one's time eating, being more cognizant of one's meal and setting, using one's 5 senses when eating, being aware of one's intrinsic bodily hunger versus hunger because of external factors, being aware of satiety, being aware of a balanced meal, using mindful eating for weight control, and control of binge and emotional eating [2,4-9]. Our criteria were broad to ensure that we included any eating app that had a mindful eating central component or purpose.

The exclusion criteria were apps for general weight loss and eating/diet apps that did not have a central mindful eating component. Mindfulness apps that taught mindfulness meditation such as mindfulness-based stress reduction (MBSR techniques) without a central focus on mindful eating for binge/emotional eating, teaching slow eating, or weight were excluded. In addition, if apps had extra add-on features as an extra cost beyond their main standard functions, these extra add-on costs were not included for budgetary reasons.

Appraisal

The apps were appraised for overall quality using the criteria adapted from the Mobile App Rating Scale (MARS) [15] that assesses quality on 5 domains, including engagement, information, functionality, aesthetics, and subjective impression. We also included the domains that assess if the app has a privacy policy [16] from the Enlight criteria and its therapeutic effectiveness partially adapted from the Royal College of Physicians Health Informatics unit guidelines [17]. We assessed whether the apps had included any of this or not.

Individual scores for the 5 domains in MARS were calculated by averaging the score in the questionnaire sections for each domain, which was on a scale from 1 to 5. Subjective scores were not included in the overall MARS app quality score. In addition to assessing these 4 domains for an overall MARS score, the domains of privacy and therapeutic effectiveness [16,17] as well as a consideration of user information were included in our global overall assessment score of the 5 domains.

Across the individual overall MARS and the overall global assessment with MARS scoring, we used the same cutoffs to grade the apps. Scores below 60% were weak (eg, 2/5). It should

be noted that the scores were not strict whole numerical values at times as a mean score on the Likert scale was calculated from 1 to 5. For example, a mean score of 2.5/5 would also result in a score in the low percentile range less than 60%. Scores of 60% and above were considered to be moderate (eg, 3/5) and scores of 80% (eg, 4/5 in MARS or 3.5/4 in the global assessment) or above were strong. Scores above 95% (eg, 4.75/5 in MARS or 3.8/4 in the global assessment) would be classified as very strong. These cutoffs were agreed upon by the reviewers on the general basis that scores above 80% are generally considered to be good, whereas 60% represented a pass, and anything less than this was deemed to have not met at least 50% of the required criteria.

In addition to using MARS, we also appraised the apps for mindful eating against a set of domains that we agreed upon as being important to consider based on implementation by mindfulness practitioners in formal mindfulness interventions and based on research evidence drawn from the literature [2,4-9,18-21]. Mindfulness practitioners have previously recommended that individuals who struggle with eating behaviors, such as binge eating, use guided and specialized eating audios [7]. General guided audios for mindful eating have also been a part of MBSR programs, whereby the practitioner uses a fruit as an example and guides the participant through an entire mindful eating example using the 5 senses [4,6,7,9]. Our previous exploratory focus group study also found that the participants desired to have examples on how to actually practice mindfulness and eat mindfully [20]. For these reasons, we assessed whether the mindful eating apps offered any kind of guided mindful eating example. Furthermore, mindful eating involves awareness of one's internal hunger and satiety, coupled with an awareness of external triggers, such as stress, that may influence eating [2,5,9]. Thus, the mindful eating process often involves a self-assessment of one's hunger and whether it is because of true hunger [2,5,9]. For this reason, we appraised whether the apps helped with increasing self-awareness through an assessment of hunger (internal vs external).

Although the MARS appraisal recently added a supplementary document about assessing whether the app would change behaviors in general, as an extra add on to the scoring, we did not have access to this at the time in the original MARS scoring sheet, and it was not a part of the scoring itself [15]. Instead, we undertook a more thorough assessment of whether the apps integrated behavior change techniques (BCTs). Abraham and Michie developed a list of BCTs that are common in behavior change interventions [18]. This list includes 26 BCTs. This is essentially a qualitative appraisal that involves simply checking off a yes for any BCTs that are used in interventions [18]. There are a total of 9 domains. Weak was classified as having a total score of less than 4/9 domains (<50%). Moderate was classified as having a yes for 5 to 6 out of 9 domains. Strong was classified as having a yes for 7 to 9 of 9 domains (77%-100%).

A previous systematic review and meta-analysis of mHealth interventions for weight loss involving diet and exercise found that BCTs such as reminders, goal setting, feedback, prompts, encouragement, motivation, education, and practical tips, to name a few off the list, were commonly implemented [19]. Our previous systematic review on user perspectives on mHealth also found that users preferred BCTs in mHealth interventions [21]. Similarly, our mindfulness exploratory mHealth study also found that participants desired practical tips, reminders, encouragement, education, and motivation [20]. For these reasons, we examined whether the mindful eating apps had integrated any BCTs such as the ones described above and from the list developed by Abraham and Michie [18]. Finally, we also assessed whether mindful eating was taught through a variety of media such as audio, articles, and videos, as research indicates that individuals have different learning preferences; hence, diversity in educational materials was regarded as being desirable [22]. We also assessed the apps for quality of information in terms of whether the apps mentioned the benefits of practicing mindful eating and if they considered educating participants about a balanced diet. Our previous focus group study found that participants wished to receive information on the benefits of mindfulness and general tips about being mindful of a balanced diet [20]. In summary, we assessed whether they offered guided teaching examples, quality information about mindful eating, whether they integrated specialized eating audios, heightened self-awareness (internal hunger vs external), used a variety of media to teach mindful eating, and whether they integrated BCTs adapted from Abraham and Michie's BCT list [18].

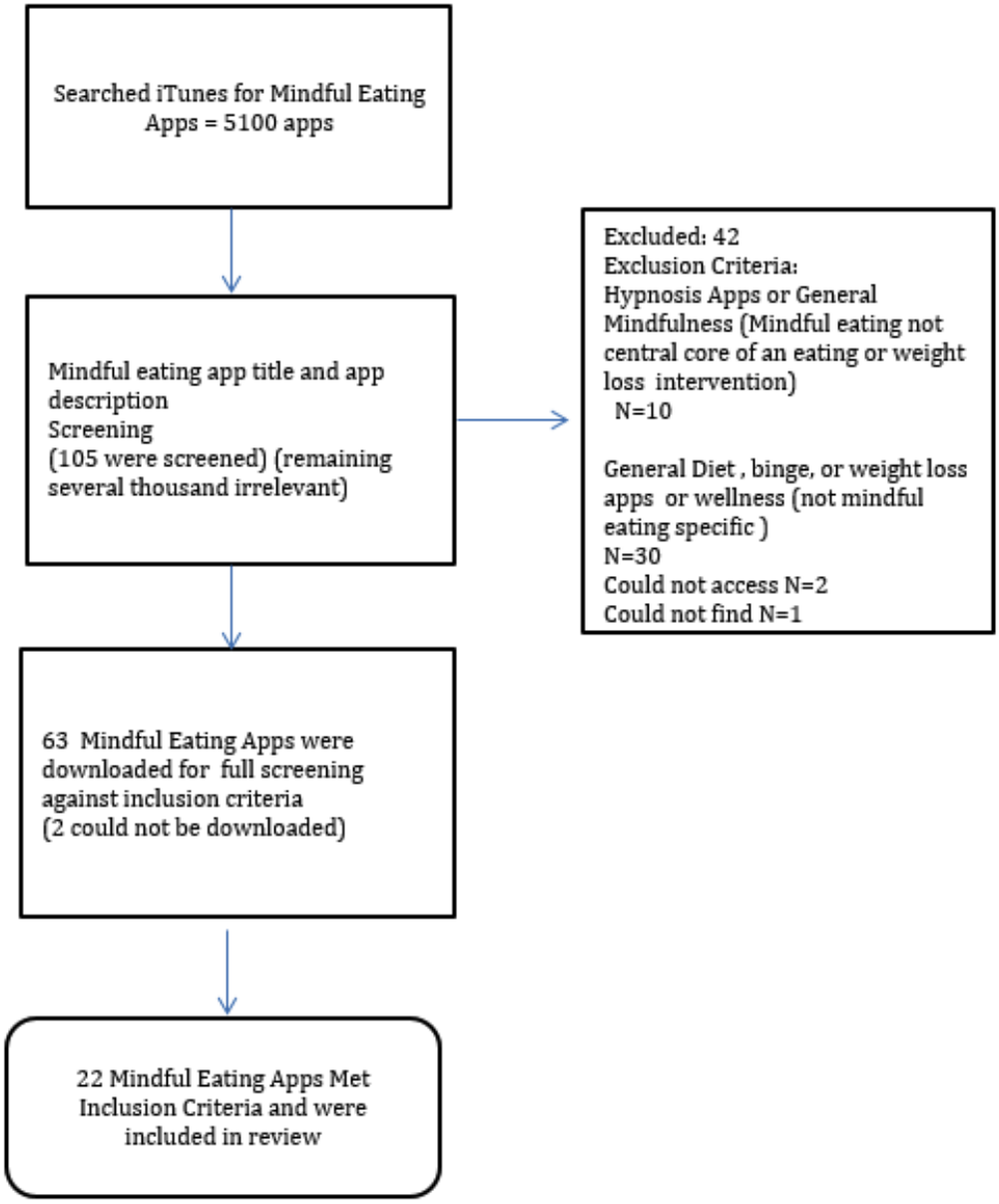
Two authors, LNL and SE, appraised and scored the apps. An average score was created. When there was a large disparity in the reviewer's scoring, LNL and SE discussed the apps until there was agreement.

Results

Search Process

The search generated 5100 apps. It should be noted that because manual counting of the apps had to be undertaken, only an estimate was generated. However, 2 reviewers estimated the number of hits the search gave and an average was generated to represent the best approximation. After screening the app titles and app descriptions for relevancy, 63 apps (2 could not be accessed and 1 could not be found) were downloaded for further screening against the inclusion and exclusion criteria. Among them, 40 were not specific to mindful eating for binge eating, weight, or general mindful eating after reviewing their content and were excluded. A total of 22 apps met the inclusion criteria and were included in this review [23-44]. The flow chart in Figure 1 illustrates the search process.

Figure 1. Flow chart of search process for relevant apps.



The Types of Mindful Eating Apps

Most of the apps (n=11) were mindful eating diaries that involved journal entries, hunger rating scales, or hunger/fullness self-assessment questions, with a few using both [1,25,38,23-42]. Some of the mindful eating apps (N=4) were mindful eating timers that measured how slowly individuals ate or focused on slow eating [28,45]. Furthermore, 3 apps were entirely audio based [27,31,41], 2 were mindful eating food menus without any mindful eating information [37,39], and 1 was based on mindful eating inspirational quotes in cards [26]. The mindful eating app descriptions are summarized in Multimedia Appendix 1.

General App Feature Appraisal Scoring Using the Mobile App Rating Scale

The mindful eating app scores using MARS and other guidelines discussed [14,16-17] are summarized in Table 1. The mean MARS scores ranged from 1.96 (59) to 3.75 (47) out of a maximum score of 5 in the global summary score when privacy, therapeutic effectiveness, and user information was added as a domain [16-17] and out of a score of 4 in the general MARS scoring [15]. The MARS scoring system was on a 5-point scale for individual domains. The top apps receiving the highest score in the mid-3-point range out of the 5-point scale were In the Moment, Am I hungry, Weightless, and Eat-C [1,36,38,44]. None of the apps received a high-quality score of 4, overall. In addition, 3 apps received a high score, though not a very strong score on the MARS overall score, but when the domains of privacy, therapeutic effectiveness, and user information were added, the scores became moderate on the global overall score [36,38,44].

Table 1. General app scoring domains adapted from the Mobile App Rating Scale.

Mindful eating app	Engagement	Functionality	Information	Aesthetics	Subjective	MARSs[a]; Global score[b]	Presence of privacy policy[c]; Global score	Source of privacy policy[d]
EAT-C	2.55	4.125	2.75	3.33	2.66	3.18/4; M[e]	No; 3.18/5; M	N/A[f]
Mindfulness meals	1.55	2.52	1.65	3	1.625	2.18; W[g]	N/A; 2.18/5; W	N/A
Mindful Eating Coach: Am I Hungry?	3.55	3.75	3.75	3.4	3.515	3.6; S[h]	N/A; M	N/A
Mindful eating Tracker (Green apple icon)	3.165	3.5	2.33	3.58	2.5	3.14; M	N/A; M	N/A
The Savour Coach	3.25	3.5	2.8	2.75	2.5	3.075; M	N/A; M	N/A
Crave Mate	2.65	4	2.25	2.58	1.625	2.87; M	N/A; W	N/A
Weightless	3	4	3.18	3.35	2.125	3.38; S	N/A; M	N/A
10S Fork (related app would not load)	2.65	2.22	2.8	2.75	2.55	2.605; M	N/A; W	N/A
Intuitive	1.8	3.26	2	2.3	1.25	2.3; W	N/A; W	N/A
Lose Weight Audio Guide	2.1	2.75	2.65	3	2.625	2. 625; M	N/A; W	N/A
Mindful by Sodexo	1.65	2.375	1.35	2.5	1.125	1.96; W	N/A; W	N/A
Eat Slowly	2.35	3.75	2.4	2.165	1.75	2.66; M	N/A; W	N/A
Mindful Eating Calendar	3	3.85	2	3	2.625	2.96; M	N/A; W	N/A
Eat Breathe Thrive	2.8	1.9	2.25	2.315	2.075	2.316; W	N/A; W	N/A
In the Moment	3.55	4.25	2.8	4.36	3.275	3.74; S	N/A; M	N/A
Mindful Bite	1.9	3	2.25	3.25	2.5	2.6; M	N/A; W	N/A
Eating (Egg)	2.45	3.75	2.25	3.265	3.08	2.92; M	N/A; W	N/A
Slow Eating	2.1	3.25	2	2.53	1.35	2.47; W	N/A; W	N/A
Rise Up	3.45	3.5	2	3	1.875	2.98; M	N/A; W	N/A
Eating Thin	2.55	2.625	2.35	2.85	2.415	2.59; M	N/A; W	N/A
Jourvie	2.35	2.9	1.77	2.58	1.625	2.4; M	Yes[i]; W	Yes
Empowerment cards	2.5	4.25	2	3	2.275	2.93; M	N/A; W	N/A

[a]Mobile App Rating Scale score (mean score excluding subjective).

[b]Overall global score with privacy.

[c]Privacy policy, terms and conditions, user information, and therapeutic effectiveness [16-17]. Overall global score with these factors.

[d]Adapted from the BCTs list [18].

[e]Moderate.

[f]Not available / no.

[g]Weak.

[h]Strong.

[i]General privacy policy=1.

MARS Domain Score for Engagement, Functionality, Information, Aesthetics, and Subjective Individually Appraised: mean score of each domain criteria 5: Very strong, (VS) ≥95%; Strong (S), ≥80%; Moderate (M), 60%; and Weak (W), <60%.

MARS mean sum score/4 domains (excluding subjective): Very strong, ≥95%; Strong, ≥80%; Moderate, 60%; and Weak <60%.

Overall score with privacy policy added as an extra domain/5 domains: Very strong ≥95%; Strong, ≥80%; Moderate, 60%; and Weak <60%.

The majority of the apps functioned well; hence, they received good scores for functionality. Specifically, a total of 5 received strong scores (22%) [26,29,35,38,44] and 9 received moderate scores in the higher end (>3/5) nearing strong (41%) [23,25,27,32-34,36,43], with the rest receiving moderate scores in the lower range of the 3-point scale of 5 or low scores in the higher range of 2/5. However, a few (18%) received low scores in the lowest point score range of less than 2/5 as they were slow or some of the content did not load or moving between sections was difficult when returning to the home screen (back button had to be used if there was no home screen icon)

[28,39,42,45]. In terms of aesthetics, most of the apps were average, mostly receiving scores of above 3 in this domain (n=11) [23-26,29,31,32,36,37,43,44], whereas others received weaker scores in the range of 2/5. One app received a high score in this domain [38]. They were neither visually unpleasant nor extraordinary in their presentation with nice designs or specialized graphics or animations. They generally used a standard color with a basic design. Most of the apps received weak scores for information in the point range of 2/5 (19/22, 86%) [23-28,31,33,35,37,39-43,45]. Very few had any informational content in them and were mostly tracking apps for slow eating or journal entry apps. Thus, the quality of the information and the quantity of the information were weak overall. A few received higher scores for showing graphs based on users' entries for their mindful eating.

The apps also received lower scores for engagement as few were entertaining for longer than 5 min and were mostly uninteresting. A total of 14/22 apps (63%) [23,25,26,28,29,31,34,35,37,39-42,45] received low scores for engagement, with the rest receiving moderate scores. In terms of customization, a few apps allowed users to select how often they wanted notifications, but they lacked in providing personalized messages specific to mindful eating.

In terms of credibility and evidence, these apps were not tested in trials. In addition, most of the apps did not have an information section icon with instructions or any kind of privacy policy section. Little is known about their therapeutic effectiveness as they have not been trialed.

Mindful Eating–Specific Content Assessment of the Apps

Overall, the majority of mindful eating apps (19/22, 86%) received weak scores in the mindful eating–specific assessment content of the apps of less than 4/9 domains (<50%) summarized in Multimedia Appendix 2 [23-29,31-35,37,39-43,45].

Assessment of Diversity of Media to Teach Mindfulness

Assessment of the mindful eating content of the apps is summarized in Multimedia Appendix 1. There were very few apps that contained multiple features for mindful eating. Most of them only used 1 type of medium, which was mostly written content or space for writing by the users. Out of the apps, only 3 (3/22, 1%) had any meditation audios, and these apps lacked other content such as written content or videos [27,31,41].

Assessment of Quality of Information

Mindful Eating Examples

Most apps had little information about mindful eating, including guided examples using a food meditation example by tuning into all 5 senses when eating. Only 2 considered the senses but not in detail [27,43]. None had specially tailored mindful eating audios for hunger, fullness, and binge eating, apart from the few apps that had any audio. However, 1 app mentioned assessing hunger in different body parts such as the eyes and heart [25] and another had a brief note about using the senses without a thorough guided example [43].

Information on the Benefits of Mindful Eating and a Balanced Diet

The apps did not mention the benefits of mindful eating on health in anything more than a vague form. The main emphasis was mostly on counting how slowly one ate. Most of them lacked general information about a healthy balanced diet, including the World Health Organization's target guideline information [46,47]. Specifically, only 4 apps (4/22, 18%) considered teaching users about some form of healthy eating directly in the app itself [23,35,38,44]. However, this information was very general. In addition, 1 app had links to information on a website [36].

Assessment of Internal Versus External Hunger Cues

Overall, 10 apps allowed (45%) users to reflect on their eating motives such as stress versus internal hunger by ratings [42,43] or by audio [27], general hunger motives [1,25,36], and a few asked about general emotions and cravings [23,35,44,45].

Assessment of Integration of Behavior Change Techniques

Furthermore, 6 apps (27%) had integrated a range of BCTs [29,38,36,25,43,44]. The most common BCTs in the reviewed apps involved self-monitoring, such as self-monitoring of mindful eating through a journal, hunger rating, or using an eating timer. None of the apps had push notifications that had specialized or tailored messages for mindful eating specifically rather than general reminders. The apps did not offer tips or advice for integrating mindful eating into users' daily lives.

Discussion

Summary and Implications of Findings

In summary, this was the first review to appraise mindful eating apps for their overall quality. We aimed to appraise the quality of the mindful eating apps for iOS in the iTunes store by using the MARS appraisal tool [15]. We further appraised the quality of content on mindful eating apps using a set of criteria agreed upon by the reviewers as being important based on the relevant literature and based on mindful eating practices taught by practitioners [4-10,18-20,48].

Overall, most of the apps received a weak global summary score when considering the key domains in MARS [15]. This included a consideration of the domains of privacy, information policy, and therapeutic effectiveness. Most of the apps had an overall weak-to-moderate MARS score as well. The weakest MARS areas were in the quality of information and engagement. Most of the apps were average in terms of aesthetics. Most apps received strong scores for overall functionality as there were no major technical functionality issues that we had encountered. In addition to this, our assessment of the content of mindful eating apps found that most of the apps received weak scores, overall, for the quality of content on mindful eating. The areas that needed improvement included providing more information about mindful eating such as using mindful eating examples that involved tuning in with all 5 senses, teaching users to assess their internal hunger and satiety cues, offering real-life mindful eating practical tips and advice, using a variety of media to teach

mindfulness, and integrating a range of BCTs. The implications of these findings are discussed below.

Although there are many apps that claim to be based on mindful eating, few comprehensively cover the essential aspects of mindful eating or MBEAT. The review by Mani et al also found that less than 5% of mindfulness app are truly based on mindfulness [13]. Mindful eating requires attuning oneself to all 5 senses when eating by really focusing on the sight, smells, sounds, flavors, and physical sensations of the food one is eating, without allowing one's thoughts to wander [6,9]. It is essentially a type of eating meditation [4,7].

Most of the apps tracked how slowly someone ate. Eating slowly is indeed an important aspect of mindful eating [4-9]. Although mindful eating involves slow eating, there is much more to a mindful bite than simply chewing slowly because if an individual is not truly present and all of their 5 senses are not immersed in the experience, they are just eating slowly but not mindfully [4-9]. Thus, mindful eating apps need to do more than track slow eating or hunger and fullness ratings. They need to ask users about what they are tasting, sensing, feeling, seeing, and hearing when eating as these are essential to the mindful eating process according to mindful eating practitioners and the literature [4-9]. This could be in the form of ratings or through journal entries that allow users to reflect on their mindful eating after they listen to a mindful eating meditation audio, for instance.

Furthermore, none of the apps guided users through a mindful eating example, with the exception of 1 audio app that was only audio based. Guiding users through an eating meditation is important to teach them how to truly eat mindfully as in the leading books made by mindfulness practitioners that have accompanying audios [4,6]. For example, in Dr Kabat-Zinn's introductory book, he guides users through the whole sensory mindful eating meditation experience, which may be listened to with the accompanying CD [4]. Mindfulness practitioners also provide tailored binge eating, hunger, and fullness meditation audios that are valuable, yet none of the reviewed apps had these options [7]. This would be valuable for the apps that claim to assist with binge eating in particular.

In addition, having a journal alongside an eating audio would help users to record their experiences during a mindful eating meditation as this is found in traditional mindfulness-based training book programs [6]. If the apps do not thoroughly explain what mindful eating is and guide users through an example, the potential for knowledge acquisition and proper mindful eating practice may be limited.

Mindful eating can be as detailed as paying attention to the entire meal setting itself including the dining room, the placement of cutlery, and the movement of one's hands [8]. Mindful eating can also involve trying different foods and discerning between the different textures and flavors with closed eyes to increase one's taste bud sensitivity, which enhances the mindful eating experience, as a leading mindful eating practitioner recommends [8]. Integrating these types of examples in an app would be insightful. Only 1 app mentioned paying attention to cutlery and the meal setting very briefly [48]. Thus, mindful eating apps could integrate these components and tips in their apps to further stimulate mindful eating and interest. In addition, practical real-life suggestions could help users with eating mindfully throughout the day at work, out with friends socially, and at home. Practical real-life suggestions were found to be important for participants in our previous exploratory pilot study [20].

A variety of media to teach mindful eating would be desirable as individuals have different learning preferences, which can include learning through listening or watching according to research on learning styles [22]. Furthermore, research suggests that most individuals stop using their apps because of boredom, costs, and having to manually key in data [49]. As most apps had weak scores in the engagement and information domains in the MARS appraisal, using diverse media could enhance the informational content and provide more user engagement. Most of the apps were uninteresting, and it is unlikely that users would continue using them for longer periods of time. Hence, ensuring the app is entertaining and fun and has a variety of content is key to sustainability. Only 1 app had a reward [38]. Most were either boring diaries that required users to manually key in data or timers that did not have any other information or content. The review of mindfulness apps similarly found that most apps had weak scores in the engagement and information domains [13]. Our exploratory pilot qualitative study also found that users expressed a preference for mindfulness apps that could provide real-life exercises that are entertaining and relevant, with plenty of practical educational content [20]. Thus, it seems that developers could work on ensuring higher quality of information and user engagement.

In addition, few apps integrated a range of BCTs. Our postrandomized controlled trial focus group results indicate that learning mindfulness requires habit formation, which in turn not only takes time but also requires reminders [48]. Our pretrial exploratory study also found that students expressed a preference for a range of BCTs that also included prompts, education, tips, reminders, encouragement, and motivation, to name a few [20]. Moreover, our systematic review of consumer preferences further found that BCTs are desired by participants in mHealth weight loss interventions [21], and they have been commonly integrated in past mHealth interventions for weight loss involving diet and exercise [19]. Thus, future mindful eating apps could consider integrating a range of BCTs.

The push notifications also were not mindful eating specific nor were there any practical tips on how to eat mindfully throughout the day. To truly motivate individuals and remind them to eat mindfully, messages should aim to be mindful eating specific, ideally with practical tips [20]. We found that participants in our previous study expressed a preference for mindfulness-based messages with practical tips on how to practice mindfulness in their daily lives [20]. Thus, future apps could consider constructing mindfulness-based messages that would have real-life mindful eating practical tips in them.

In addition, there is a need to further improve the apps in the information domain. Most of the apps also did not fully explain the benefits of mindful eating for users such as reduced binge, emotional eating, stress, and weight [3,50,51]. It is important for users to know why they should aim to eat mindfully because

being aware of the benefits could motivate them to practice it. Our previous focus group exploratory pilot study found that participants needed more information about the benefits of mindfulness practice to be mindful [20]. Thus, the apps could provide some basic information from the literature that has linked mindful eating with improved binge eating [50] and reduced stress [3], for example. This would make the app more relevant for individuals with specific problems that the app could address.

Furthermore, although mindful eating does not require caloric restriction [5], to achieve a balanced diet and make mindful decisions about one's nutrition, there should be basic information in an app. According to Kristeller and Ruth, mindful eating requires a general knowledge of what is healthy food and what one should aim to meet [52]. We also found in our focus group study that students wanted more general health and nutritional information [20]. Thus, future apps could consider providing basic information about a balanced diet.

Mindful eating apps should also provide more information on stress eating and how to assess if one is eating in response to external stressors or internal hunger as not all apps considered this. Why is this important? Mindful eating practitioners often ask participants to rate their hunger and appraise whether it is because of true internal hunger and satiety or because of extrinsic reasons as this increases present moment self-awareness [2,5,6,8,9]. Increased present-moment awareness may in turn lead to improved eating behaviors such as reduced binge eating [2,50]. Research on stress indicates that stress is one of the determinants of unhealthy eating behavior [53-56] and that mindfulness practice assists with stress and eating behaviors [3,50]. Special breathing techniques could be taught in the app that help users breathe out the craving and relax, hence, minimizing binge or emotional eating as leading mindfulness practitioners recommend [7]. Although some apps provided visual feedback for when users said they ate slowly, receiving feedback on actual emotional states and stress levels before and after meals in tandem with logging breathing exercises for craving control could be helpful, for instance, as emotional awareness and awareness of internal bodily cues during eating are part of the mindful eating process [2,5].

Finally, most of the apps did not have information on privacy policies, which is an important requisite [16]. A review found that 81% of diabetes apps did not have privacy policies and that 76% of diabetes apps that did not have privacy policies had distributed sensitive information to others [57]. A recent review of mental health apps for bipolar disorder also found that most of the apps did not have privacy policies nor had they cited their informational resources [58]. This raises serious ethical and safety concerns surrounding privacy and confidentiality as individuals do not have the opportunity to provide their informed consent which is the basis for health ethical practice [59] and should be applicable to health promotion and mental health apps as they deal with health information, yet reviews have found that these apps have not provided privacy policies [57,58]. This is especially concerning when sensitive health data are potentially shared with third parties, and research indicates that 7 out of 10 apps shared data with third parties [60]. Although apps collect things such as location or have access to one's camera [61], they may have access to more sensitive health information if this information is stored and recorded by the individual. Although privacy is a human right [62], research also indicates that privacy laws in countries with strict regulation do not protect citizens when their information is passed on to third parties in other countries [60]. Thus, future mindful eating apps should ensure that they have clear privacy policies. iTunes now has a requirement for all apps to have a privacy policy to be accepted [63].

In addition to the lack of privacy policies, the apps also lacked information on proven therapeutic effectiveness. Hence, future researchers should undertake research to determine what the evidence base really is for commercial mindful eating apps. In other words, are they effective?

Strengths and Limitations

Although this is the first review to appraise mindful eating apps for iOS, Android apps were not reviewed. As a result, there is always a possibility that we may have missed additional apps. However, we believe we have included the main mindful eating apps available in the marketplace. There is also an overlap in apps between iTunes and Google Play. Furthermore, it is possible that the expensive mindfulness subscription apps may have mindful eating components as add-on features, but our focus was on mindful eating apps made for the primary purpose of teaching mindful eating and assisting with binge eating or weight management.

Conclusions

We undertook the first review of mindful eating applications for iOS. We found that many of the mindful eating apps did not have sufficient information on how to eat mindfully to deliver appropriate mindful eating training. Most of them lacked in comprehensiveness and were mostly eating timers, diaries, or hunger rating scales. There was very little information on how to eat mindfully or how to make mindful eating decisions when confronted with cravings. There was little diversity in app media and little that could increase engagement in the user experience. Most of them also did not offer mindful eating meditations or guided examples, and there was little information on privacy for users. Future mindful eating apps could be improved by developing these various domains.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Mindful eating apps description.
[PDF File (Adobe PDF File), 2MB - mental_v6i8e12820_app1.pdf]

Multimedia Appendix 2
Mindful Eating Specific Content Assessment of Apps.
[PDF File (Adobe PDF File), 145KB - mental_v6i8e12820_app2.pdf]

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Abbreviations

BCT: behavior change technique
MARS: Mobile App Rating Scale
mHealth: mobile health

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Original Paper

A Smart Toy Intervention to Promote Emotion Regulation in Middle Childhood: Feasibility Study

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Abstract

Background: A common challenge with existing psycho-social prevention interventions for children is the lack of effective, engaging, and scalable delivery mechanisms, especially beyond in-person therapeutic or school-based contexts. Although digital technology has the potential to address these issues, existing research on technology-enabled interventions for families remains limited. This paper focuses on emotion regulation (ER) as an example of a core protective factor that is commonly targeted by prevention interventions.

Objective: The aim of this pilot study was to provide an initial validation of the logic model and feasibility of in situ deployment for a new technology-enabled intervention, designed to support children's in-the-moment ER efforts. The novelty of the proposed approach relies on delivering the intervention through an interactive object (a *smart toy*) sent home with the child, without any prior training necessary for either the child or their carer. This study examined (1) engagement and acceptability of the toy in the homes during 1-week deployments, and (2) qualitative indicators of ER effects, as reported by parents and children. In total, 10 families (altogether 11 children aged 6-10 years) were recruited from 3 predominantly underprivileged communities in the United Kingdom, as low SES populations have been shown to be particularly at risk for less developed ER competencies. Children were given the prototype, a discovery book, and a simple digital camera to keep at home for 7 to 8 days. Data were gathered through a number of channels: (1) semistructured interviews with parents and children prior to and right after the deployment, (2) photos children took during the deployment, and (3) touch interactions automatically logged by the prototype throughout the deployment.

Results: Across all families, parents and children reported that the *smart toy* was incorporated into the children's ER practices and engaged with naturally in moments the children wanted to relax or calm down. Data suggested that the children interacted with the toy throughout the deployment, found the experience enjoyable, and all requested to keep the toy longer. Children's emotional connection to the toy appears to have driven this strong engagement. Parents reported satisfaction with and acceptability of the toy.

Conclusions: This is the first known study on the use of technology-enabled intervention delivery to support ER in situ. The strong engagement, incorporation into children's ER practices, and qualitative indications of effects are promising. Further efficacy research is needed to extend these indicative data by examining the psychological efficacy of the proposed intervention. More broadly, our findings argue for the potential of a technology-enabled shift in how future prevention interventions are designed and delivered: empowering children and parents through *child-led, situated interventions*, where participants learn through actionable support directly within family life, as opposed to didactic in-person workshops and a subsequent skills application.

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KEYWORDS

mental health; children; families; stress, psychological; emotional adjustment

Introduction

Background

Mental health conditions are the main contributor to the substantial increase in childhood disability in the last decade [1], with most having their onset in childhood or adolescence [2,3]. Recent estimates suggest a 10% prevalence of mental disorders in children and adolescents in Great Britain [4] and 12% in Europe [5], whereas approximately 1 in every 4 to 5 youth in the United States meets criteria for a mental disorder with severe impairment across their lifetime [6,7]. This realization is fueling calls for interventions in childhood to avert the development of long-term disability [8-10]. Research in prevention science showcases the feasibility of such interventions in child populations: prevention programs develop key cognitive and emotional protective factors—such as emotion regulation (ER) or coping strategies—which, in turn, can reduce the incidence of mental health disorders in later life [11-17]. There are a variety of types of prevention programs, from *universal interventions* that are designed to be used with all children to *indicated* interventions that are targeting those already presenting with early signs of serious disorders [12]. Similar to therapeutic settings, existing prevention programs rely predominantly on in-person training. As a result, these interventions struggle with the challenges of cost, reach, and intervention fidelity [18-22].

Although existing programs are relatively successful in targeting children within the *captive audience* context of schools [21-25], a principal challenge remains in extending this support into the day-to-day contexts in which protective competencies are applied, practiced, and developed [22]. The current model relies on parents to deliver such at-home interventions and requires extensive training to do so effectively: For example, a shortened version of the Incredible Years program [26,27] still required 12 to 24 weeks of parent training in groups of 6 to 10 parents for 2.5 hours, once a week. Other programs, such as the seminal Perry Preschool program, were even more intensive, comprising a 2-year program of 2.5 hours of interactive academic instruction daily for children at school, coupled with 1.5-hour weekly home visits by trained staff [28]. Such approaches experience low enrollment rates, and the lack of continued engagement with interventions beyond formal delivery classroom context is also a common limitation [18-20]. These difficulties in bridging the formal school and informal home contexts are crucial in prevention science: family interactions are a strong mediating factor for developing resilience and impacting core socioemotional competencies, especially for younger children [29-33]. Moreover, lack of consistency of at-home and at-school support diminishes the effects of prevention programs [22,34].

New delivery mechanisms and intervention approaches are sorely needed to address these issues [8]. Digital mental health interventions are increasingly seen as having the potential to deliver on these aims, revolutionizing when, how, where, and to whom interventions can be delivered [10,35-37]. Although the interest in technology-enabled mental health continues to soar—especially in the context of treatment for adult populations—a consistent set of challenges has, however, emerged around ensuring uptake and long-term engagement of digital interventions [10,38]. Reliance on didactic and information delivery models, limited use of user-centered design, and lack of immediately perceived benefits leading to low motivation are commonly cited reasons [39-41]. These difficulties are likely to be exacerbated for prevention interventions for children, but surprisingly little research has investigated it empirically [42,43]. As such, it is not clear if and how technology could be used to facilitate transfer of such learning from school into families; or to enable new types of interventions that would empower parents and children to further develop protective competencies independently of formal training programs.

This Research

This work investigates a proof-of-concept prototype of a newly proposed intervention delivery mechanism within the context of (1) universal prevention programs [25] for children aged 6 to 10 years and their families and (2) ER as a specific instance of a psychological protective factor. We chose ER as it is a fundamental life skill, with effects on life outcomes comparable in size to those of IQ or family social status [44,45]. Research shows that these effects are wide-reaching: if ER is poorly developed, it leads to increased incidence of both internalizing and externalizing mental health disorders [46-49] and is associated with societal problems such as criminal behavior [50], low personal well-being [44], and academic underachievement [51]. Moreover, existing intervention research shows that ER is difficult to develop without detailed in situ guidance and support [26,52-54]; and parenting strategies play a key role in shaping child emotional coping and regulatory skills [55-63]. This is particularly important within underprivileged families: prior research repeatedly shows that children from these populations are at risk of low self-regulation competencies at an early age [64,65], and the gap further widens over the school years [66].

The data reported here build on an iterative user-centered design process, which led to the development of a novel intervention prototype described in the next section. Within the 2-year-long development phase (reported in full elsewhere [67]), we worked with children, parents, and prevention science experts to codesign a proof-of-concept technology platform to support children in developing ER skills. Theoretically, the intervention is grounded both in basic models of ER [68], as well as close collaboration with developers of evidence-based interventions (*Second Step*), while also deeply involving children and families in codesign to ensure the intervention fits into their daily lives [39,40,69]. In effect, the designed prototype attempts to fuse the understanding of evidence-based methods from prevention science (what works), human-computer interaction (what is technically feasible and acceptable to users), as well as insights into the everyday practices of families within the social context we designed for (what people actually do). This iterative design process has led to a novel *situated* intervention model: the intervention is delivered through an interactive object (*smart toy*) sent home with the child, without any prior training necessary for either the child or their carer (see the next section for design details and logic model).

Feasibility Study Aims

The aim of this qualitative study was to provide an initial validation of the feasibility of core fundamental principles underpinning the proposed novel intervention model [70], which was developed in previous research [67]. Specifically, the intervention model assumes that (1) children will be naturally compelled to keep interacting with the intervention without external guidance; (2) it will become incorporated into their everyday emotion regulatory practices, even without any formal training; and finally (3) the intervention would be perceived as acceptable to parents. Given the novel nature of the proposed delivery mechanisms, it is crucial to test whether these principles are fulfilled by the current prototype before more expansive investigations take place.

Data from exploratory deployments reported in our previous study [67] are promising; however, these are limited by short post hoc interviews with children, no information from parents, no objective log data, and only very short deployment times (median 3 days). This study builds on these preliminary findings using a range of data-collection methods (pre- and postinterviews with parents and children, log data analysis, and child photo diaries) to investigate (1) engagement and acceptability of the device in the homes during 1-week deployments and (2) subjective indicators of effects on emotion regulatory practices (whether positive or negative), as reported by parents and children.

Intervention Design and Logic

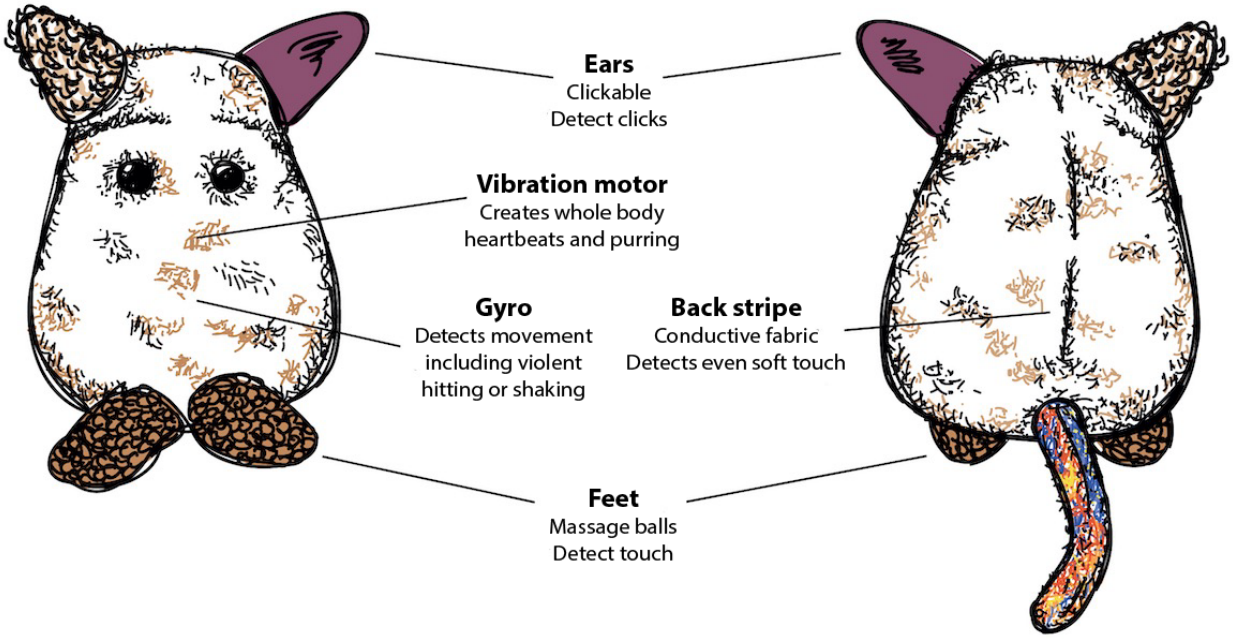
The prototype takes the form of a hand-crafted plush toy (see Figure 1 and the study by Slovak et al [67] for the design process), which was designed to travel home with the child from school and support in-the-moment soothing. The toy is introduced to the child as an *anxious creature that needs kind attention from humans*, such as soft stroking and hugging. Embedded electronics enable the prototype to produce vibration patterns that simulate a heartbeat (ranging from frantic to slow and steady). When picked up, the toy emits a frantic heartbeat that slows down if the child uses calm stroking movements, as registered by the embedded sensors (see Figure 2). If the toy is *soothed* for long enough, the prototype transitions into a purring vibration indicating a calm, contented state. For a full description of the physical design, interactive features, and a more detailed logic model, see Multimedia Appendix 1. We included 29 publications in Multimedia Appendix 1 [65,68,71-99].

The logic model underlying the intervention is assumed to operate on 3 levels building on each other: Level 1 pertains to directly *providing in-the-moment soothing support* to children in naturally occurring emotional moments when they would attempt to calm down. The prototype's physical and interaction design was aimed to tap into a number of known regulatory factors, grounded theoretically in Gross' extended process model of ER [68]. Specifically, we designed the prototype interaction with the aim to impact 2 separate stages: the *attentional deployment stage* [71-75], by shifting children's attention from the emotion-eliciting situation toward interacting with the toy and the *response modulation stage*, by facilitating downregulation through pleasant tactile interaction analogously to the mechanisms assumed to underpin emotion regulatory effects of human-animal interaction [76-81].

Level 2 is concerned with mechanisms that *facilitate children's long-term engagement* with the intervention, building on the positive subjective experience of in-the-moment soothing. The framing of the toy as an *anxious creature in need of assistance* is the hypothesized key driver: we assume that this framing will not only support conveying the benefits resulting from extrinsic ER [77,82,83], but also facilitate the creation of a sense of relationship and responsibility for the *well-being* of the creature, similar to the long-term engagement seen with child-oriented robots [75] or products such as Tamagotchi [84-86].

Figure 1. The physical prototype.

Figure 2. Overview of the prototype's interactive components.



Finally, level 3 is assumed to emerge from repeated experience of soothing interactions over time, leading to a *shift in children's ER practices and implicit beliefs about emotion*. Specifically, we hypothesize that repeated interactions with the toy will result in the establishment of more adaptive ER patterns and shift children's implicit beliefs about the controllability of emotion [87,88], a well-known target for intervention [89-93]. As these effects are expected to arise only through ongoing long-term interactions and, thus, rely strongly on appropriation in situ, we did not expect to see any indicative data for these proposed mechanisms within this pilot study; however, these will be crucial for long-term effect of the smart toy intervention. This study aimed to provide pilot indicative data pertaining to levels 1 and 2.

Methods

Overview

The goals of this early feasibility study were to investigate the engagement and acceptability of the device in the homes during 1-week deployments with children aged 6 to 10 years and their families and also subjective indicators of effects on emotion regulatory practices (whether positive or negative), as reported by the parents and children. Together, the aim was to collect indicative qualitative data pertaining to level 1 and 2 of the underlying logic model: we were interested to see if children would find the individual interactions comforting, whether they would sustain engagement over the week periods (and what role any emerging *relationship* with the toy might play here), and whether the toy will become embedded into their everyday activities, including being explicitly used for ER.

Study Design

As we were interested in studying natural appropriation in situ, children were given a prototype, a *discovery book* that presented the simple narrative and suggested playful activities, and a simple digital camera to keep at home for 7 to 8 days. We gathered data through a number of channels. The main sources were (1) semistructured interviews with parents and children before and right after the deployment; (2) any photos the children took during the deployment, which also served as *ticket to talk* about their experiences during the week; and (3) automatically collected logs by the prototype, which recorded all touch interactions throughout the weekly deployment.

The discovery book contained some information about the *creature's* background and various activities the child could fill in on their own or with the help of their parents, such as *photo challenges* around the toy, and an *emoji diary* where they could use emoji stickers to keep track of how they and their *creature* were feeling on each day of the deployment. In designing the discovery book and activities, our aim was to facilitate children's engagement with the toy in a playful manner as well as complement the interview data with a richer understanding of how families experienced having the toy at home. As such, the discovery book was as much a research tool as a part of the intervention (implicitly providing the narrative and suggested activities).

The study was funded by a personal fellowship and University College London (UCL) and received ethical approval from UCL's ethics committee (3923/005).

Recruitment

The prototypes and accompanying materials were deployed in waves to 10 families of 11 children (3 girls, 8 boys; aged 6-10 years) from August to November 2018. One additional family had been recruited, but experienced a malfunctioning prototype and has not been included in the dataset. Participants were recruited from 3 communities in the United Kingdom through a range of methods, including online advertisements, in-person recruiting in 2 schools which had served as recruitment sites for previous phases of the project, and snowball sampling. The majority of participating families (7/10, 70%) lived in an area falling within the 20% most deprived in England (measured

according to English Indices of Multiple Deprivation [100]), with the remaining 30% (3/10) living in areas falling within deciles 3 to 5. Recruitment was stopped based on data saturation [101]: the interview data collected were highly consistent across families, with only limited new insights emerging by the tenth interview, within the context of a pilot study.

Procedure

All engagements with families were conducted by the first author, who holds an MSc in developmental psychology. The researcher visited families who had orally agreed to take part to obtain consent from parents and assent from children, conducted a semistructured interview with at least 1 parent, and gave children the toy, discovery book, and a simple digital camera to keep at home for 7 to 8 days (1 deployment was extended for a day because of a technical failure and 2 more for scheduling reasons). The first semistructured interview with parents focused on families' existing emotion regulatory practices, perceived challenges to ER, and parents' expectations from the week-long deployment. After 3 or 4 days, the researcher visited families again to change the toy's battery. On the last day of the deployment, the researcher visited the families to pick up the toy and materials and interview each child and at least 1 of their parents individually (see Multimedia Appendix 2 for the interview guides). The interview sessions (approximately 1 hour) were conducted in person in participants' homes. After the end of the interview, parents completed a brief demographic questionnaire with items on age, race, ethnicity, education level, current employment status, marital status, and housing situation. Engagement with the toy was tracked automatically by the toy throughout the deployment, by registering and logging every interaction with a timestamp.

The semistructured interview conducted at the end of the deployment included questions designed to elicit participants' views and experiences of using the toy as well as their expectations of long-term outcomes if they were to keep it for longer. During the interviews, the photos children took and the completed activities in their discovery books were used as prompts to ask families about the child's engagement with the toy. The interview sessions (approximately 1 hour for the parent interview and 30 min for the child interview) were conducted in person in participants' homes when the researcher visited the families to collect the toy and accompanying materials. Families were offered £50 compensation for their time. All interviews throughout the development were audio-recorded, with permission from the parents and children; the researcher also collected simple field notes about who was present during the visits and also detailed any additional observations that seemed important but would not be captured by the audio recordings .

Data Analysis

Analysis of Interview Data

We decided to focus the analysis in this study predominantly on the postdeployment interviews as the existing emotion regulatory practices reported by families during the predeployment interviews were similar to those described in prior work [67] (eg, strong parental emphasis on external behaviors rather than underlying emotions, expectation of self-soothing by children, and use of disengagement and distraction as 2 main ER strategies), and postdeployment interview data were rich enough to answer the research questions. Interview recordings were transcribed verbatim by the first author and an independent research assistant and then included into an inductive thematic analysis. Following Braun and Clarke's 6-step recursive process of thematic analysis [102], the transcripts were checked against audio recordings for accuracy and then read and reread by the first author to ensure familiarization with the data. Initial codes were then generated across the dataset. As new ideas emerged, and codes were refined while working through the transcripts, previously coded transcripts were revisited to ensure that the codes still applied. Once code application was complete, resulting in 603 coded passages and 2226 code applications, different codes were sorted into potential themes by the first and fourth authors, which were then refined to generate an initial thematic map of the analysis. The refinement of the thematic map involved several iterations until authors agreed that the final themes and subthemes told a coherent story about the data. To protect anonymity, participants are referred to by using P for parents and C for children, followed by a participant number.

Analysis of Log Data

The prototypes logged every interaction throughout the deployment. Due to Arduino limitations, the sampling rate differed depending on the quickness of the *heartbeat* as the sensors were polled in between every 2 beats: the sampling rate was about 2 Hz in the *anxious* state and about 0.7 Hz in the *happy* state. The first author kept a detailed log about the time and date when the toys were introduced and removed from the families. The resulting log files (approximately 4.5 million lines) were then processed in R, post deployment. It is important to note here that as the data only represent activation of the toy's sensors (on its back, ears, feet, or gyro), interpretation is limited: for instance, if the toy was moved from one place to another, or placed in a bag to be transported, a sensor could be unintentionally activated by the pressure. To partially mitigate such *accidental activations*, we have removed minutes with less than 20 separate sensor signals from the analysis.

Results

Demographics

The study included 11 children from 10 families as a pair of siblings received 1 toy each during the same week (female children n=3; female parents n=11; mean age of children 7.1 years [SD 1.22, range 6-10]; mean age of parents 37 years [SD 5.36, range 28-44]). For a more detailed description of participants' demographic characteristics, refer to Multimedia Appendix 3). One additional family had a malfunctioning prototype and has been removed from the main analysis. Table 1 includes individual information for age, gender, and other deployment-related information for each of the children. We had no attrition; all participants finished all phases of the study.

Table 1. Overview of child demographics and the labels they associated with the prototype.

Child	Age (years)	Gender	Toy's name (gender)
C1	6	Male	Jade/Pipsqueak (female)
C2	6	Female	Coco (male)
C3	6	Female	Winter (female)
C4	6	Male	Mr Scared (male)
C5	7	Male	Frankie (male)
C6	7	Male	Creature (female)
C7	8	Female	Rainbow (female)
C8a	7	Male	Wootie (female)
C8b	10	Male	Missy (female)
C9	7	Male	Happy (male)
C10	8	Male	Buddy (male)

Qualitative Results

Engagement and Appropriation

In describing their experiences over the week, all the children (11/11) outlined how the toy became included in their everyday routines, whether these were cuddling and stroking the toy when watching TV, playing with their other toys, or going to bed, or more active play such as role play scenarios (see Figure 3 for example photos taken by the children). For most children (10/11), their parents or themselves reported that they wanted to carry the *creature with them wherever they went* and were keen to show it to family and friends. Every child named their toy and treated it as a living being that needed to be cared for, with feelings and mental states they seemed to take into consideration. For example, most children (7/11) were very protective of the toy and looked after *its feelings*, for example, by making a bed for it to sleep in or clothes so that it would not be *cold*, making sure to soothe it when it was getting *stressed*, and being very particular about how others could interact with it in fear that they would *stress it*, break it, or take it from them. These findings are illustrated by quotes mentioned below; Multimedia Appendix 4 then provides a much more extensive set of quotes pertaining to each of the themes throughout the results section.

> *They were like instantly connected. Everywhere she went, she'd hug him, she spoke to her dad about Coco, to her grandmother, to her cousins. Very proud.* [P2]

> *Creature goes wherever [my child] goes...Creature comes to bed, Creature sits with us at dinner, Creature watches his tablet, Creature does just everything does. Even if we go shopping, we come to mum, creature has to come!* [P6]

Another indication of the children's emotional connection to the toy was that every child was sad to part with the toy, as was reported either by children themselves or by their parents. Beyond the interview data, this was also experienced by the first author during her visits to pick up the toy, when most children would ask to keep the toy for longer or would hide it and pretend they did not know where it was. Seeing these strong impacts with the first 3 children, we decided to make repeated checks with the parents (at about a week and then 4 weeks post deployment) to make sure this was only a transient state, as well as slightly alter the narrative when deploying the toy to add that the *creature* would be returning to its family at the end of the week. We presumed that this framing would resonate with children and make it easier for them to part with the toy, thus lessening the emotional impact of the separation. Parents did not report any persisting issues during the phone checks; instead, they emphasized that children had fond memories of the toy and would still occasionally mention it:

> *[It was really sad when] I didn't have it today. [...] It's because I really loved it. And now I can't even have it for more days.* [C1]

Children's sustained engagement with the toy appears to stem from the enjoyment they gained from the in-the-moment interaction. All the families reported that interacting with the toy had a positive impact on children's mood; a finding that is discussed in more detail in the following section. In addition, more than half of the parents (7/10) highlighted the sense of responsibility the back-story instilled in children as something that children really enjoyed and that in turn drove consistent engagement over the week-long deployment:

> *When I tried calming the creature down, I felt...I felt like I was actually doing something useful.* [C8a]

Figure 3. Example photos taken by children.

Impact on Emotion Regulation

Both parents and children reported that the toy was incorporated into the children's emotion regulatory practices in a number of contexts, and all the parents recognized that the interaction with the toy had a calming effect on their children. Common observations included children naturally interacting with the toy to self-soothe after an emotion-eliciting situation, such as a conflict with their parents or siblings, or in moments they wanted to relax, such as before bedtime. Although these emotion regulatory effects were most commonly observed in situations where children were particularly upset or angry, it was also reported that having the toy had an overall calming effect, with children appearing *a lot calmer* or *more settled* over the duration of the deployment. These parental reports were complemented by the child interviews: A total of 10 out of the 11 children deliberately used the toy to calm down and reported that soothing the toy had a positive effect on their mood, making them feel *happy* or *calm*. A total of 4 children also used the toy at times they were in physical pain and described how this helped them cope with it:

> *Mum: What did [your sibling] do? Did you just go in the bedroom this time and he told you off? C: He told me to get out, that it's not mine. M: Okay. But it is your bedroom. R: Oh, so that made you angry? (child nods) R: What did you do afterwards to calm down? C: I ran in, got past [sibling's name] and started stroking the creature and hugging it. R: And how did that make you feel? C: Really happy. Overjoyed I would say.* [C10]

> *When my mum was brushing my hair...it hurts, so I usually have the creature by me so it can distract me from the pain.* [C8b]

Although children seemed to engage with the toy naturally during emotional moments, half of the parents (5/10) also mentioned instances where they would explicitly encourage their children to use it to soothe themselves. Only 1 parent (P1, quote below) mentioned that the toy was not on their or their child's mind in highly emotional situations such as meltdowns, and they thought the child needed to cool down first before they could interact with the toy in a calm manner:

> *I saw her looking after Winter, hugging Winter, calming Winter down, using it to calm herself down. [...] Especially like when she got angry. I'm like (speaking softly) "Go and get Winter". [...] So, yeah, sometimes I'll direct her, sometimes she will just do it herself.* [P3]

> *I know a problem is that sometimes when they're angry it's not really the first thing that comes to head. Because, you know, when a child is angry, they're angry! Do you understand? Maybe it's just when they cool down, then that's when they might think "you know what? Let me..." (imitates stroking movement). And then that's when they start cooling down even more.* [P1]

Parental Views on the Causes of Observed Effects

Some parents made their own inferences as to how the toy worked to help their children calm down. Most (6/10) reported that the toy was comforting for children, with a few drawing a comparison between the toy and their children's comfort objects, that is, items they cherished and used to comfort themselves when younger, such as blankets or soft toys. A total of 2 parents and 1 child described how the sense of responsibility children felt for the toy made them shift their attention to caring for it rather than focusing on what might have been upsetting them, thus serving as a distraction. One parent (P6) thought the toy gave her child a sense of control over the toy's emotions that he was usually lacking in himself; the child's account seems to support this claim as he mentioned that he liked deliberately stressing the toy so he could soothe it and himself in doing so:

> *Because my mind was on her, and calming her down...like she was a child to me. Because when I'm calming her down...technically my mind is completely on her...So I'm technically blocking out everything and trying to keep my child safe!* [C8b]

> *Parent: It's something that I think...Like I said, he can control to an extent. Obviously, he can't control when it gets upset. But it's something that he has control over, because he doesn't have control over those specific emotions in him. [...] So it's the one thing that he can't control in himself, but he can control in something else. And I think, that really worked with him...I really do.* [P6]

> *Child (independently): We can do this (cuddles the toy) and do this (presses toy's ears) if he just keeps*

> *purring and you want him to get mad and then make him purr again. I like calming him down...because when he's just purring it's just...it makes me calm.* [C6]

Interestingly, parents' accounts suggest that, in their view, the toy's impact on ER was not limited to children. Half of the parents (5/10) reported that they found the interaction with the toy calming for themselves or other members of the family too, such as younger siblings or other adults.

> *Definitely, it can help both the mother and the child. Definitely. Which is a good thing because sometimes, some toys, people just create them just to help the child. But then, knowing there's something that can help the adult as well, it's even a plus! Because the same way a child needs help, the adult needs it as well. Because we get mad as much as they do! [...] It's nice to know that there's something that can help both!* [P1]

Parents' Acceptance of the Intervention

Parents reported that the toy had met—or in some cases even exceeded—their initial expectations and did not have any negative feedback to relay. Parents' accounts suggest that they held positive views of the toy and enjoyed their experience of having it at home. Notably, a parent (P4) who was initially skeptical about her child's interest in the toy and expected that it would quickly wane described how surprised she was with her son's strong attachment to the toy and how caring he was with it. Finally, almost every parent (9/10) reported that they would like to keep the toy at home for longer if possible and inquired if and when it would be made available to the public. Most parents (9/10) thought that the toy would continue to be a valuable resource for the children as *somewhere they could go to* to calm down when needed:

> *I'm impressed! I didn't think it would be the way it has. And I didn't expect the attachment. Really, really didn't. Especially him being a boy and being six. [...] I personally wouldn't change anything. I think it's great the way it is. There's nothing I can say "Oh, you should add this, or take away that" [...] Because it's worked!* [P4]

> *I liked being able to refer to it, like when it was needed. And sometimes I just liked... hugging him! (chuckles) Or like seeing [my children] hug him. [...] I'll be quite sad to let it go (chuckles). Cos you'd think they're quite inanimate, but they're also quite giving!* [P9]

Quantitative Log Data Results

In this section, we are reporting on the interaction data automatically collected by the toy during the deployments. As outlined in the Data Analysis section, we classify any given minute as *active* only if the toy logged at least 20 different sensor interactions during that 1-min interval. This is to avoid counting accidental touches, or just moving the toy from one place to another.

Overall, the log data support the qualitative observations, showing sustained engagement throughout the deployment: the families used each toy, on average, for 74.9 active min per day (median 60.5; SD 64.1; see Figure 4 for box plots for individual children). We did observe that, overall, the average interaction times per day were longer for the first 3 days of the deployments compared with the last 3 days—but even then, the average active engagement was 43.8 min per day (median 30.5, SD 35.7). This might indicate that the engagement was stronger in the first few days because of novelty effects, and the children's interest in the toy started to wane toward the end of the deployment. Another plausible explanation that would be in line with interview data is that in the first days, children and other family members interacted more with it as they were exploring the features, whereas in the last 3 days, the children already knew how the toy worked and used it as and when they needed it. Long-term deployments are needed to understand the stability of engagement beyond the first week.

As expected, we observed a stronger engagement on weekends and holidays when most children would interact frequently with the toy throughout the day, whereas on school days, children interacted with it the most early in the morning (before school) and in the afternoon. To illustrate this, Figure 5 visualizes the weekly active minutes for child 7, selected as a typical example: child 7's overall active minutes length is close to the median of the dataset and also qualitatively typical to the interaction patterns we observed for other children. In this case, comparing the data on a weekend day (Sat 22nd) and on a school day (Wed 26th) exemplifies how the active times have been influenced by school times: with the child having frequent interactions with the toy from the morning up to the evening on the weekend day, while briefly engaging with the toy in the morning before school and throughout the afternoon after their return on the school day. The log data also seem to confirm participants' reports that children would at times interact with the toy around bedtime to relax. In some cases, interactions were also registered at nighttime, suggesting that children had the toy in bed with them; because of the inherent limitations of the log data in terms of interpretability, we cannot ascertain if these touch traces represent intentional (eg, children waking up in the middle of the night and stroking the toy) or accidental interactions.

When all interaction data are aggregated, the most frequently activated sensor was that of the back (35%), followed by the gyroscope (26%), feet (20%), and ears (20%). The large percentile of back sensor activation is consistent with the patterns of interaction reported in participants' interviews, as hugging and stroking the toy's back—both of which would activate the back sensor—were reported as children's preferred soothing interactions. Although the percentile of gyroscope activation was higher than we expected, considering it consistently happened alongside the activation of the back sensor, it does not seem likely that it indicates shaking or rough handling by the children.

Figure 4. Box plots for active minutes of interaction per day for individual children.

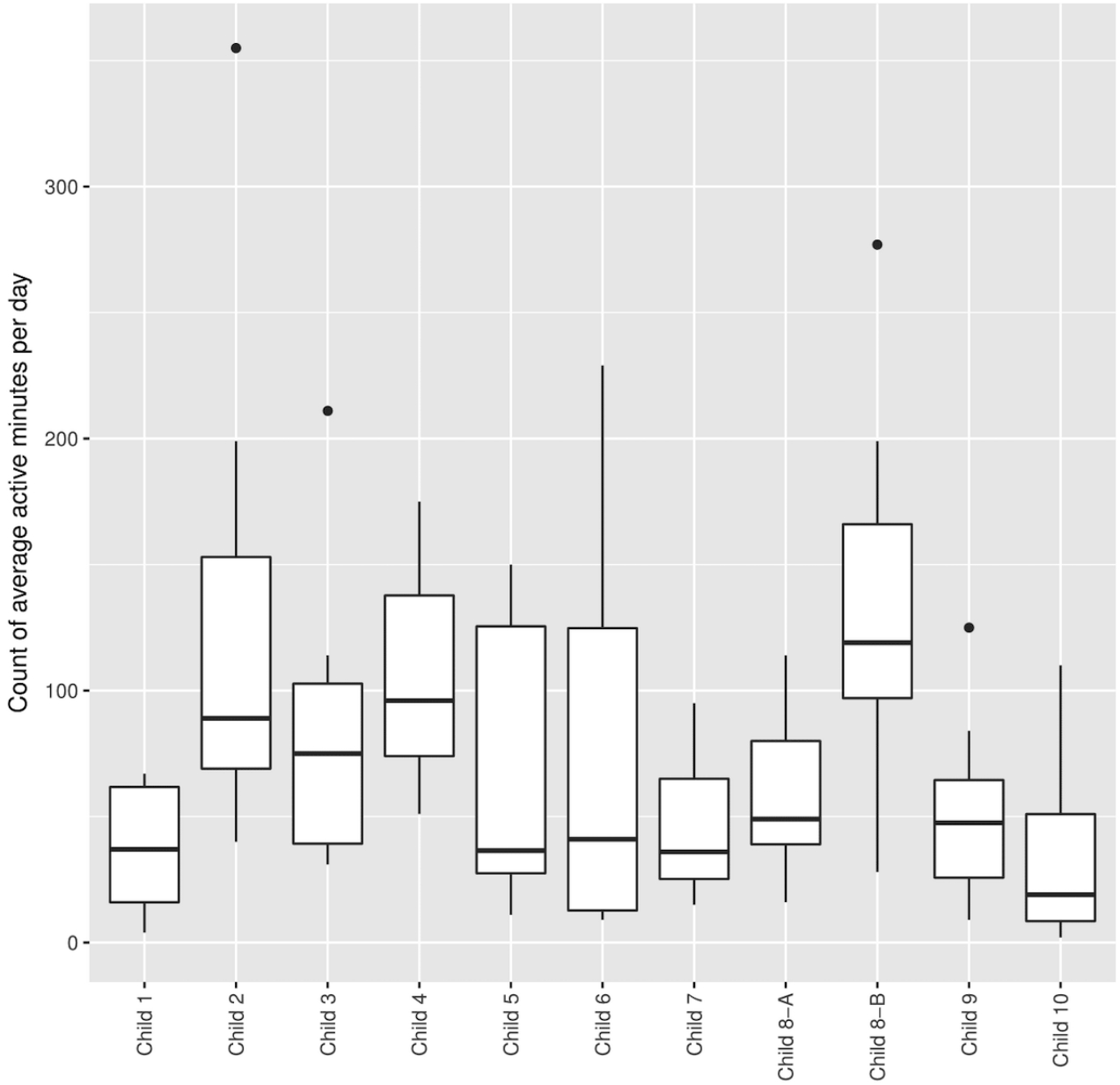
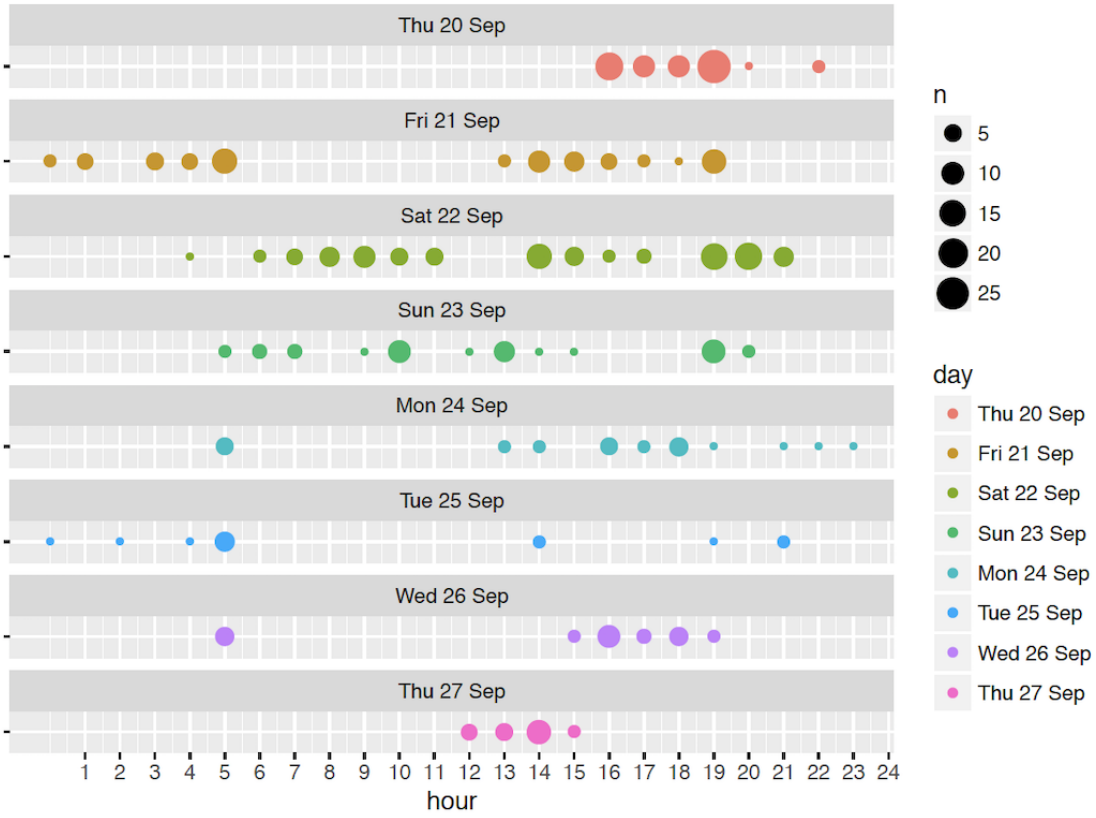


Figure 5. Example day-to-day summary for a child (child 7).



Discussion

Principal Findings

The aim of this qualitative in situ study was to investigate the engagement, acceptability, and initial subjective indicators of emotion regulatory effects for a proof-of-concept intervention model, as instantiated in a *smart toy* prototype. The novelty of the proposed approach was to deliver at-home interventions through an interactive object that becomes incorporated into child's everyday interactions to provide in-the-moment regulatory support, without any explicit training necessary for the child or the parent.

The fundamental assumptions underpinning the logic model of such *situated and child-led* intervention was that (1) children would be naturally compelled to keep interacting with the intervention without external guidance; (2) it would become incorporated into their everyday emotion regulatory practices, even without any formal training; and finally (3) the intervention will be perceived as acceptable to parents. The qualitative findings described above suggest that all 3 conditions were satisfied: all children reported sustained engagement with the prototype, without any externally imposed conditions and have been consistently labeling such interactions as subjectively pleasing. Both parents and children further described the observed emotion regulatory effects of child-toy interaction under a variety of contexts (eg, self-soothing after an interpersonal conflict, reduction in subjective anxiety levels, relaxation support, and coping with pain). Finally, all children and 9/10 parents were keen on keeping the prototype for longer, suggesting a high acceptability and suitability with respect to social practices in the home.

The qualitative findings also provided some indicative support for the hypothesized mechanisms underpinning the first 2 levels of the logic model: level 1 as facilitating in-the-moment regulatory support (relying on attentional deployment and response modulation) and level 2 as scaffolding ongoing engagement (through the creation of an emotional attachment to the toy).

For level 1, the experiences described by both parents and children supported the in-the-moment regulatory effects: the children described the moments of holding the prototypes as *happy* and *calming*, and some have reported to deliberately seek the interaction to calm down. Interestingly, half of the parents have described similar soothing experiences themselves, suggesting that the effects might be consistent across a wider age range, as could be expected given the reliance on fundamental emotion regulatory mechanisms [68,71,73,76,77]. Although it is impossible to disentangle the assumed attentional deployment and response modulation mechanisms based on the retrospective interview data, the stories captured in the interviews provide some support for the hypothesis that physiological effects arise from a combination of tactile stimulation (eg, "I just put it to my chest and it worked" type of quotes common across the dataset) and more conscious focus on *changing the creature's emotions*.

Similarly, the hypothesized level 2 mechanisms have received indicative support in the interview dataset. All children referred

to the prototype as if it were alive, attributing a range of human-like mental states to the toy, together with an associated range of caring behaviors (eg, making a bed or custom-made clothes to help it *feel warm*, making sure it is not *stressed*, and controlling how others interact so as to not *hurt it*). Combined with the sadness associated with the end of deployment, these observations suggest that the prototype was successful in generating an emotional attachment, which appeared to facilitate the continued engagement. These relationship-building effects appear analogous to those observed with other animal-like robots in other contexts: see Turkle et al [103] for a critical analysis of the mechanisms behind such computational devices presenting themselves as *relational artifacts*.

The study data do not provide indications of any effects on longitudinal shifts in emotion regulatory practices (level 3) because of the short-term deployment and lack of baseline and follow-up measurements. Further efficacy research, including in situ studies (such as randomized wait-listed designs in schools), is needed to understand the effects of the existing prototype on child ER practices and mindsets. Interesting research directions also include questions around the impact of associated materials (such as the discovery book) on the intervention effectiveness.

Similarities and Differences to Existing Interventions

To the best of our knowledge, the proposed intervention model is unique in prevention science as it suggests an intervention delivery method that becomes fully embedded in children's everyday lives, does not require any explicit training, and is relying on in-the-moment experiential support rather than information delivery. It draws inspiration from the large body of research on animal-assisted interventions (see Crossman [104] for a review), which has suggested promising outcomes in a number of populations. These include increased social interaction among children with autism spectrum disorder [105], increased social behaviors and reduced agitation and aggression among persons with dementia [106], reduction in symptoms among patients with depression [107], and increased emotional well-being such as reduced anxiety and fear [108]. A related area of work is focused on *social assistive robots* [84,105-108], which are designed to act as pet surrogates, such as the robotic seal Paro [109]. A majority of such socially assistive robotics (SAR) interventions has so far, however, focused on occasional use by older adults, particularly those suffering from dementia [109-114].

The design of SAR with typically developing children has been limited to educational interventions outside of mental health domain [115-117]. Despite the reported promising outcomes of SAR interventions in other contexts, no studies to date explored the use of SARs as part of prevention interventions (for ER or other protective factors) with typically developing children, and only 1 recent study [80] has explored the effects of interacting with Paro robot on children's mood, anxiety, and arousal after exposure to a lab-based, stress-inducing task: interaction with the robot resulted in greater increases in positive mood than any of the control conditions but did not have a significant effect on negative mood, anxiety, or arousal.

Broader Implications: Potential for Situated and Child-Led Interventions

More broadly, this proof-of-concept prototype can be seen as illustrative of a conceptual shift in how early prevention interventions might be created and delivered with technology: the notion of *situated interventions* and *child-led rather than parent-driven* approach.

The goal of a *situated intervention* refers to designing programs that will allow the families to draw on—and learn from—specific lived experiences as part of the intervention. This goes beyond purely *just-in-time* intervention delivery such as reminders or activity suggestions [37,118]: the purpose is to flip the existing intervention model that is based on information delivery and didactic learning (eg, at an in-person workshop or classroom lesson) *to be applied later* toward a model where the intervention directly supports both children and parents to learn from the daily emotional challenges they encounter. As with the example prototype discussed here, successful situated interventions would aim to embed intervention delivery as an implicit part of everyday situations—such as those of stress, anxiety, or sadness in the case of the toy presented in this study. The goal is then to utilize these everyday moments as an opportunity for ongoing, iterative training, rather than having to rely on vignettes, role-plays, or the recollection of past experience as is common now [18,22,34]. Psychologically, the notion of *situated interventions* thus corresponds to the need for in-the-moment scaffolding of experiential learning that underpins all socioemotional competencies [22,51,119-121] but has been pragmatically impossible to date.

The second key shift toward *child-led* interventions argues for the potential of repositioning the child as the immediate recipient of some or all aspects of the technology-enabled intervention. In the current prevention science models, the child is either seen as a *captive audience* within the in-school programs or as a secondary actor who is impacted by parental training. The reasons for this are understandable: the existing interventions could not rely on young children to drive the intervention as it is, for example, unlikely that a child aged 6 years would be able to teach their parents new parenting strategies as a workshop coach might, or directly engage (or want to engage) with a written text on a leaflet sent home. The ongoing, in-the-moment scaffolding facilitated by situated, technology-enabled interventions could address both of these issues and reposition the child as the main actor of the intervention, both in terms of who is driving the intervention transfer to home as well as who is to be engaged with the intervention once it is there.

Strengths and Limitations

One strength of the study was the emphasis on in situ unstructured deployments, which provided ecologically valid data about possible appropriation in families. Most parents were from underprivileged neighborhoods, and many were in difficult personal situations; we have avoided tapping into the proverbial *worried well* and instead worked with a population who could be expected to strongly benefit from ER interventions [122-124]. The detailed interviews then provided a holistic understanding of how the prototypes have been used and the impact they might have on the family life. Another strength was including the

interview data from both parents and children (in addition to photographs collected by participants during the week), triangulating the evidence across all stakeholders.

The data have been promising in terms of observed engagement and acceptability, which were high across all 10 families recruited into the study. This consistency—together with analogous positive effects from earlier deployment [67]—is particularly promising in view of the commonly high attrition rates and nonengagement for technology-enabled mental health interventions [10,38-41]. However, there may have been some self-selection recruitment effects: the families have explicitly opted into the study and, thus, might be more likely to respond positively than the *general* population. Further studies should investigate the engagement rates when deployed, for example, as part of school-based approaches and with reduced researchers' engagement (eg, questionnaire rather than interview methods).

An expected limitation of a pilot qualitative study is the lack of definitive data on psychological effects. Although participants' reports suggest that they experienced subjectively significant changes to their everyday emotion regulatory practices, more rigorous studies are necessary to understand the strength of psychological effects and whether these would scale up. In particular, it is not yet clear if these would lead to long-term changes, and whether the magnitude would lead to a clinically significant change in emotion-coping mechanisms and strategies [45]. As such, the lack of data on the presumed level 3 effects is the most important gap. It will require not only rigorous efficacy study designs to estimate the current effects but also likely further iterative codesign development (with parents, children, and prevention science experts) to strengthen the intervention impact. The qualitative pilot data from this and previous publication [67] provide a good starting point for such future work.

Conclusions

This is the first known study investigation of the use of object-enabled intervention delivery to support ER in situ. To understand the feasibility of such novel intervention mechanism, this qualitative study examined its appropriation and engagement by 11 children from low-socioeconomic status families over the period of 1 week. Triangulating both parental and child interviews, the data provide a holistic picture of how the prototype was incorporated into the family life. The strong engagement and qualitative indications of effects are promising—children were able to use the prototype without any training and incorporated it into their ER practices during daily challenges. Future work is needed to extend these indicative data with larger studies examining the psychological efficacy of the proposed intervention. More broadly, our findings suggest the potential of a technology-enabled shift in how prevention interventions are designed and delivered: empowering children and parents through *child-led, situated interventions*, where participants learn through actionable support directly within family life, as opposed to didactic in-person workshops and a subsequent skills application.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Design of the smart toy prototype and detailed logic model.

[DOCX File, 24KB - mental_v6i8e14029_app1.docx]

Multimedia Appendix 2

Interview guides.

[DOCX File, 16KB - mental_v6i8e14029_app2.docx]

Multimedia Appendix 3

Demographic profile of participating parents.

[DOCX File, 14KB - mental_v6i8e14029_app3.docx]

Multimedia Appendix 4

Summary of themes and illustrative quotes.

[DOCX File, 21KB - mental_v6i8e14029_app4.docx]

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Abbreviations

ER: emotion regulation
SAR: socially assistive robotics
UCL: University College London

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Original Paper

Young People Seeking Help Online for Mental Health: Cross-Sectional Survey Study

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Abstract

Background: Young people are particularly vulnerable to experiencing mental health difficulties, but very few seek treatment or help during this time. Online help-seeking may offer an additional domain where young people can seek aid for mental health difficulties, yet our current understanding of how young people seek help online is limited.

Objective: This was an exploratory study which aimed to investigate the online help-seeking behaviors and preferences of young people.

Methods: This study made use of an anonymous online survey. Young people aged 18-25, living in Ireland, were recruited through social media ads on Twitter and Facebook and participated in the survey.

Results: A total of 1308 respondents completed the survey. Many of the respondents (80.66%; 1055/1308) indicated that they would use their mobile phone to look online for help for a personal or emotional concern. When looking for help online, 82.57% (1080/1308) of participants made use of an Internet search, while 57.03% (746/1308) made use of a health website. When asked about their satisfaction with these resources, 36.94% (399/1080) indicated that they were satisfied or very satisfied with an Internet search while 49.33% (368/746) indicated that they were satisfied or very satisfied with a health website. When asked about credibility, health websites were found to be the most trustworthy, with 39.45% (516/1308) indicating that they found them to be trustworthy or very trustworthy. Most of the respondents (82.95%; 1085/1308) indicated that a health service logo was an important indicator of credibility, as was an endorsement by schools and colleges (54.97%; 719/1308). Important facilitators of online help-seeking included the anonymity and confidentiality offered by the Internet, with 80% (1046/1308) of the sample indicating that it influenced their decision a lot or quite a lot. A noted barrier was being uncertain whether information on an online resource was reliable, with 55.96% (732/1308) of the respondents indicating that this influenced their decision a lot or quite a lot.

Conclusions: Findings from this survey suggest that young people are engaging with web-based mental health resources to assist them with their mental health concerns. However, levels of satisfaction with the available resources vary. Young people are engaging in strategies to assign credibility to web-based resources, however, uncertainty around their reliability is a significant barrier to online help-seeking.

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KEYWORDS

mental health; eHealth; mHealth; Internet; help-seeking behavior; health literacy; young adults; survey and questionnaires

Introduction

Globally, there is a growing recognition of the public health challenge associated with mental disorders [1-4]. Particularly, the mental health of young people is becoming of increasing concern [5,6]. It has been recognized that young people are especially vulnerable to experiencing mental health difficulties, with very few seeking treatment or help during this time [5,6]. A systematic review by Ibrahim et al [7] found that students, most of whom were between the ages of 18 to 25, experienced higher rates of depression than other age groups from the general population. This age group faces unique challenges and stressors as they transition into adulthood [8], as young people are expected to learn adult responsibilities, and many experience high levels of distress as they potentially make sense of numerous changes taking place in their lives [9]. The personal and emotional concerns associated with this stage of a young person's life, and how they seek help for these worries, are of critical concern.

Help-seeking for mental health difficulties is often understood to be an adaptive coping method where an individual engages in behavior that communicates their distress to others with the goal of getting help in the form of understanding, advice, information, treatment or general support [10,11]. Help-seeking is a complicated process influenced by a person's attitudes, preferences and goals. For this reason, many people make use of a multitude of sources of help [12-14]. Previous research has found that engaging in help-seeking behavior, both formal and informal, is an important protective factor for young people's mental health [15]. Despite this, evidence suggests that those experiencing higher levels of suicidal or self-harming thoughts and behaviors are less likely to seek help for their mental health difficulties [16].

Growing use of computer-mediated technologies and web-based resources have changed the nature of help-seeking, making it possible for users to engage in help-seeking behaviors without an interpersonal component [10]. While offline resources remain an important source of help to young people, the accessibility of the Internet has created an opportunity for more sources of help and information to become available [17,18]. A study by Dooley & Fitzgerald [15] indicated that 77% of young people were likely to use the Internet to find information or support for a mental health concern. The increased role of alternative sources of help, such as YouTube, bloggers or Influencers, self-help websites and discussion forums, have to be considered [12]. There is a need to investigate how young people use the Internet as part of their help-seeking strategies and how they can be supported in these strategies.

Although many web-based information resources and interventions are available, they are of varying quality [19]. A study by Feng et al [20] found that while there are many online resources available, this does not necessarily result in user engagement or show that their use is helpful to the help-seeking process. The amount of evidence regarding the usefulness of online resources in facilitating the help-seeking process is a notable gap in the literature [21].

As with offline help-seeking, each young person has their own preferences for both online sources and preferred pathways in order to cope with their mental health difficulties and concerns [22]. Thus, the need to identify these sources and why they are attractive to young people is important. The aim of this study was to investigate and better understand the online help-seeking behaviors of young people. This was achieved through an online survey addressing several key issues, including current areas of concern, intentions to seek help, preferred online resources, credibility of online resources, and finally the current wellbeing of this sample.

Methods

Overview

Ethics approval for this research was provided by the University College Dublin Office of Research Ethics (LS-17-116-Pretorious-Coyle). All data was collected through an anonymous online survey.

Survey Development

This survey was undertaken with the support of a youth mental health charity, ReachOut Ireland, who are the sister organization of ReachOut Australia. ReachOut is a mental health service that offers online mental health resources specifically for young people, but they also run a youth participation program that ensures young people's involvement through all their work. Prior to the survey going live, it was piloted with five young people from the ReachOut Ireland youth panel to hear their thoughts on the survey and its acceptability. This survey was developed iteratively and informed by research in the area [13,17,23,24], and along with input and previous research from ReachOut Ireland [25] and the commentary from the youth panel, it was made as accessible and nonthreatening to as many young people as possible. In adhering to this input from the youth panel, the final survey did not refer specifically to symptoms such as feeling anxious or having a low mood and instead asked young people about the personal concerns that were causing them the most stress or worry. The term personal or emotional concern was selected, as the authors wanted to use nonmedicalized language throughout the survey. The concerns addressed in the survey also represent the most frequently expressed concerns on the ReachOut Ireland website.

Survey Procedure

This study made use of a survey link to direct participants to the survey. This link was made available through various online sources, such as youth mental health-related websites (ReachOut Ireland, SpunOut, and BodyWhys), and through targeted advertisements posted on Facebook and Twitter. The adverts consisted of a short title, an image, and the survey link. The Facebook and Twitter advertisements were specifically targeted to appear on the feeds of Irish users between the ages of 18 and 25. The survey was hosted on LimeSurvey on a local server. The first component of the survey consisted of the information page, which included information regarding the purposes of the study, how the data would be used, anonymity, confidentiality and data protection. Participants were then asked to provide consent and confirm that they were both between the ages of

18-25 years old and living in Ireland, if they wished to continue with the survey. Information on mental health support was provided on the landing page of the survey as well as on the survey termination page. The survey consisted of 22 questions, over 6 screens, and took between 15 and 20 minutes to complete (see Multimedia Appendix 1 for the survey questions). Multiple responses from the same user were prevented by using cookies, and no incentive was offered. Participants were permitted to skip any question they were unwilling to answer during the survey. In total, 2352 people began the survey, but a total of only 1308 participants successfully completed the entire questionnaire. Data from uncompleted surveys was not used as withdrawal from the survey indicated withdrawal of consent.

Survey Measures

The survey consisted of both quantitative and qualitative questions to assess: (1) demographics; (2) young people's technology use; (3) propensity to seek help from different sources as measured by the General Help-Seeking Questionnaire (GHSQ) [23]; (4) current personal and emotional concerns; (5) preferred online resources; (6) credibility of online resources; (7) facilitators and barriers to online help-seeking; and (8) wellbeing of participants measured by the Short Warwick–Edinburgh Mental Well-being Scale (SWEMWBS) [24].This paper will discuss findings from (2), (4), (5), (6), and (7) in detail, and findings from (3) and (8) are included under the description of the survey participants.

Data Analysis

The survey data were analyzed using IBM SPSS Statistics for Mac, Version 24, (IBM Corporation, Armonk, NY) primarily using descriptive statistics. Only completed surveys were analyzed. Open response questions were analyzed using thematic analysis [26].

Results

Survey Participants

A total of 1308 participants were examined in this study, of which 78.52% (1027/1308) were female, 18.50% (242/1308) were male, 1.68% (22/1308) were non-binary and 0.84% (11/1308) identified as transgender. The mean age of the population was 20.68 (SD 2.22), with a minimum and maximum age of 18 and 25, respectively. The survey had good national coverage, with respondents from all Irish counties. Of the whole sample, 67.13% (878/1308) reported that they were currently living in a city or town, 59.17% (774/1308) reported their current level of education to be undergraduate, and most of the sample accessed the survey link through Twitter (68.88%; 901/1308) and Facebook (24.08%; 315/1308). The results from the GHSQ were like findings from previous studies, with a very high propensity for respondents to not seek help at all (45.2%; 591/1308). Informal sources of help were preferred over formal sources. Only 18.5% (242/1308) of the sample indicated that they would be likely or extremely likely to seek help from a mental health professional, whereas 53.3% (697/1308) of the sample were likely or extremely likely to seek help from an intimate partner (see Multimedia Appendix 2). The SWEMWBS has good internal consistency, with a reported Cronbach alpha=0.84. In the current study, the Cronbach alpha=0.835. This sample mean (19.0362; SD 3.522) is one standard deviation lower than the normative group mean (23.6093; SD 3.90264). Scores on the SWEMWBS can range from 7 to 35, and higher scores on the SWEMWBS indicate higher positive mental well-being.

Young People's Technology Use

Most respondents owned a mobile phone (99.62%; 1303/1308) and a laptop or computer (92.35%; 1208/1308), with fewer owning a tablet (38.91%; 509/1308) or gaming console (34.10%; 446/1308). Mobile phones were the preferred device for using the Internet in order to look for help online (80.66%; 1055/1308), with only 32.65% (427/1308) of the sample indicating that they would use their laptop or computer. A negligible proportion of the sample used a tablet or games console to access the Internet or to look for help (see Multimedia Appendix 1).

Areas of Personal and Emotional Concern and Online Help-Seeking

The closed response questions indicated that school or college was a source of personal concern for most of the sample, with 87.08% (1139/1308) indicating that it had recently caused them stress. This was followed by concern caused by body image (73.01%; 955/1308) and exams (72.02%; 942/1308). These results are like ReachOut's previous findings, which also found exams, school and body image to be major stressors for young people [25]. Table 1 lists the other triggers of stress responded to by respondents.

In the open response section of these questions, 100 respondents provided additional data. These concerns were grouped into the following themes: mental health, work, finances, harm from others, housing, sports, identity, interpersonal difficulties, parenting, physical health, transitional challenges and societal concerns. Table 2 outlines each theme with a quote taken from the survey as an example for each.

This question was followed by a question asking whether young people had gone online to look for help for these concerns. For this question, 85.32% (1116/1308) of the sample had gone online to look for help with their stress caused by school or college, 70.41% (921/1308) had gone online to look for help with concerns over body image, and 71.25% (932/1308) had looked for help with exams. In addition, most of the respondents, 85.78% (1122/1308), had also gone online to look for help with deciding on a career.

Respondents were asked if they had ever gone online to look for help for a family member or friend. A total of 68.43% (895/1308) indicated that they had gone online to look for help or information for a friend, while 55.58% (727/1308) indicated they had searched for help for a family member.

Table 1. Areas of personal or emotional concern (N=1308). All values are listed as n (%).

Stressor	Caused significant stress (yes)	Looked online for help (yes)
School or College	1139 (87.08)	1116 (85.32)
Body Image	955 (73.01)	921 (70.41)
Exams	942 (72.02)	932 (71.25)
Family	678 (51.83)	
Money	888 (67.89)	727 (55.58)
Deciding on a career	859 (65.67)	1122 (85.78)
Relationships	830 (63.46)	838 (64.07)
Friends	808 (61.77)	763 (58.33)
Social Media	524 (40.06)	485 (37.08)
Illness of family member or friend	513 (39.22)	797 (60.93)
Local or World News	400 (30.58)	815 (62.31)
Personal Illness	370 (28.29)	858 (65.60)
Bullying	367 (28.06)	312 (23.85)
Sexuality	312 (23.85)	502 (38.40)

Table 2. Personal or emotional concerns qualitative responses.

Theme	Illustrative Quote
Mental Health	*Just mental health, specially general anxiety.* [P1011]
Finances	*Unemployment after 4 years in college.* [P1926]
Work	*Participating in a work environment, ie: an office or the service industry*. [P622]
Housing	*Living in rented accommodation- cost, relations with house mates.* [P1242]
Sports	*Competitive sport*. [P1812]
Identity	*Developing a sense of identity, trying to be the best*. [P1097]
Interpersonal Difficulties	*an ability to understand people, the fear of not accepted as a member of a group or have actual friends, fear of trust due to let downs*. [P938]
Parenting	*Being a parent.* [P203]
Physical Health	*Physical health (no diagnosed illness).* [P2109]
Transitional Challenges	*The process of finishing college and transitioning from a world where others organised so much of my life to having to find a job and be the only one with the responsibility to progress my life.* [P732]
Societal Concerns	*Guilt about seeing world atrocities such as the homelessness crisis and racism/sectarianism and not being able to do much about it.* [P376]

Young People's Preferred Online Resources

Respondents were asked which online sources they use to gain more information for personal or emotional concerns, and 82.57% (1080/1308) indicated that they would make use of an Internet search, 57.03% (746/1308) indicated that they would use a health website, and 32.26% (422/1308) indicated they would make use of a forum or discussion board. Fewer (12.16%; 159/1308) would use a mental health app or go to a social media blogger or influencer (8.18%; 107/1308). An Internet search was widely used across all gender groups, while the use of a blogger or influencer was low across all groups.

In the open response section of this question, other preferred sources of information identified by the respondents could be grouped in the following ways: formal offline source, informal offline source, formal online source and informal online source. Examples of formal online resources included SpunOut.ie and ReachOut Ireland, while informal online sources included Reddit, YouTube and Tumblr.

In the subsequent question, respondents were asked how satisfied they were with their experiences of these sources if they had used them. The previous question indicated that the most preferred online resource by young people was the Internet search, and this question indicated that 36.94% (399/1080) of respondents were satisfied or very satisfied with an Internet search. The second most used online resource was a health website, and in this question 49.33% of respondents (368/746) indicated that they were satisfied or very satisfied with this resource (Table 3).

Table 3. Levels of satisfaction with online resources. All values listed as n (%).

Resource	Not sure	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
Health website (N=746)	53 (7.1)	4 (0.54)	74 (9.92)	247 (33.11)	344 (46.11)	24 (3.22)
Mental health app (N=159)	19 (11.95)	4 (2.52)	22 (13.84)	55 (34.59)	52 (32.7)	7 (4.4)
Internet search (N=1080)	104 (9.63)	12 (1.11)	125 (11.57)	440 (40.74)	370 (34.26)	29 (2.69)
Influencer or blogger (N=107)	9 (8.41)	3 (2.8)	2 (1.87)	31 (28.97)	50 (46.72)	12 (11.21)
Forums or discussion board (N=422)	21 (4.97)	3 (0.71)	34 (8.06)	186 (44.08)	155 (36.73)	23 (5.45)
Websites already used (N=136)	10 (7.35)	2 (1.47)	17 (12.5)	62 (45.59)	38 (27.94)	7 (5.15)

Credibility of Online Sources

Respondents were also asked how they would rate the trustworthiness of the above online resources. Health websites were found to be the most trustworthy, with 39.45% (516/1308) of respondents indicating that they found them trustworthy or very trustworthy. Respondents did not rate an Internet search as very trustworthy, with 47.09% (616/1308) saying that it was not trustworthy or only slightly trustworthy. Overall, none of the online sources listed were rated as trustworthy or very trustworthy by a majority of the respondents (Table 4). Following on from this question, respondents were asked which elements of an online resource would make it more credible. The vast majority (82.95%; 1085/1308) indicated that a health service logo was an important indicator of credibility, but an endorsement by schools and colleges (54.97%; 719/1308) or the presence of another government logo (57.57%; 753/1308) also played important roles (Table 5). Many respondents, specifically 80.43% (1052/1308), indicated that references to scientific data and authors were a key indicator of credibility in an online resource.

These indicators were followed by an open response question that asked, “Is there anything not listed above that makes an online resource trustworthy/reliable?”. In this section, respondents indicated that online security was important, citing elements such as the green padlock in the Internet browser as well as the lack of ads on webpages. Other themes identified in this open response section included: written or informed by a reputable person or organization, links to local support services, grounded in research, design and layout, quality of content, the ability to rank or comment on content, and the ability to contact someone directly through the source. Participants also mentioned cross-checking sources with other sources to ensure reliability and credibility of that source, as stated by one participant:

> *If its consistent with other online resources. If 3 or 4 sites say the same thing, they I begin to trust it.*

Table 4. Trustworthiness of online resources (N=1308). All values listed as n (%).

Resource	Not trustworthy	Slightly trustworthy	It’s OK	Trustworthy	Very trustworthy	Don’t know
Health website	21 (1.61)	247 (18.88)	441 (33.72)	423 (32.34)	93 (7.11)	83 (6.35)
Mental health app	19 (1.45)	135 (10.32)	302 (23.09)	295 (22.55)	43 (3.29)	514 (39.30)
Internet search	163 (12.46)	453 (34.71)	482 (36.85)	123 (9.40)	3 (0.23)	84 (6.42)
Influencer or blogger	466 (35.63)	311 (23.78)	137 (10.47)	71 (5.43)	9 (0.69)	314 (24.01)
Forums or discussion board	222 (16.97)	395 (30.20)	285 (21.79)	126 (9.63)	13 (0.99)	267 (20.41)
Website already used	422 (32.26)	295 (22.55)	172 (13.15)	69 (5.28)	2 (0.15%)	348 (26.22)

Table 5. Elements that indicate credibility (N=1308). All values are listed as n (%).

Element	Disagree	Not sure	Agree
Links to social media	698 (53.36)	480 (36.70)	130 (9.94)
Government logo	254 (19.42)	301 (23.01)	753 (57.57)
Health service logo	82 (6.27)	141 (10.78)	1085 (82.95)
Good design and layout	434 (33.18)	334 (25.6)	540 (41.3)
Top of Google search results	460 (35.2)	331 (25.54)	517 (39.53)
College or school endorsement	190 (14.53)	399 (30.50)	719 (54.97)
References to scientific data and authors	64 (4.89)	192 (14.68)	1052 (80.43)
A quiz or assessment	618 (47.25)	474 (36.24)	216 (16.51)
Contains personal stories or experiences	177 (13.53)	433 (33.10)	698 (53.36)

Another participant suggested that sources could make this cross-checking process easier by providing hyperlinks to related work.

Facilitators and Barriers to Seeking Help Online

Respondents were asked which factors would encourage them to seek help online if they were facing a personal or emotional concern (Table 6). Young people affirmed that the anonymity and confidentiality offered by the Internet was an important motivating factor when deciding to search for help online, with 80% (1046/1308) of the sample indicating that it influenced their decision a lot or quite a lot. Similarly, the low monetary cost of using the Internet was also an important motivator in selecting the Internet, with 84.41% (1104/1308) indicating it encouraged them to seek help online a lot or quite a lot. Some of the important barriers highlighted by young people included being unsure if information was reliable, as well as wanting to solve problems on their own (Table 7). Even though the Internet offers more anonymity than offline pathways, young people are still concerned about others finding out that they are experiencing a difficulty.

In the open response section, respondents were asked "Is there anything not listed above that would encourage you to seek help online for a personal or emotional concern?". A total of 124 respondents provided answers. These answers were grouped together in themes, including anonymity, reduced stigma, validation of experiences, current situation in the health service and ease of access (Table 8). Respondents also highlighted barriers to online help-seeking in this space, such as the cost of some online services, lack of surety of credibility of some online resources, not being able to find personalized information, and a lack of mental health literacy which impacted their ability to find the right online resource (Table 8).

Table 6. Facilitators to online help-seeking (N=1308).

Facilitator	Mean (SD)	Not at all, n (%)	A little, n (%)	A lot, n (%)	Quite a lot, n (%)
It's free	3.31 (0.81)	43 (3.29)	160 (12.23)	452 (34.56)	652 (49.85)
Anonymous and confidential	3.26 (0.89)	67 (5.12)	195 (14.91)	378 (28.90)	668 (51.07)
Can take it at own pace	3.16 (0.82)	47 (3.59)	205 (15.67)	547 (41.82)	509 (38.91)
Abundance of information	3.12 (0.80)	38 (2.91)	231 (17.66)	574 (43.88)	465 (35.55)
Others like me	3.10 (0.91)	74 (5.66)	257 (19.65)	437 (33.41)	540 (41.28)
Access any time of day	3.01 (0.88)	63 (4.82)	305 (23.32)	494 (37.77)	446 (34.10)
Unsure if I'm unwell enough	2.75 (1.09)	230 (17.58)	291 (22.25)	367 (28.06)	420 (32.11)
Too unwell to reach local support services	2.20 (1.04)	409 (31.27)	421 (32.19)	281 (21.48)	197 (15.06)
There are no other options available	2.13 (1.04)	447 (34.17)	436 (33.33)	238 (18.20)	187 (14.30)

Table 7. Barriers to online help-seeking (N=1308).

Barrier	Mean (SD)	Not at all, n (%)	A little, n (%)	A lot, n (%)	Quite a lot, n (%)
Unsure if information is reliable	2.70 (0.91)	111 (8.49)	465 (35.55)	440 (33.64)	292 (22.32)
Solve problems on my own	2.58 (1.09)	277 (21.18)	342 (26.15)	344 (26.30)	345 (26.38)
Concerns others might find out	2.36 (1.17)	417 (31.88)	329 (25.15)	230 (17.58)	332 (25.38)
Thinking I don't have a problem	2.34 (1.04)	324 (24.77)	446 (34.10)	307 (23.47)	231 (17.66)
Unsure what to search for	2.13 (0.92)	348 (26.61)	570 (43.58)	261 (19.95)	129 (9.86)
Not sure of my privacy and anonymity	2.10 (1.05)	472 (36.09)	416 (31.80)	235 (17.97)	185 (14.14)
Prefer alternative forms of help	1.88 (0.94)	555 (42.43)	453 (34.63)	197 (15.06)	103 (7.87)
Having no one help navigate options	1.84 (0.97)	630) 48.17%	365 (27.91)	205 (15.67)	108 (8.26)
Being too unwell to look for help	1.73 (0.94)	703 (53.75)	351 (26.83)	155 (11.85)	99 (7.59)
Having previous bad experiences	1.61 (0.88)	786 (60.09)	320 (24.46)	125 (9.56)	77 (5.89)

Table 8. Qualitative responses indicating facilitators and barriers to online help-seeking.

Theme	Quote
Facilitators	
Affordability	*Not having enough money to afford counselling in person.* [P889]
Anonymity	*Some issues can feel embarrassing to talk about. The anonymity online cancels this out.* [P617]
Ease of Access	*Its mostly just the speed of it that helps me out. In my case I can find so much info. on social anxiety with just one click rather than driving 30 minutes from my college to speak to the college counsellor.* [P1412]
Validation of Experience	*Thinking that you are making up the illness in your head and that it isn't real and you are putting it on for attention.* [P1018]
Reduced Stigma	*I often go online because I know there is something wrong, but I don't want to tell anyone in my real life for fear that they will judge me or they won't care and ill just be bothering them. Online help can help me deal with my problem alone so I will not have to tell anyone.* [P470]
Privacy	*It provides a level of privacy and I feel like I can control my own feelings.* [P392]
Response to negative life events	*A huge trauma maybe.* [P33]
Barriers	
Affordability	*Hard to find a free option for when times are really bad.* [P1401]
Lack of personalization	*It's not personal: all the information out there already exists and is not tailored for me.* [P132]
Lack of mental health literacy	*Being unsure what to search/look for online instead of searching for hours for a website that I am comfortable with.* [P242]
Unsure of credibility	*Something to reassure me that the content I am viewing is reliable and trustworthy and having a person to discuss issues with.* [P863]

Discussion

Primary Findings

The results of this survey clearly indicate that the Internet plays a major role in the help-seeking process for young people. The survey has highlighted that young people are already going online to look for help for issues that are causing them distress, and they are engaging with different online sources for their help-seeking needs. Given the proportion of young people who encounter mental health difficulties and turn to the Internet to meet some of their mental health needs, it is important that researchers and service providers have an accurate and holistic understanding of what these needs encompass.

Help-seeking is a complicated process, and young people use different online mental health resources based on their needs. Rickwood's model [27] of help-seeking refers to 4 stages of help-seeking: (1) becoming aware of and appraising the problem; (2) expressing the need for support; (3) knowledge of available and accessible sources of help; and (4) being willing to disclose personal information. This model acknowledges that there are several barriers that may impede help-seeking at any stage. It can be hypothesized that different online mental health resources are used at different stages of this process. Most of the sample, 82.6%, indicated that they would make use of an Internet search to locate information when experiencing a personal or emotional difficulty. The Internet search could be conceptualized as playing a role in both the expression and availability stages of the process. However, only 37% of the sample indicated that they were satisfied with this mode of finding help. This could indicate that the Internet search is being used due to its easily accessible nature and the anonymity it offers, but this appears insufficient to meet the mental health needs of the present sample. For these reasons, it is possible that an Internet search could act as both a facilitator and a barrier to further help-seeking.

Like findings in a study by Reavley, Cvetkovski & Jorm [22], health websites and discussion boards or forums seem to play an important role in meeting young people's mental health needs, which may be due to varied reasons. A health website is likely to provide more accurate information substantiated by research and written by subject experts, while forums allow users to engage with peers who are like them and have lived their same experiences. Comparably, a study by Lal, Nguyen & Theriault [28] indicated that young people value resources that allow them to access the personal stories of peers with lived experiences, which gives them the opportunity to process the information at their own pace. The current study found that other popular online resources include formal youth mental health websites, such as ReachOut Ireland, and informal sites such as YouTube. It is worth noting that these sources are likely to change with time and new or other platforms grow in popularity.

Young people are often described as digital natives [29]. This includes the assumption that young people can effectively identify and locate credible resources in the online space [30]. A study by Montagni et al [31] found that half of their sample trusted what they found on the Internet, but their sample identified one of the disadvantages of using the Internet was its unreliability. This survey also indicates that assigning online credibility can be confusing, but young people have developed different strategies to determine the reliability of an online resource. Some of these strategies include checking multiple sources and cross-checking information. The results from this survey have shown endorsements from reputable and known

government bodies and educational institutions can play an important role in helping young people to identify credible and reliable online resources. It is evident, though, that the sources young people were surveyed on, apart from health websites, are not deemed to be very credible or reliable. This disparity between a plethora of online sources being available and their perceived lack of credibility could have a jarring effect on the help-seeking process of the young person, so this needs to be investigated.

There are a multitude of facilitators and barriers associated with online help-seeking. Many studies have found that the ease of access of the Internet plays an important role in helping young people, a finding that this study supports [24,32-34]. Particularly, a study by Birnbaum et al [35], highlighted that the Internet plays an important role in early intervention and in young people's further help-seeking. Young people are drawn to the Internet because of the wealth of free resources available, but further help-seeking, such as talking to a professional, may be too costly for this demographic. A systematic review by Kauer, Mangan & Sanci [21] confirmed that online help-seeking is attractive to many young people because of its confidentiality and anonymity. This survey found that concerns about anonymity and privacy remain, and although it seems that the anonymity offered by the Internet does go a long way in circumventing the stigma associated with mental health help-seeking, young people are still concerned about others finding out. It may be for this reason that many of the sample indicated that they would use their mobile phone to search for help online.

Limitations

The survey findings were based on self-reported data from the respondents, so the results might not be generalizable. Given that recruitment of participants happened through online platforms, this sample is limited to young people who access Facebook, Twitter and other charity websites. Thus, this survey may not have captured the views of help-seekers who access alternative resources on the Internet. Future studies should include alternative recruitment strategies targeting those who are less likely to seek help, particularly men, and help-seekers who may not access mainstream social media platforms or charity websites. In addition, a large majority of the participants were female and undergraduate students, which also limits the generalizability of the results. This survey focused on emotional concerns that cause participants significant distress for which they might go online to look for help but did not ask about searches for symptoms such as feeling depressed or feeling anxious. Thus, it cannot comment on the types of mental health symptoms participants might seek help for online. This should be taken into consideration in future work. Finally, the list of online resources offered was not extensive, so future studies should further investigate both the preferences between online and offline sources and whether there are potential differences between preferences for informal and formal online resources.

Conclusion

The findings of this study indicate that young people are engaging in help-seeking behavior online to look for help for personal and emotional concerns that are causing them distress. Levels of satisfaction regarding different online resources are varied, so web-based mental health resources need to ensure that they meet the needs of online help-seekers in providing support. Young people have established strategies to assign credibility online, however, the availability of credible, online resources needs to be addressed. Steps should also be taken to help governmental organizations and educational bodies identify and support trustworthy and reliable online resources. Finally, as with traditional offline help-seeking, several barriers exist to deter help-seeking; however, the Internet circumvents some of these through its offering of privacy and confidentiality.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey Questions.
[PDF File (Adobe PDF File), 4MB - mental_v6i8e13524_app1.pdf]

Multimedia Appendix 2
Additional Tables.
[PDF File (Adobe PDF File), 89KB - mental_v6i8e13524_app2.pdf]

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Abbreviations

GHSQ: General Help-Seeking Questionnaire
SWEMWBS: Short Warwick–Edinburgh Mental Well-being Scale

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