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Original Paper

Complaint-Directed Mini-Interventions for Depressive Complaints: A Randomized Controlled Trial of Unguided Web-Based Self-Help Interventions

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Abstract

Background: Prevention of depression is important due to the substantial burden of disease associated with it. To this end, we developed a novel, brief, and low-threshold Web-based self-help approach for depressive complaints called complaint-directed mini-interventions (CDMIs). These CDMIs focus on highly prevalent complaints that are demonstrably associated with depression and have a substantial economic impact: stress, sleep problems, and worry.

Objective: The aim was to evaluate the effectiveness of the Web-based self-help CDMIs in a sample of adults with mild-to-moderate depressive symptoms compared to a wait-list control group.

Methods: A two-armed randomized controlled trial was conducted. An open recruitment strategy was used. Participants were randomized to either the Web-based CDMIs or the no-intervention wait-list control group. The CDMIs are online, unguided, self-help interventions, largely based on cognitive behavioral techniques, which consist of 3 to 4 modules with up to 6 exercises per module. Participants are free to choose between the modules and exercises. Assessments, using self-report questionnaires, took place at baseline and at 3 and 6 months after baseline. The control group was given access to the intervention following the 3-month assessment. The primary goal of the CDMIs is to reduce depressive complaints. The primary outcome of the study was a reduction in depressive complaints as measured by the Inventory of Depressive Symptomatology Self-Report (IDS-SR). Secondary outcomes included reductions in stress, worry, sleep problems, and anxiety complaints, and improvements in well-being. Data were analyzed using linear mixed models.

Results: In total, 329 participants enrolled in the trial, of which 165 were randomized to the intervention group and 164 to the control group. Approximately three-quarters of the intervention group actually created an account. Of these participants, 91.3% (116/127) logged into their chosen CDMI at least once during the 3-month intervention period (median 3, range 0-166). After 3 months, there was a significant reduction in depressive symptomatology for participants in the intervention group compared to participants in the wait-list control group (reduction in depression: mean –4.47, 95% CI –6.54 to –2.40; Cohen *d*=–0.70). Furthermore, significant effects were observed for sleep problems, worry, anxiety, and well-being, with effect sizes ranging from –0.29 to –0.40. The intervention did not significantly reduce stress. At 6-month follow-up, the improvements in the intervention group were generally sustained.

Conclusions: This study shows that the online self-help CDMIs have a positive impact on various mental health outcomes. Future research should focus on which specific strategies may boost adherence, and increase the reach of the CDMIs among people with low socioeconomic status.

ClinicalTrial: Netherlands Trial Register (NTR): NTR4612; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=4612 (Archived by WebCite at http://www.webcitation.org/6n4PVYddM)

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KEYWORDS

prevention; depression; Internet-based intervention; randomized controlled trial

Introduction

Depressive disorders are highly prevalent and are estimated to affect approximately 350 million people worldwide [1-3]. Depression is among the leading causes of disease burden globally [4]. Depression is also associated with substantial societal costs, with depression-related costs in Europe estimated at €92 billion annually [5].

Currently available effective pharmacological and psychological treatments only moderately reduce the enormous burden of disease associated with depression [6,7]. Therefore, interest in approaches to prevent depressive disorders has been growing. Meta-analytic studies indicate that preventive interventions can be effective in reducing the incidence rate of depressive disorders [8-10]. Moreover, depression prevention appears to be cost-effective and may even be cost-saving from a societal perspective [11,12].

However, the reach of preventive mental health interventions is far from optimal, particularly in the population with low socioeconomic status (SES), among whom the incidence and prevalence rates of depression are especially high [13-15]. In the Netherlands, for example, the lifetime prevalence of depression in the low SES population is 21.4% compared to 15.2% in the population with high SES [16]. There is a need for preventive interventions that can easily be implemented with limited costs and are suitable for a broad range of target populations. This has led to the development of the complaint-directed mini-interventions (CDMIs). These brief and low-threshold interventions focus on highly prevalent complaints that are demonstrably associated with depression, have a substantial economic impact, and are also frequently presented to the general practitioner (GP): psychological stress, sleep problems, and worry [17-21].

In line with recent symptom-network and transdiagnostic approaches to mental disorders [22-24], the unique feature of the CDMIs as an approach for depression is that they were developed by taking into account that symptoms preceding or underlying depression may not be disorder-specific (eg, worry) and may also vary by individual. Therefore, they are oriented toward complaints (symptoms) rather than disorders, thus allowing each individual to choose the complaint(s) they want to focus on.

In addition, CDMI participants are also free to choose which modules and exercises they want to do and in what order, rather than having to adhere to a fixed set of modules that are offered in a sequential manner. This latter feature of the CDMIs, which allows users to choose, has been employed in other online interventions [25,26]. Possible advantages are more user satisfaction and insight into which individual modules are of most use to users of the intervention.

The CDMIs were initially developed as group interventions and preliminary findings of a pilot study with a single-group pre-post design showed reductions in symptoms of depression, sleep, stress, and worry [27]. Importantly, interest in the CDMIs was high as evidenced by the rapid recruitment of participants into the pilot study. These findings prompted the development of an unguided Web-based self-help version of the CDMIs, with the potential to reach a large number of people at low cost. Previous findings show that online self-help interventions for depression and depressive symptoms can be effective [28]. Although guided interventions generally show larger effect sizes and adherence rates than unguided interventions [29-31], we expected the preference-based and low-threshold nature of the CDMIs to be a novel and potentially effective approach for depressive symptoms.

The primary aim of this trial was to evaluate the effectiveness of the Web-based unguided self-help CDMIs in a sample of adults with mild-to-moderate depressive symptomatology compared to a wait-list control group. We hypothesized a greater reduction in depressive complaints for the participants using the online CDMIs. A secondary aim was to evaluate the effects of the CDMIs on stress, worry, sleep, anxiety, and well-being.

Methods

Design

A two-armed randomized controlled trial (RCT) was conducted that compared the effectiveness of the Web-based CDMIs with a no-intervention wait-listed control group that had unlimited access to usual care. Participants were assessed at three time points: at baseline and at 3- and 6-month follow-ups. The trial is reported in accordance with the CONSORT-EHEALTH checklist V1.6.1 (see Multimedia Appendix 1). The Medical Ethics Committee of the University Medical Center Utrecht approved the study protocol in 2014, and the trial was registered at the Netherlands Trial Register on May 27, 2014 (No: NTR4612).

Eligibility Criteria

Participants were eligible for participation if they were adults (≥18 years), had access to a computer with an Internet connection, sufficient proficiency of the Dutch language, adequate computer skills to participate in the training, and

mild-to-moderate depressive symptoms defined as a score of 14 to 38 on the Inventory of Depressive Symptomatology Self-Report (IDS-SR) [32,33]. These IDS-SR cut-off scores imply that the CDMIs in this study were used for, at least but not limited to, an indicated preventive purpose. Suicidal thoughts or plans, as measured with item 18 of the IDS-SR, were a reason for exclusion (a score of >1 was used; initially a score of >0 was used, but this was deemed too strict). If participants indicated they had suicidal thoughts or plans, they were advised to contact their GP or an anonymous online platform for people with suicidal thoughts or behaviors (113Online [34]).

Recruitment and Procedures

Participants were recruited from June 2014 to January 2015 via open recruitment (ie, through relevant websites, messages on social media, and messages in digital newsletters of the Trimbos Institute). People interested in participation were referred to a special study website where they were given more information about the study and could register to take part in the study by completing a written or an online informed consent form including their name and email address. Once informed consent was given, the eligibility criteria were assessed. Applicants were requested to complete the first part of the self-report online baseline questionnaire, which acted as a screening instrument and consisted of the IDS-SR and questions about age, Internet access, and computer skills. People who did not fulfill the inclusion criteria were informed during or immediately after completing the first part of the baseline questionnaire and the reason for exclusion was provided.

Eligible participants received the second part of the online baseline questionnaire. To be randomized, the applicants were required to complete the entire baseline questionnaire. To be able to conduct the stratified block randomization, applicants were asked which CDMI they would want to take part in ("sleep better," "stress less," or "worry less"). Randomization to the intervention group or control group occurred automatically using a 1:1 ratio. Directly after randomization, participants allocated to the experimental condition received an email with an activation code for creating an online account that gave them access to the CDMI of their choice. The account was valid for one year. Participants in the control condition were sent an email with the outcome of the randomization, including the message that the CDMI would become accessible to them after 3 months.

Intervention

The CDMIs are Web-based self-help interventions without therapist guidance [35], developed by the Trimbos Institute, a nonprofit organization. There are three different CDMIs: "sleep better," "stress less," and "worry less." The CDMIs target people with mild-to-moderate symptoms of depression who experience problems with sleep, stress, or worry. In the interventions, users learn to better understand and deal with the problem of their choice. In fact, a unique feature of the CDMIs as an approach for depressive symptoms is that they were developed taking into account that symptoms of depression or a developing depression vary by individual. Therefore, they are complaint-focused rather than disorder-focused, thus participants can choose the CDMI they want to use based on their personal needs and do not have to use CDMIs that are not relevant to their situation. The primary goal of the CDMIs is to reduce or prevent depressive complaints. Secondary goals are to reduce sleep problems, stress, or worry.

The content of the CDMIs is largely based on cognitive behavioral techniques and incorporates elements from solution-focused therapy, mindfulness, and positive psychology. The CDMIs are made up of three to four modules, each module consisting of four to six exercises. Some modules are relevant for sleep, stress, and worry and are, therefore, part of all three CDMIs (eg, the module "relaxation"). Fixed elements in every CDMI are a home page, a diary, a list with the user's favorite exercises, an exercise book, a to-do list, and a library. A more detailed account of the CDMIs (including screenshots) can be found in Multimedia Appendix 2. To gain access to the CDMIs, an account had to be created by entering a username and email address. Users were free to choose between the modules and exercises and could work independently through the CDMI, without supervision. The advised amount of time to spend on the CDMI was 2 to 3 hours a week for a period of at least 4 weeks.

In case any assistance was needed during the study, a contact form on the website of the CDMIs could be used or participants in the study could email or call one of the researchers. Participants were allowed to use any other type of care in addition to the online CDMIs.

Control Group

Participants in the control group were placed on a waiting list and received access to the online CDMI of their choice after 3 months (following the 3-month postbaseline assessment). The wait-listed participants were aware of this procedure. Participants in the control group were also free to use any other types of care.

Outcomes

Measurements

Participants received an email with a personal link to the online questionnaires at baseline (T0) and at 3 and 6 months after baseline (T1 and T2). At every assessment, up to three reminder emails were sent and a reminder phone call was made in case participants did not complete the survey. If there was an indication of suicidal thoughts or plans during the measurement at T1 or T2, these participants were given the same recommendation as at baseline, namely to contact their GP or an anonymous online platform for people with suicidal thoughts or behaviors (113Online [34]). After completion of the questionnaire at T1, the participants in the control condition gained access to the CDMIs provided that they had no suicidal thoughts or plans and no severe depressive symptoms (ie, score >39 on the IDS-SR) as measured at the 3-month postbaseline assessment. Six months after baseline there was an additional assessment (T2) to ascertain whether the effects of the CDMIs were sustained in the experimental condition and to obtain a postintervention measurement in the control condition. The primary and secondary outcomes were assessed at each measurement point.

Primary Outcome

The primary outcome of the study was depressive symptomatology as measured by the IDS-SR [32,33]. The IDS-SR consists of 30 items relating to the last 7 days that cover nine diagnostic symptom domains used to characterize a major depressive episode as well as items to define melancholic and atypical symptom features, commonly associated symptoms (eg, irritability, anxiety), and features of endogenous symptoms defined by the Research Diagnostic Criteria [36]. Items are scored on a four-point Likert scale and can be summed to obtain a total score. Scores range from zero to 84, with higher scores indicating greater depressive symptom severity.

Secondary Outcomes

Secondary outcomes consisted of the complaints targeted by the CDMIs and additional psychological outcomes, namely sleep problems, stress, worry, anxiety symptoms, and well-being.

To determine the frequency of sleep problems, the Jenkins Sleep Evaluation Questionnaire (JSEQ) was used [37].This questionnaire assesses the frequency of sleep problems in the past month and has been shown to have good internal consistency [27,37]. It consists of four items that are rated on a six-point scale (0=not at all; 5=22-31 days). To obtain a total score, the items are summed. Hence, the range of the total score is zero to 20, with higher scores representing greater sleep disturbance.

Stress was evaluated with the Perceived Stress Scale (PSS-10) [38]. The PSS consists of 10 questions and measures the degree to which situations in one's life are appraised as stressful. People are asked to rate on a scale of zero to four (0=never; 4=very often) how often they experienced specific feelings and thoughts during the last month. Scores are summed to produce a total score ranging from zero to 40, with higher scores indicating more stress. Internal consistency has been found to be good (Cronbach alpha range .78-.90) [27,39].

The Penn State Worry Questionnaire (PSWQ) was used to assess the intensity, excessiveness, and uncontrollability of worry [40]. This version consists of 11 items. Respondents can indicate to what degree each item applies to them by giving a score on a five-point Likert scale (1=not at all typical of me; 5=very typical of me). A total score is computed by summing all items (range 11-55), with higher scores indicating a stronger tendency to worry. This instrument shows good psychometric properties including Cronbach alpha as high as .93 [40-43].

For assessing the severity of anxiety symptoms, the Generalized Anxiety Disorder Scale (GAD-7) was used [44,45]. Respondents are asked to rate seven items over the last 2 weeks on a four-point scale (0=not at all sure; 4=nearly every day). The sum of the seven items represents the total score (range 0-28), with higher scores defining a higher level of anxiety severity. Internal validity is good (Cronbach alpha range .88-.92) [27,45].

Well-being was measured with the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) [46]. All 14 items of this scale are positively worded, cover topics of positive mental health, and show good reliability [27,47]. Items are scored on a five-point Likert scale and summed to obtain a total score, which ranges from 14 to 70. Higher scores indicate a higher state of well-being.

Covariates and Illness Characteristics

Demographic variables were assessed at baseline. Data on age (in years), gender (male/female), living arrangements (single/living together), educational level (low/high), work status (paid/unpaid), and gross wage (more/less than €2618, the average monthly Dutch income for 2014) were obtained. Duration of complaints was assessed with an item using a five-point scale asking "how long have the complaints been present?" and dichotomized into less than 1 year (0=a few weeks; 1=a few months; 2=6 months to a year) or 1 year or longer (3=approximately one year; 4=more than one year). Severity of complaints was assessed by an item asking participants to rate their experienced symptom severity level on a five-point scale. Severity of complaints was merged into two categories: low severity (0=not or 1=rather severe) and high severity (2=severe, 3=more than severe, or 4=very severe).

Use of and Satisfaction With Intervention

At the 3-month assessment (T1), the participants in the intervention group were asked to rate 15 statements covering satisfaction with the content, effects, usefulness, and overall satisfaction with the CDMIs. Suggestions for improving the intervention were also elicited. Items were rated on a five-point scale (1=completely disagree; 5=completely agree). An example of an item is "The intervention helped me deal with my complaints." Overall satisfaction with the intervention was rated on a scale one to 10 (1=not at all satisfied; 10=very satisfied). Furthermore, participants were asked to estimate the number of minutes that they spent, on average, using the intervention during the 3-month intervention period. For the control group, the satisfaction and use questions were incorporated in the 6-month assessment because they gained access to the CDMI following the T1 assessment. In addition, user logs were used to determine the number of log-ins per participant.

Sample Size

Based on Lipsey and Wilson [48], we aimed to detect a standardized effect size (Cohen *d*) of at least 0.33, which corresponds to the lower bound of a medium effect size. To achieve this effect size of 0.33 with a power of 0.80 and a two-tailed test with alpha of .05, a sample size of 146 participants per condition was needed, thus 292 participants in total. The sample size was calculated prior to the start of the study using Stata version 12.1.

Randomization

To guarantee an even distribution of participants with different complaints and education level across the two study conditions, stratified block randomization was used. The block randomization was conducted in a block size of six, stratified by two blocks for level of education (low, high) and three blocks for the preferred type of CDMI intervention (stress, sleep problems, or worry). A computer-generated random allocation sequence was obtained using RANDOM.ORG, which was performed and handled by an independent researcher outside of the research team.

Blinding

The participants could not be blinded because they needed to be informed about whether they could start immediately after randomization or after 3 months.

Statistical Analysis

Descriptive statistics were used to describe the characteristics of the study sample at baseline. Attrition analysis was conducted by comparing demographic characteristics and primary and secondary outcome variables of the participants who completed the questionnaire at T1 with those who did not complete the T1 assessment. For this purpose, differences between the groups were tested using independent *t* tests and chi-square statistics.

Analyses of the effectiveness of the CDMIs were carried out according to the intention-to-treat principle. Linear mixed models were used to estimate the effects of the CDMIs on the primary and secondary outcomes. This technique allows for the correlation between longitudinal data and uses all available data points, thus not discarding cases due to a missing value. Missing values are accounted for using the maximum likelihood method to estimate coefficients. A random intercept was fitted with an identity covariance structure. Time was defined as the within-group factor and the study condition (CDMI or wait-list) as the between-groups factor. The mean difference in the outcomes between the study conditions over time is expressed by the condition×time interaction.

The 6-month follow-up data were analyzed separately for the intervention and control group (ie, only within-group changes analyzed) because the control group had gained access to the CDMI intervention by that time. Growth curves were examined to determine whether any effects in the intervention group remained or increased at 6 months (ie, no significant decrease in effect between T1 and T2) and whether effects increased in the control group after the 3-month follow-up (ie, significant increase in effect between T1 and T2). An exploratory analysis was undertaken into the relationship between intervention use (number of log-ins) and effectiveness within the intervention group during the 6-month intervention period. To this end, the interaction between use and time was tested in a linear mixed model.

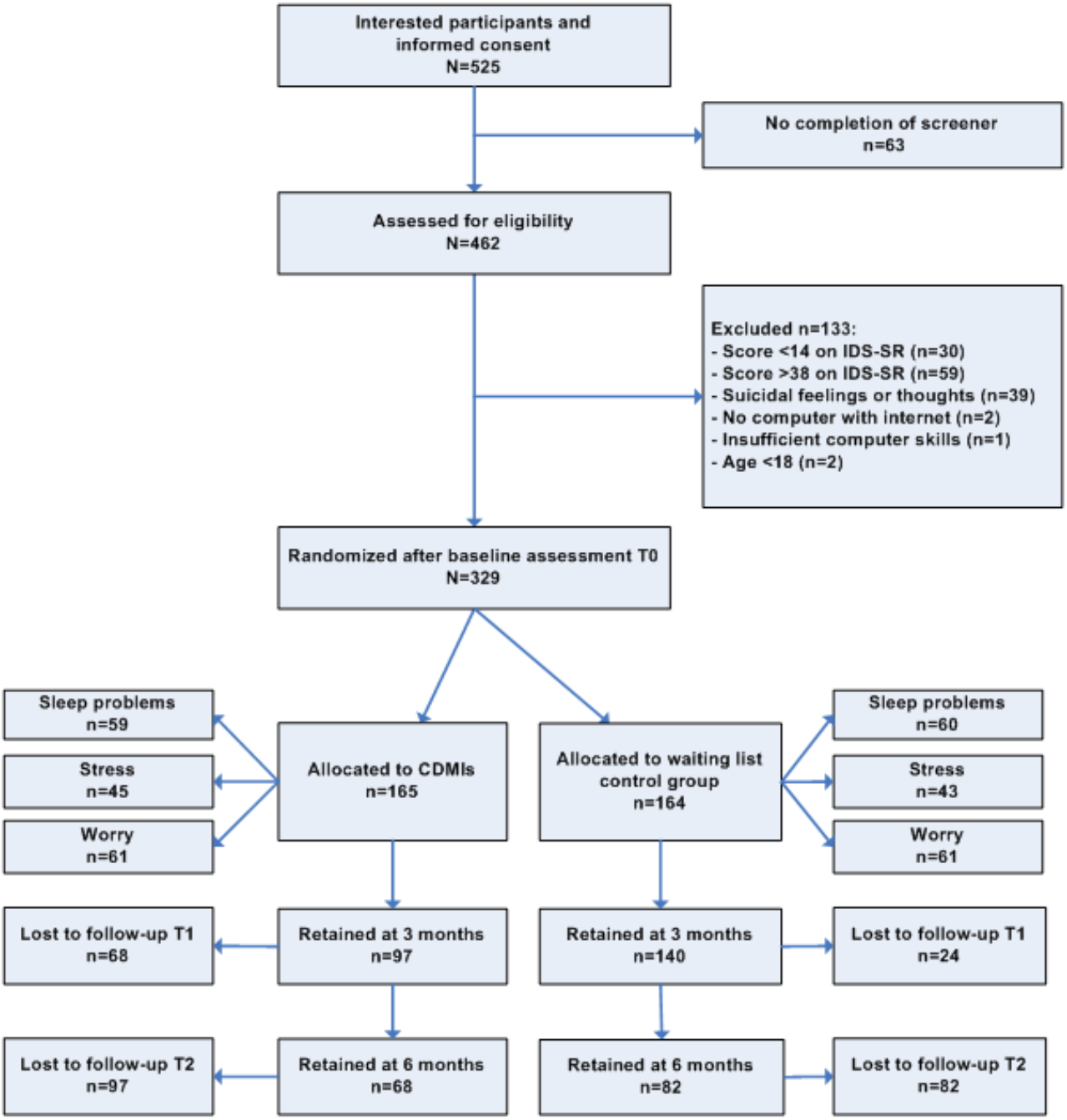
All analyses were adjusted for baseline demographic factors (age, gender, living arrangement, and education level). Adjustments were also made for factors that were related to dropout as indicated by the attrition analysis. Standardized effect sizes (Cohen *d*) were calculated using the estimated (adjusted) mean differences of the outcomes from the linear mixed models divided by the pooled standard deviation of the outcomes at baseline. Analyses were performed using SPSS version 22 and Stata version 12.1 statistical software packages.

Results

Recruitment of Participants

In total, 525 people showed interest in the study by giving their informed consent. These individuals were invited to complete the first (screening) part of the baseline questionnaire. Sixty-three people did not complete the baseline questionnaire and were excluded from the study. Another 133 people did not meet the inclusion criteria, primarily because of too few or too many depressive symptoms or because of the presence of suicidal thoughts or behaviors. This resulted in a study population of 329 participants, of which 165 were randomized to the experimental condition and 164 to the control condition. Of the 165 participants in the experimental condition, 59 participated in the sleep CDMI, 45 participated in the stress CDMI, and 61 participated in the worry CDMI. Figure 1 shows the flow of participants during the trial.

Figure 1. Flowchart of participants. CDMI: complaint-directed mini-intervention; IDS-SR: Inventory of Depressive Symptomatology Self-Report.



Baseline Characteristics

Table 1 shows an overview of the baseline characteristics of the participants. The participants had a mean age of 43 (SD 12.93, range 18-81) years and the majority were female (75.7%, 249/329). More than 98% (323/329) had Dutch nationality, and a majority had a paid job (70.8%, 233/329), a high education level (72.0%, 237/329), and a high income (70.2%, 231/329). Participants in the control condition rated the experienced severity of their complaints as high less often (49.4%, 81/164) than the participants in the intervention condition (58.8%, 97/165).

Table 1. Baseline characteristics of the participants in the complaint-directed mini-intervention (CDMI) and control groups (N=329).

Characteristic	CDMI (n=165)	Control (n=164)
Age (years)		
Mean (SD)	42.85 (12.83)	43.65 (13.05)
Range	18-76	18-81
Gender, n (%)		
Female	122 (73.9)	127 (77.4)
Male	43 (26.1)	37 (22.6)
Marital status, n (%)		
Single	83 (50.3)	84 (51.2)
Living with partner	82 (49.7)	80 (48.8)
Nationality, n (%)		
Dutch	2 (1.8)	4 (2.4)
Other	163 (98.2)	160 (97.6)
Living arrangement, n (%)		
Alone	40 (24.2)	39 (23.8)
With others	125 (75.8)	125 (76.2)
Education, n (%)		
Low	47 (27.4)	45 (28.5)
High	118 (72.6)	119 (71.5)
Income, n (%)		
Low	50 (30.3)	48 (29.3)
High	115 (69.7)	116 (70.7)
Employment, n (%)		
Paid	116 (70.3)	117 (71.3)
No paid	49 (29.7)	47 (28.7)
Duration complaints, n (%)		
<1 year	59 (35.8)	63 (38.4)
≥1 year	106 (64.2)	101 (61.6)
Severity complaints, n (%)		
Low	68 (41.2)	83 (50.6)
High	97 (58.8)	81 (49.4)

Attrition

At T1, data were available for 237 participants (dropout rate 28.0%, 92/329). The loss of participants at T1 was significantly higher in the experimental condition (41.2%, 68/165) compared to the control condition (14.6%, 24/164; χ^2_1=28.8, P<.001). Analysis of baseline factors showed there was a significant association between baseline anxiety scores and attrition. The mean score on the GAD-7 at T0 was 1.2 points lower in participants who completed the T1 assessment as compared to those who did not (t_{327}=–2.45, P=.02). Consequently, we adjusted for this variable in all analyses. Ten participants indicated suicidal thoughts or plans at T1, of which eight belonged to the control condition and hence did not gain access to the CDMIs.

At T2, 150 participants completed the questionnaire (dropout rate 54.4%, 179/329). Again, attrition was higher in the experimental condition (58.8%, 97/165) than in the control condition (50.0%, 82/164), but this difference was not significant. Suicidal thoughts or plans were indicated by seven participants at T2: five from the experimental condition and two from the control condition.

Effectiveness of the Intervention

The observed and estimated marginal means (estimated means adjusted for all factors in the model) for all outcomes at baseline and 3-month follow-up are presented in Table 2. The results of the linear mixed models analysis showed significant time×intervention effects for all outcomes except stress (see Table 3). This means that greater reductions in depression, sleep

problems, worry, and anxiety were detected between baseline and the 3-month follow-up in the intervention group compared to the control group. Moreover, greater improvements in well-being were observed over time in the intervention group. The intervention did not have a significant effect on stress complaints. The standardized effect size for the primary outcome of depression was large (Cohen *d*=–0.70). The magnitude of the effect sizes for the secondary outcomes were generally in the small-to-medium range across the outcomes (Cohen *d*=–0.20 to 0.40).

Table 2. Observed and estimated marginal means (EMM) of the outcomes at baseline and 3-month follow-up.

Outcome	Observed means, mean (SD)		Estimated means, EMM (SEM[a])	
	CDMI[b] intervention (n=165)	Control (n=164)	CDMI intervention (n=165)	Control (n=164)
Depression (IDS-SR[c])				
Baseline	26.08 (6.53)	25.01 (6.16)	25.69 (0.64)	24.91 (0.65)
3 months	20.34 (9.54)	24.28 (9.40)	20.35 (0.79)	24.04 (0.69)
Sleep (JSEQ[d])				
Baseline	11.61 (5.42)	11.21 (5.34)	11.98 (0.48)	11.78 (0.48)
3 months	8.91 (5.25)	10.62 (5.41)	9.48 (0.55)	11.03 (0.50)
Stress (PSS[e])				
Baseline	21.82 (5.86)	21.48 (5.37)	21.53 (0.47)	21.35 (0.48)
3 months	17.71 (6.54)	18.97 (5.73)	17.87 (0.57)	18.80 (0.50)
Worry (PSWQ[f])				
Baseline	37.76 (9.26)	38.28 (9.61)	36.92 (0.77)	37.61 (0.78)
3 months	32.46 (10.07)	36.44 (9.70)	31.88 (0.88)	35.81 (0.81)
Anxiety (GAD-7[g])				
Baseline	10.09 (4.16)	10.04 (3.73)	10.24 (0.35)	10.42 (0.35)
3 months	6.37 (4.27)	7.76 (4.06)	6.87 (0.42)	8.19 (0.37)
Well-being (WEMWBS[h])				
Baseline	42.99 (6.03)	43.66 (6.67)	42.84 (0.60)	43.25 (0.61)
3 months	46.53 (7.73)	44.34 (7.38)	46.17 (0.73)	44.01 (0.64)

[a]SEM: standard error of the mean.

[b]CDMI: complaint-directed mini-intervention.

[c]IDS-SR: Inventory of Depressive Symptomatology Self-Report.

[d]JSEQ: Jenkins Sleep Evaluation Questionnaire.

[e]PSS: Perceived Stress Scale.

[f]PSWQ: Penn State Worry Questionnaire.

[g]GAD-7: Generalized Anxiety Disorder Scale.

[h]WEMWBS: Warwick-Edinburgh Mental Well-being Scale.

Table 3. Estimated differences in mean change of outcomes (crude and adjusted)[a] between baseline and 3-month follow-up for the for complaint-directed mini-intervention (CDMI) intervention group versus the control group.[b]

Outcome	Estimate of mean change difference (95% CI)	*t* (*df*)	*P*	Cohen *d* (95% CI)
Depression (IDS[c])				
Crude model	–4.78 (–6.88 to –2.68)	–4.49 (297)	<.001	
Adjusted model	–4.47 (–6.54 to –2.40)	–4.25 (309)	<.001	–0.70 (–1.03 to –0.38)
Sleep (JSEQ[d])				
Crude model	–1.79 (–2.93 to –0.65)	–3.10 (258)	.002	
Adjusted model	–1.75 (–2.89 to –0.62)	–3.05 (262)	.003	–0.33 (–0.54 to –0.12)
Stress (PSS[e])				
Crude model	–1.32 (–2.77 to 0.13)	–1.79 (271)	.08	
Adjusted model	–1.12 (–2.55 to 0.31)	–1.54 (284)	.12	–0.20 (–0.45 to 0.06)
Worry (PSWQ[f])				
Crude model	–3.56 (–5.37 to –1.76)	–3.89 (260)	<.001	
Adjusted model	–3.25 (–5.04 to –1.47)	–3.59 (270)	<.001	–0.34 (–0.53 to –0.16)
Anxiety (GAD-7[g])				
Crude model	–1.17 (–2.22 to –0.12)	–2.19 (267)	.03	
Adjusted model[h]	–1.14 (–2.19 to –0.09)	–2.13 (271)	.03	–0.29 (–0.55 to –0.02)
Well-being (WEMWBS[i])				
Crude model	2.74 (0.87 to 4.61)	2.89 (289)	.004	
Adjusted model	2.57 (0.70 to 4.44)	2.70 (289)	.007	0.40 (0.11 to 0.70)

[a]Crude model: crude association (model includes only intervention condition, time, and time×intervention condition). Adjusted model: adjusted for age, gender, living arrangement, education, symptom severity, and anxiety scores at baseline.

[b]Regression coefficient for the time×condition interaction term.

[c]IDS-SR: Inventory of Depressive Symptomatology Self-Report.

[d]JSEQ: Jenkins Sleep Evaluation Questionnaire.

[e]PSS: Perceived Stress Scale.

[f]PSWQ: Penn State Worry Questionnaire.

[g]GAD-7: Generalized Anxiety Disorder Scale.

[h]Model 2 for anxiety does not include baseline anxiety scores as a covariate because they are included in the outcome.

[i]WEMWBS: Warwick-Edinburgh Mental Well-being Scale.

Outcomes at 6-Month Follow-Up

Figure 2 shows the course of the (estimated) primary and secondary outcomes in the two groups. In the intervention group, the greatest effects were observed between baseline and T1. These effects did not significantly increase or decrease at the 6-month follow-up, except for further reductions in sleep complaints (see Table 4). Generally, effects in the intervention group were sustained until 6 months. This pattern was reversed in the control group because they did not receive the intervention until after the T1 assessment. The greatest effects were observed between T1 and T2 in the control group, and were of similar magnitude as those found between T0 and T1 in the intervention group (see Table 4). However, there were some exceptions. Stress complaints showed a similar pattern of change in both groups: the greatest reduction between T1 and T0 (which is also reflected in the nonsignificant difference in the effectiveness analysis, see previous), and a smaller reduction between T1 and T2. Moreover, anxiety complaints also seemed to decrease a little more between T0 and T1 than between T1 and T2 in the control group.

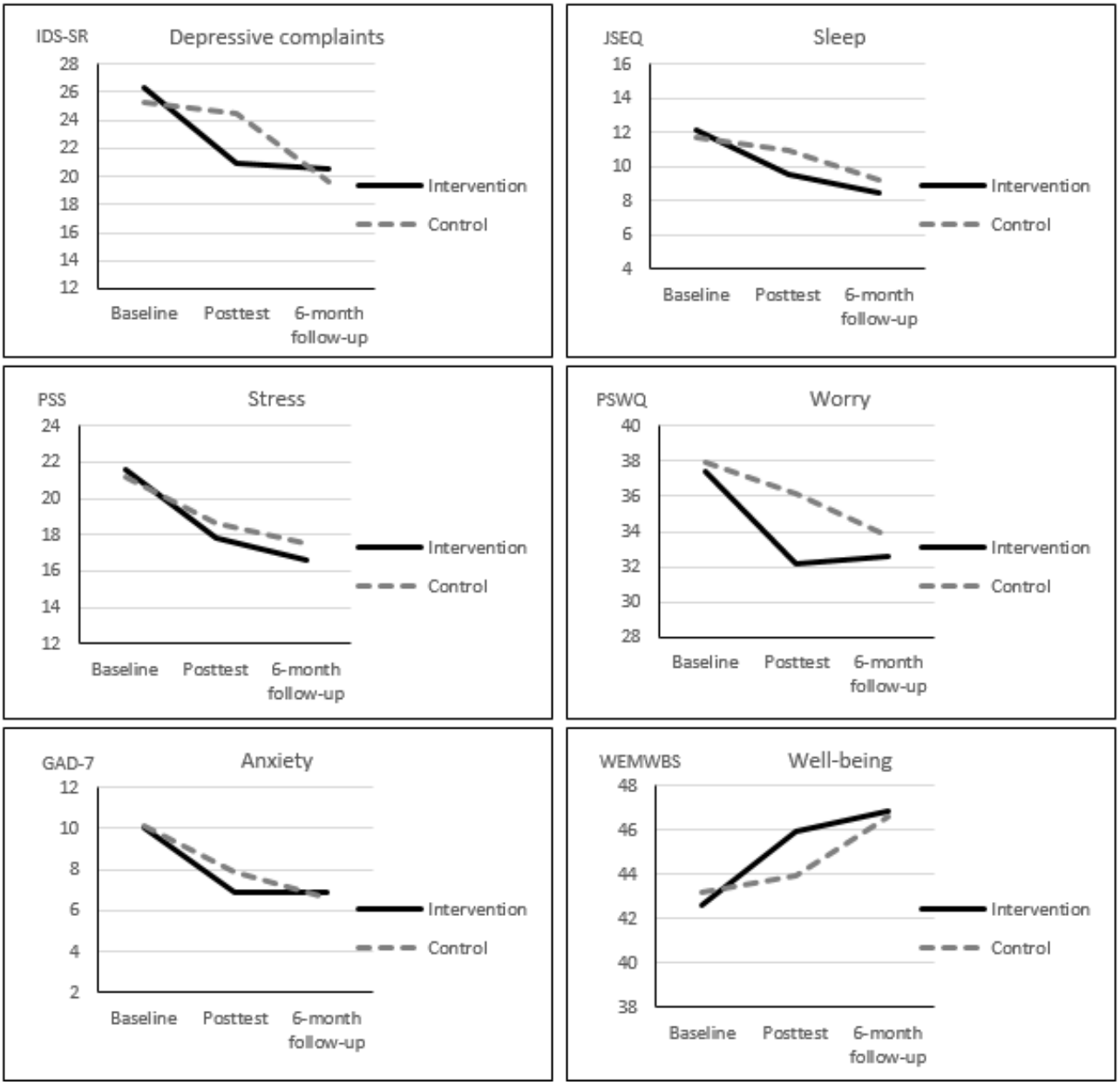
Table 4. Within-group estimated changes in outcomes between T1 and T0 and between T2 and T1.[a]

Outcome	*F* (*df*)	*P*	Intervention		Control	
			Estimate (95% CI)	*P*	Estimate (95% CI)	*P*
Depression						
Time	44.49 (2,482)	<.001				
T1 vs T0			–5.40 (–7.00 to –3.81)	<.001	–0.84 (–2.24 to 0.56)	.24
T2 vs T1			–0.41 (–2.37 to 1.55)	.68	–4.83 (–6.55 to –3.11)	<.001
Sleep						
Time	42.40 (2,426)	<.001				
T1 vs T0			–2.54 (–3.41 to –1.67)	<.001	–0.75 (–1.49 to 0.00)	.05
T2 vs T1			–1.11 (–2.17 to –0.06)	.04	–1.74 (–2.67 to –0.81)	<.001
Stress						
Time	67.14 (2,452)	<.001				
T1 vs T0			–3.75 (–4.82 to –2.68)	<.001	–2.56 (–3.48 to –1.63)	<.001
T2 vs T1			–1.21 (–2.51 to 0.09)	.07	–1.17 (–2.31 to –0.03)	.045
Worry						
Time	43.99 (2,429)	<.001				
T1 vs T0			–5.23 (–6.64 to –3.83)	<.001	–1.74 (–2.94 to –0.54)	.004
T2 vs T1			0.46 (–1.25 to 2.17)	.60	–2.42 (–3.91 to –0.93)	.002
Anxiety[b]						
Time	81.47 (2,440)	<.001				
T1 vs T0			–3.41 (–4.20 to –2.61)	<.001	–2.22 (–2.92 to –1.53)	<.001
T2 vs T1			0.19 (–0.78 to 1.16)	.70	–1.23 (–2.08 to –0.37)	.005
Well-being						
Time	27.11 (2,462)	<.001				
T1 vs T0			3.40 (2.03 to 4.76)	<.001	0.77 (–0.42 to 1.95)	.21
T2 vs T1			0.84 (–0.82 to 2.5)	.32	2.63 (1.17 to 4.09)	<.001

[a]All estimates are adjusted for age, gender, living arrangement, education, symptom severity, and anxiety scores at baseline.

[b]Estimate for anxiety does not include baseline anxiety scores as a covariate because they were included in the outcome.

Figure 2. Estimated marginal means for outcomes in the intervention and control groups for total follow-up period.



Use of and Satisfaction With Intervention

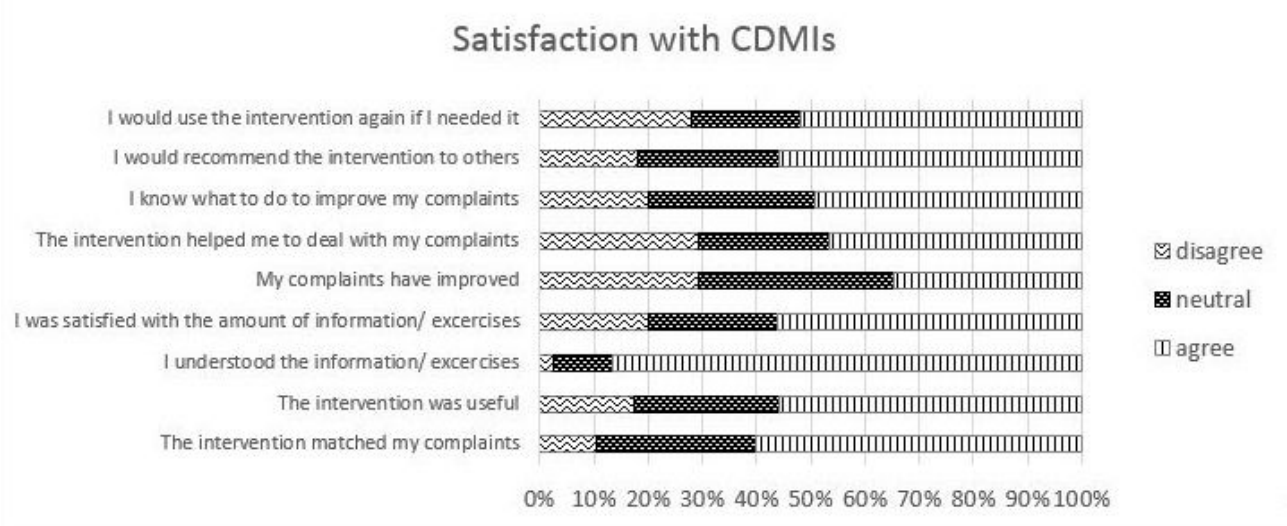
Approximately three-quarters of the intervention group actually created an account (127/165, 77.0%); of these participants, 91.3% (116/127) logged into their chosen CDMI at least once. During the 3-month intervention period, the participants logged in a median 3 times (range 0-166, IQR=5). Approximately half of the control group actually created an account (86/164, 52.4%) after completing the T1 measurement; of these participants, 85% (73/86) logged into their chosen CDMI at least once. During the 3-month period between T1 and T2, the participants in the control group logged in a median 2 times (range 0-85, IQR=4). Of the 75 participants in the intervention group who completed the use and satisfaction questions, a majority (56%, 42/75) reported that they spent an average of 30 minutes or more a week on the CDMIs and 8% (6/75) of participants spent 2 hours or more a week on the CDMIs. Of the 48 participants in the control group who completed the use and satisfaction questions, a majority (54%, 26/48) reported that they spent an average of 30 minutes or more a week on the CDMIs and 10% (5/48) spent 2 hours or more a week on the CDMIs.

Exploratory analysis into the relationship between log-ins and effectiveness showed no discernible dose-response relationship, and this was underlined by the finding that there were no significant interaction effects between the number of log-ins and time (see estimated marginal means and test statistics in Multimedia Appendix 3). However, although the overall tests of the interaction terms across the complaints were not significant, there were a number of significant contrasts. Participants who logged in four or more times showed greater decreases in depressive complaints between baseline and 3-month follow-up than those who did not log in (t_{226}=–2.12, P=.04). Those who logged in one to three times showed greater decreases in worry complaints between baseline and 3-month follow-up than those who did not log in (t_{191}=–1.98, P=.049).

Overall satisfaction with the intervention was moderate to high. The median satisfaction score given by the intervention group (n=75) was 7 (on a scale of 1 to 10) and the mean was 6.3 (SD 1.8). Participants in the control group who accessed the intervention gave a near identical satisfaction rating (n=45; mean 6.4, SD 1.5). Figure 3 shows the ratings participants in the intervention group scored on the various satisfaction items. These results show a similar pattern of moderate to high satisfaction across the various topics.

Various suggestions were made for future improvements. Among the most mentioned were to include reminders, additional information, and more structure to exercises.

Figure 3. Satisfaction with complaint-directed mini-interventions (CDMIs).



Discussion

Summary of Findings

This RCT evaluated the effectiveness of unguided Web-based self-help interventions that aimed to decrease depressive complaints by targeting stress, sleep problems, or worry. The results at 3-month follow-up showed a significant reduction in depressive symptoms for participants in the intervention group compared to participants in the wait-list control group. Furthermore, significant effects were observed for sleep problems, worry, anxiety, and well-being. The CDMIs did not significantly reduce stress complaints, but reductions were seen in both the intervention and control groups. At 6-month follow-up, the improvements in the intervention group were generally sustained. The control group, which started with the CDMIs after 3 months, experienced significant improvements at the 6-month follow-up compared to the 3-month follow-up for all outcome variables but stress. In general, participants were moderately to highly satisfied with the CDMIs.

Comparison With Other Studies

Online self-help interventions targeting symptoms of depression and the prevention of cases of depressive disorder have been found to be effective in previous studies [9,28,49]. A recent meta-analysis found that online interventions for the prevention of depression can reduce depressive symptoms in the short and medium term compared to no-intervention control conditions (eg, short-term pooled effect size of Hedges *g*=–0.35, 95% CI –0.57 to –0.12) [28]. A meta-analysis by Davies and colleagues [49] also showed that computer-delivered and Web-based interventions can be effective in improving depression in university students, with a pooled standardized mean difference of Hedges *g*=–0.43 (95% CI –0.63 to –0.22, *P*<.001). Zhou and colleagues [50] conducted a meta-analysis to the efficacy of Internet-based cognitive behavioral therapy (CBT) for people who fulfill the criteria for at least subthreshold depression. They concluded that in the short-term the efficacy of Internet-based CBT is superior to a nonactive control group (pooled standardized mean difference of –0.28, 95% CI −0.42 to −0.14), whereas the long-term efficacy is inconclusive. Moreover, a recently published meta-analysis about the effectiveness of online mindfulness-based interventions reported a small effect size on depressive symptoms (Hedges *g*=0.29, 95% CI 0.13-0.46, *P*=.001) [41].

The effect size for depressive symptoms found in our study (Cohen *d*=–0.70) is somewhat larger than reported in these meta-analyses. In some cases, this may be due to more restrictive eligibility criteria that were applied in these meta-analyses, including diagnosis and exclusion of depressive disorders at trial entry (eg, [28]), compared to our study. However, other online, unguided psychological interventions for participants with increased levels of depressive symptomatology also showed lower effect sizes [51].

Methodological Considerations

First, we encountered a high dropout rate of participants during the course of the study. High dropout rates are a problem often encountered in eHealth trials [52,53], with rates as high as 50% to 72% reported. Dropout rates tend to be higher for unguided versus guided eHealth trials [53]. Dropout also tends to be higher in intervention groups than control groups as was the case in our study. Although this is not an uncommon occurrence in eHealth studies, it may nonetheless give rise to attrition bias. However, analyses showed that the only measured difference between participants who completed the T1 assessment versus those who did not was the mean score on the GAD-7 (anxiety),

which was adjusted for in the analyses. Furthermore, in the analyses, all participants were included according to the intention-to-treat principle and missing data was accounted for by using linear mixed models (ie, maximum likelihood), which is a recommended strategy for estimating unbiased treatment effects [54].

Second, the CDMIs were developed as a preventive approach to depression, but the diagnostic status of the participants in this study was not assessed with a clinical interview because it was not feasible. To avoid being too restrictive and denying people access to the CDMIs who might benefit from the interventions, we included people with mild and moderate depressive symptoms in our trial. We cannot rule out that some participants in the trial might have fulfilled diagnostic criteria for depression at trial entry. Therefore, the findings and effect sizes should be interpreted in light of this fact.

Third, the participants could not be blinded. The reduction in complaints observed by the control group at T2 versus T1 were comparable to the reduction seen in the intervention group at T1 versus T0. Therefore, it is likely that the effects found are not largely influenced by the lack of blinding.

Another point of consideration is the limited use of the intervention, despite the positive effects. The use of the CDMIs was slightly more limited in the control group. This might have been due to a reduction in complaints in the control condition in the first 3 months of the study, reducing the need for the control condition to use the CDMIs once access was provided. The evaluation of the CDMIs by the users does suggest there is room for improvement of the intervention. Adding reminders was a frequently given suggestion for improvement. However, it would be worthwhile to further question users about strategies that may increase the use of the intervention. We conducted some exploratory analyses to examine the relationship between the number of log-ins and effectiveness, which showed no discernible dose-response relationship. However, it is important to interpret these exploratory findings with caution due to potential selection bias. Moreover, different operationalizations of adherence may be differentially related to effectiveness in eHealth research [55], which would be interesting to examine in future research.

Fifth, although our trial applied an open recruitment strategy, meaning that there were no restrictions for participation other than the inclusion criteria, it is possible that potential participants were missed due to the use of mainly Internet-based recruitment avenues. On the other hand, people who do not use the Internet might be less open to using an unguided Web-based self-help intervention. Nevertheless, the participants of the trial might not have truly reflected the general Dutch adult population with access to the Internet and sufficient computer skills.

Finally, the study population consisted of mainly highly educated female participants. Therefore, the generalizability of the findings with respect to males and other educational levels remains to be determined. Moreover, as mentioned in the Introduction, the CDMIs were developed to also suit a range of target groups, including the low SES population, but participation in the CDMIs and in this study was not restricted to individuals with a low SES. The baseline characteristics indicate that 72% of the participants had a high educational level. This means that without specific efforts aimed at inclusion of low SES people, the usage of the intervention among this group will be relatively low.

Future Research Directions

Integration of the CDMIs in primary care may be a useful next step for several reasons. As mentioned in the Introduction, patients frequently present to their GP with psychological stress, sleep problems, and worry [17-21]. Moreover, the guidelines of the Dutch College of General Practitioners recommend e-mental health as first step interventions for patients with depressive complaints. During and after the trial, we received several requests from GPs and GP nurses for information about and the use of the CDMIs. As such, the CDMIs seem to be suitable interventions for use in the GP setting that satisfy a demand. When implementing the interventions in the GP setting, the CDMIs can also be offered with some guidance from the GP nurse, which might be a way of boosting adherence and effectiveness [30,31]. Guidance may also be needed to increase the reach to low SES populations.

In addition to human guidance, technology itself may offer opportunities for support through persuasive system design features [56], which may be just as effective as human support [57]. Prompts are an example of a feature that may increase adherence [58]. Based on user feedback, we have recently developed an app to supplement the CDMIs by providing motivational quotes, tips, and prompts to use the CDMIs. Recent advances in mHealth provide opportunities for systems to learn about their user and offer meaningful personalized interventions when they are necessary and, thus, potentially offering more sophisticated technology-based support with or without human support (eg, [59]). It is likely that such personalized interventions will contribute to adherence and ultimately to effectiveness, and it would be interesting to explore this avenue more in future research.

A focus on research questions addressing the use and mechanisms of change in online interventions would be a fruitful next step. This is also in line with calls to pay more attention to the evaluation of intervention components rather than intervention packages in alternative research designs to traditional RCTs as a means to better tie in with the rapid and flexible nature of e-mental health development [60,61]. With respect to the CDMIs, as noted by one of the anonymous reviewers of this paper, it may be worthwhile in the future to investigate the effect of user choice. To this end, a comparison could be made between persons who are able to choose their modules and exercises versus those who are restricted to a more traditional approach in which participants have to go through modules sequentially. Also gaining more insight into the optimal amount of time, exercises, or modules that are needed, and the relationship with user characteristics would be valuable to better personalize interventions in the future. Currently, participants of the CDMIs are advised to spend 2 to 3 hours a week for a period of at least 4 weeks. However, a recent study of Bunge et al [62] showed that even a brief, unsupported Internet intervention of 5 to 10 minutes improved depression scores at 1-week follow-up. Finally, future research should focus on

gaining insights into the most optimal strategies for reaching and engaging low SES populations in (preventive) interventions targeting psychological complaints, such as the CDMIs.

In conclusion, the online CDMIs were successful in significantly reducing depressive complaints and had an effect on, albeit to a lesser extent, sleep problems, worry, anxiety, and well-being. The intervention did not significantly reduce stress complaints. This study shows that a purely online self-help intervention can have a positive impact on mental health outcomes. Future research should focus on which specific strategies may boost adherence, and increase the reach of the CDMIs among people with low SES.

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Conflicts of Interest

The interventions that were used in this study were developed by the Trimbos Institute, the Netherlands Institute of Mental Health and Addiction, a nonprofit organization, where SL, SSL, AP, FS, and BB are employed. All authors declare that there are no conflicts of interest.

Multimedia Appendix 1

CONSORT-EHEALTH checklist (V1.6.1).

[PDF File (Adobe PDF File), 1MB - jmir_v19i1e4_app1.pdf]

Multimedia Appendix 2

Additional information and complaint-directed mini-intervention (CDMI) screenshots.

[PDF File (Adobe PDF File), 688KB - jmir_v19i1e4_app2.pdf]

Multimedia Appendix 3

Intervention use (number of logins) and effect sizes.

[PDF File (Adobe PDF File), 36KB - jmir_v19i1e4_app3.pdf]

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Abbreviations

CBT: cognitive behavioral therapy
CDMI: complaint-directed mini-intervention
EMM: estimated marginal means
GAD-7: Generalized Anxiety Disorder Scale
GP: general practitioner
IDS-SR: Inventory of Depressive Symptomatology Self-Report
JSEQ: Jenkins Sleep Evaluation Questionnaire
NTR: Netherlands Trial Register
RCT: randomized controlled trial
PSS: Perceived Stress Scale
PSWQ: Penn State Worry Questionnaire
SES: socioeconomic status
WEMWBS: Warwick-Edinburgh Mental Well-being Scale

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Original Paper

Does Usage of an eHealth Intervention Reduce the Risk of Excessive Gestational Weight Gain? Secondary Analysis From a Randomized Controlled Trial

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Abstract

Background: Excessive gestational weight gain (GWG) contributes to the development of obesity in mother and child. Internet-based interventions have the potential for delivering innovative and interactive options for prevention of excessive GWG to large numbers of people.

Objective: The objective of this study was to create a novel measure of Internet-based intervention usage patterns and examine whether usage of an Internet-based intervention is associated with reduced risk of excessive GWG.

Methods: The website featured blogs, local resources, articles, frequently asked questions (FAQs), and events that were available to women in both the intervention and control arm. Weekly reminders to use the website and to highlight new content were emailed to participants in both arms. Only intervention arm participants had access to the weight gain tracker and diet and physical activity goal-setting tools. A total of 1335 (898 intervention and 437 control) relatively diverse and healthy pregnant women were randomly assigned to the intervention arm or control arm. Usage patterns were examined for both intervention and control arm participants using latent class analysis. Regression analyses were used to estimate the association between usage patterns and three GWG outcomes: excessive total GWG, excessive GWG rate, and GWG.

Results: Five usage patterns best characterized the usage of the intervention by intervention arm participants. Three usage patterns best characterized control arm participants' usage. Control arm usage patterns were not associated with excessive GWG, whereas intervention arm usage patterns were associated with excessive GWG.

Conclusions: The control and intervention arm usage pattern characterization is a unique methodological contribution to process evaluations for self-directed Internet-based interventions. In the intervention arm some usage patterns were associated with GWG outcomes.

ClinicalTrial: ClinicalTrials.gov; Clinical Trials Number: NCT01331564; https://clinicaltrials.gov/ct2/show/NCT01331564 (Archived by WebCite at http://www.webcitation/6nI9LuX9w)

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KEYWORDS

Internet; obesity; weight gain; pregnancy

Introduction

Maternal obesity and excessive gestational weight gain (GWG) are associated with many adverse pregnancy and birth outcomes, such as gestational diabetes and cesarean delivery, in addition to an increase in obesity risk in both mother and baby [1-3]. A recent Cochrane review found that diet and exercise interventions during pregnancy reduced the risk of excessive GWG by 20% [4]. This review suggested that electronic communications interventions may have potential for addressing these growing public health problems.

Electronic health (eHealth) interventions have the advantages of wide reach, interactivity, personalization, and cost-effectiveness. eHealth interventions have been shown to be efficacious across cognitive outcomes (knowledge, intention, and self-efficacy), some behavioral outcomes (smoking cessation, reducing alcohol consumption, safer sexual behaviors, and increasing physical activity), and emotional outcomes (mild to moderate depression, anxiety, obsessive-compulsive disorder, and phobias) [5]. A review and meta-analysis by Hill et al [6] found that providing information and behavioral self-monitoring were two key strategies when intervening in GWG. However, according to a recent review, there is a lack of clarity about the effectiveness of behavioral interventions to address maternal obesity and GWG and, in particular, there is a need to identify the specific intervention components that contribute to the effectiveness of these interventions [7].

Generally, higher dose of intervention received and greater use of intervention features have been associated with greater success in achieving weight-related intervention outcomes [8-10]. This has been particularly true for eHealth or Internet-based behavior change interventions [11-13]. While Internet-based interventions provide a unique opportunity to measure use of behavior change tools and other features objectively, currently there is no consensus on the definitions and measures for usage of such interventions [14]. Previous studies have used the following measures: number of website visits or log-ins, time spent on a site, and number of features used [14-16].

In a previously published article, we described the creation of measures of intervention use that considered expected use, consistency of use across time, and patterns of use for different features of an Internet-based intervention aimed at preventing excessive GWG [17]. This study examined whether the patterns of features that were used and the amount of their use were related to GWG outcomes among women participating in a randomized controlled trial. We used the previously described usage pattern measures for the intervention arm women, created a new usage measure for the control arm women, and then examined how these measures of usage were associated with 3 different GWG outcomes.

Methods

Study Design

Data from a randomized controlled trial of prevention of excessive GWG and postpartum weight retention with women who were 18-35 years of age, normal range to obese class I body mass index (BMI), socially and racially diverse, and relatively healthy (N=1689) and conducted in a midsize city in northeastern United States were used in this study. This trial, conducted from 2011 to 2014, is described in detail elsewhere [18,19], and its ClinicalTrials.gov identifier is NCT01331564. Pregnant women were screened in prenatal clinics, private obstetric practices, practices that provide ultrasounds, and over the phone and online. To meet eligibility criteria, participants had to (1) consent at or before 20 weeks' gestation, (2) be available for a 24-month intervention, (3) plan to carry their pregnancy to term and keep their baby, (4) read and understand English, and (5) have an email address. Exclusion criteria included the following: BMI less than 18.5 kg/m^2 (underweight) or greater than or equal to 35.0 kg/m^2 (obese class II or greater), multiple gestation (eg, twins), having had eating disorders or gastric bypass surgery in the past, having had 3 or more consecutive miscarriages, and the presence of prepregnancy medical conditions that could influence weight loss or gain.

All study participants were sent an email describing the tools on the website. Email, postcard, and telephone reminders were used as prompts to encourage participants to visit the website the first time. A US $5 incentive was also given for the first website visit. The sample for this analysis includes women who were eligible, entered the study during pregnancy as indicated by at least one website log-in or completion of the baseline questionnaire, and had a singleton pregnancy that lasted at least 20 weeks (n=1335). The study protocol was approved by the University of Rochester Research Subjects Review Board and the Cornell University Institutional Review Board.

Intervention

Fishbein and Yzer's Integrative Model of Behavioral Prediction [20] was the guiding theoretical framework for the Internet-based intervention to prevent excessive GWG. Fishbein and Yzer's framework was combined with Fogg's Behavior Model for Persuasive Design [21] to link weight-associated behaviors and their predictors to intervention features. Michie's behavior change techniques [7,22] informed the development of the website features for the intervention arm (Figure 1). The website featured blogs, local resources, articles, frequently asked questions (FAQs), and events that were available to women in both the intervention and control arm. Weekly reminders to use the website and to highlight new content were emailed to participants in both arms. In addition, intervention arm participants had access to the weight gain tracker and diet and physical activity goal-setting tools. Intervention participants were emailed weekly with reminders to use the weight gain tracker and diet and physical activity goal-setting tools. Intervention features are described in more detail in the study by Graham et al [23].

Consistent Use Features

Use of the Internet-based features was automatically captured by the website. Utilization of the following 6 intervention features plus log-ins was used to characterize usage in the intervention arm: health-related information (articles and FAQs), blogs, local resources, diet goal-setting tools, physical activity

goal-setting tools, and a weight gain tracker (Figure 1). For the control arm, log-ins plus the use of the first 3 features mentioned above were included in the patterns-of-usage measure. For some features, the amount of use in relation to expected use was captured in the patterns-of-usage measure. Consistent use was expected for log-ins and entry of weights into the weight gain tracker. We expected women to track their weight in 30-day intervals, but, to allow for difference in timing of prenatal care, we created 45-day intervals from time of enrollment to delivery. If a woman entered a weight during each of the 45-day intervals of her study participation, she was categorized as a *consistent tracker*. If during at least half of the intervals a woman entered a weight, she was categorized as an *almost consistent tracker*. If a woman had entered at least one weight but not during more than half of her intervals, she was categorized as an *inconsistent tracker*. Finally, if she never entered a weight during pregnancy, she was categorized as a *nontracker*. We counted website log-ins as feature usage given the amount of content that was visible on the website dashboard after log-in for both intervention and control arm participants (Figures 2 and 3). The same procedure for consistent weight tracking was used to categorize log-ins.

Quantity of Use Features

For all other features, consistent use was not expected. Use was expected on an "as needed" basis. Therefore, quantity of use was used for the following features: health-related information, blogs, resources, diet goal-setting tools, and physical activity goal-setting tools. The usage of a feature by a woman was categorized into 3 levels for each of these features: *high* (≥median among users), *low* (<median among users), or *none* (0).

Usage Patterns

Latent class analysis (LCA) was used to identify usage patterns by women in the intervention arm and the control arm. This analysis was used to group individuals based on their similar usage patterns. All analyses were conducted using a SAS procedure, PROC LCA version 9.2 (SAS Institute). The creation of the intervention usage pattern variables is described in greater detail in the study by Demment et al [17]. The sample used in this analysis excluded women who had never logged in and had not completed a questionnaire, which influences the latent classes that emerge.

Figure 1. Website features, behavior change strategies, and expected use of intervention features.

Usage Patterns			
Intervention		Control	
Feature	Behavior Change Technique(s)	Feature	Behavior Change Technique(s)
Consistent Use Features			
Log-ins		Log-ins	
Weight Gain Tracking	Goals and planning Feedback and monitoring		
Quantity of Use Features			
Diet and Physical Activity Goal-Setting	Goals and planning Feedback and monitoring Associations Repetition and substitution Rewards and threat		
Health Related Information	Shaping knowledge Comparison of outcomes Antecedents	Health Related Information	
Blogs	Social support	Blogs	Social support
Resources	Social support	Resources	Social support
Active Intervention Ingredients			
Intervention		Control	
Feature	Behavior Change Technique(s)		
Weight Gain Tracking	Goals and planning Feedback and monitoring		
Diet and Physical Activity Goal-Setting	Goals and planning Feedback and monitoring Associations Repetition and substitution Rewards and threat		

Figure 2. Screenshot of the intervention arm website dashboard.

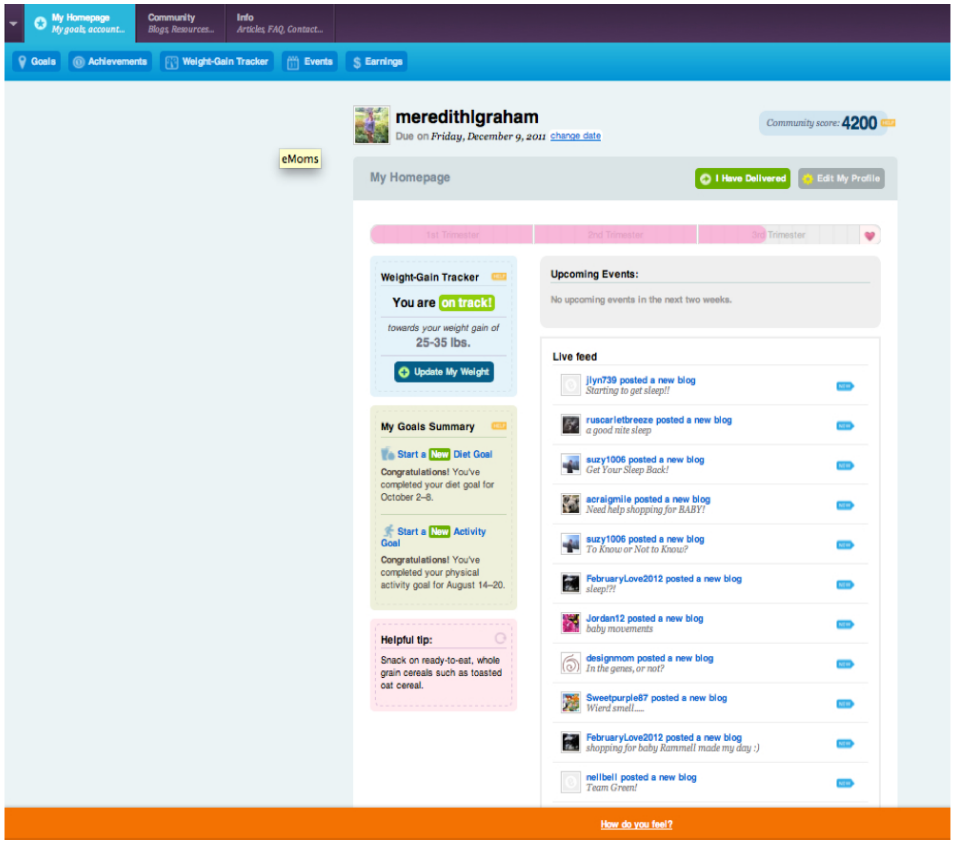
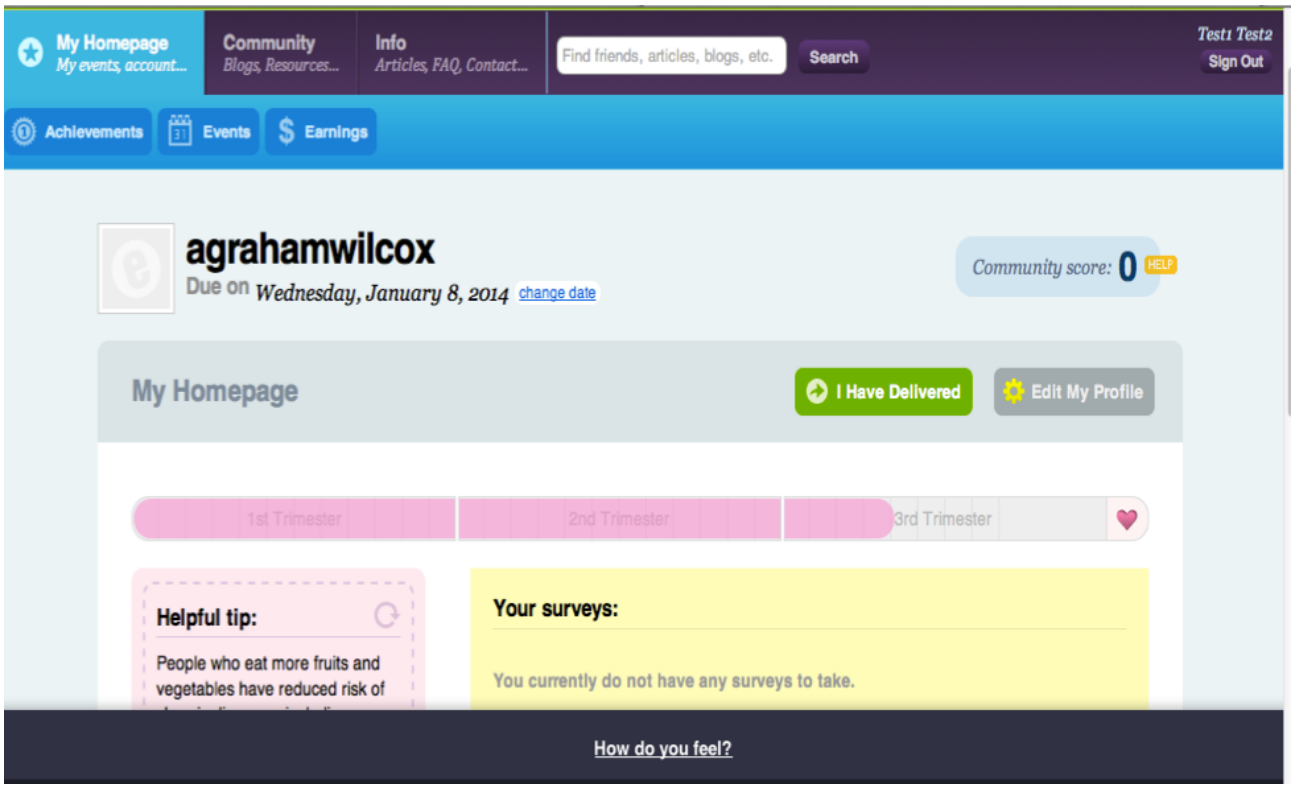


Figure 3. Screenshot of the control arm website dashboard.



Outcome Measure

GWG data were obtained through an audit of the participants' prenatal, labor and delivery, and 6-week postpartum medical records. Total GWG was calculated as the difference between the first weight and the last weight in pregnancy. Overall, 12.80% (171/1335) of the sample did not have sufficient weight information in the prenatal chart to yield a valid measured GWG. Sufficient weight information required having a measured weight at both <14 weeks' and ≥37 weeks' gestation. Missing

data were handled using multiple imputation to address issues of bias [24], which may result from analyzing only complete cases using SAS PROC MI and MIANALYZE procedures. A total of 60 imputed datasets were created for the primary analysis and also for the models presented below. The weekly rate of GWG was calculated as the difference between the last pregnancy weight and the weight measured closest to 20 weeks (±3 weeks), or the imputed average weight at 18-21 weeks if missing, divided by the number of weeks between these weights. Next, the binary outcomes of excessive total GWG and excessive rate of GWG after 20 weeks were calculated using the Institute of Medicine guidelines for each BMI group as determined at randomization. For each of the 3 BMI groups, the cutoff values for excessive total GWG and excessive weekly rate of GWG are as follows: normal range BMI, greater than 16 kilograms and greater than 0.23 kilograms per week; overweight BMI, greater than 11.5 kilograms and greater than 0.15 kilograms per week; and obese class I BMI, greater than 9 kilograms and greater than 0.12 pounds per week.

Statistical Analysis

Among those participants with measured and available GWG data, chi-square analysis was used to examine the relationship between usage patterns and (1) demographics and (2) the binary outcomes of excessive total GWG and excessive rate of GWG. For total GWG, analysis of variance was used to examine the relationship between usage patterns and GWG. Since the created usage patterns differed by arm, these analyses were performed separately within intervention arm participants and within control arm participants.

Using a modified Poisson regression approach [25], the relative risk of excessive total or weekly GWG was estimated for different usage patterns within strata. Similarly, least squares multiple regression models assessed the mean difference in total GWG (kilograms). Usage was parameterized with two approaches. First, we examined by strata whether or not various patterns of usage were associated with relative risk of excessive GWG. Second, we examined by strata how the combined usage patterns that include most frequent usage of the active ingredients of the intervention, that is, weight gain tracking and behavioral goal setting and self-monitoring (Figure 1), were associated with relative risk of GWG. All models were adjusted for BMI, age, race, and parity, as well as pregnancy timing variables including gestational age at delivery, the weeks between the first and last pregnancy weight, and the weeks between the last pregnancy weight and delivery. Significance level was set at $P \leq .05$.

Results

Usage pattern measures were created for each arm (Table 1). For the intervention arm, the 5-component solution was the best fit based on Akaike information criterion (AIC) score. All 5 usage patterns included consistent or almost consistent logging in. The 5 patterns and their components are as follows: (1) super user—consistent weight tracking; very likely to be a high user of blogs, health-related information, and local resources; likely to be a high user of diet or physical activity goal setting; (2) medium user—almost consistent weight tracking; likely to be a high user of blogs, health-related information, local resources, and physical activity goal setting; (3) consistent tracker—likely consistent weight tracking; likely low user of health-related information and blogs; unlikely to set goals or view resources; (4) almost consistent or inconsistent tracker—likely almost consistent weight tracker (although 38% likelihood of also being an inconsistent weight tracker); unlikely to have used goal-setting tools, health-related information, or local resources; unlikely to have used blogs; and (5) “nonuser”—almost consistent log-ins (likely adherent study participant); unlikely to have tracked weight; very unlikely to have used any other intervention feature.

For the control arm, the 3-group solution was the best fit based on the AIC score. The 3 patterns and their components are as follows: (1) mid or high user—very likely to consistently log in; very likely to be a high user of health-related information, blogs, and local resources; (2) low user—likely to have logged in consistently or almost consistently; likely to have been a high user of blogs (although 37% likelihood of also never viewing blogs), but unlikely to have viewed any local resources; and (3) no or minimal user—very likely to have logged in almost consistently or inconsistently; unlikely to have viewed health-related information, blogs, or local resources.

Within the intervention arm participants, there were significant demographic differences by patterns of usage (Table 2). Higher usage groups, including consistent trackers, were more likely to have higher income, be white, be older, and have ever been married. There are also differences in GWG outcomes by patterns of usage (Table 2). Nonusers and consistent trackers were least likely to exceed the recommended amount of GWG. Almost consistent or inconsistent trackers were most likely to exceed the recommended amount. Nonusers, consistent trackers, and super users have the lowest amount of total GWG.

Table 1. Usage patterns latent class probablities.

Usage pattern	Intervention (n=898)					Control (n=437)		
	Super user, 138 (15.4%)	Medium user, 89 (9.91%)	Consistent tracker, 181 (20.2%)	Almost consistent or inconsistent tracker, 275 (30.6%)	Nonuser, 215 (23.9%)	Mid or high user, 164 (37.5%)	Low user, 157 (35.9%)	No or minimal user, 116 (26.5%)
Log-in								
Consistent	*.94* [a]	.005	*.97*	.06	.03	*.88*	*.42*	.007
Almost consistent	.06	*.96*	.03	*.92*	*.79*	.12	*.58*	*.93*
Inconsistent	.0001	.04	.0001	.02	.17	0	0	.06
Never	0	0	0	0	0	0	0	0
Weight tracking								
Consistent	*.86*	.002	*.71*	.007	.009			
Almost consistent	.13	*.80*	.23	*.48*	.10			
Inconsistent	.009	.13	.03	.38	.28			
Never	.0004	.07	.03	.13	*.61*			
PA[b] goal setting								
High	*.47*	*.51*	.16	.06	.0002			
Low	.27	.15	.16	.28	.03			
None	.29	.34	*.68*	*.66*	*.97*			
Diet goal setting								
High	*.47*	.38	.15	.11	.0002			
Low	.18	.20	.20	.28	.03			
None	.34	.42	*.65*	*.62*	*.97*			
Health-related information								
High	*.81*	*.74*	.18	.11	.006	*.89*	.38	.02
Low	.19	.22	*.46*	.40	.05	.06	.31	.06
None	.001	.04	.36	*.49*	*.94*	.04	.31	*.93*
Blogs								
High	*.93*	*.81*	.24	.17	.001	*.87*	*.44*	.03
Low	.06	.15	*.43*	*.49*	.09	.09	.20	.09
None	.02	.05	.34	.34	*.91*	.05	.37	*.89*
Local resources								
High	*.87*	*.60*	.06	.05	.003	*.87*	.20	.005
Low	.13	.27	.33	.25	.04	.11	.17	.04
None	.003	.12	*.61*	*.70*	*.96*	.02	*.63*	*.95*

[a]Italics denotes probability greater than or equal to .40.

[b]PA: physical activity.

Table 2. Intervention arm: demographic and outcome differences by usage pattern (n=898).

Demographics	Super user, n (%)	Medium user, n (%)	Consistent tracker, n (%)	Almost consistent or inconsistent tracker, n (%)	Nonuser, n (%)
No. of participants	138 (15.4)	89 (9.9)	181 (20.2)	275 (30.6)	215 (23.9)
Income (*P* <.001)					
Low income	29 (21.0)	32 (36.0)	52 (28.7)	118 (42.9)	95 (44.2)
Not low income	109 (79.0)	57 (64.0)	129 (71.3)	157 (57.1)	120 (55.8)
BMI[a] at screening (*P*=.04)					
Normal range BMI	79 (57.3)	50 (56.2)	106 (58.6)	152 (55.3)	110 (51.2)
Overweight BMI	34 (24.6)	30 (33.7)	56 (30.9)	90 (32.7)	59 (27.4)
Obese BMI	25 (18.1)	9 (10.1)	19 (10.5)	33 (12.0)	46 (21.4)
Strata (*P* <.001)					
Normal weight and lower income	10 (7.2)	17 (19.1)	30 (16.6)	62 (22.5)	60 (27.9)
Normal weight and higher income	69 (50.0)	32 (36.0)	77 (42.5)	91 (33.1)	50 (23.3)
Overweight or obese and lower income	19 (13.8)	15 (16.9)	22 (12.2)	56 (20.4)	60 (27.9)
Overweight or obese and higher income	40 (29.0)	25 (28.1)	52 (28.7)	66 (24.0)	45 (20.9)
Race (*P*<.001)					
Black	6 (4.3)	14 (15.7)	21 (11.6)	54 (19.6)	87 (40.5)
White	118 (85.5)	64 (71.9)	138 (76.2)	180 (65.5)	92 (42.8)
Other	14 (10.2)	11 (12.4)	22 (12.2)	41 (14.9)	36 (16.7)
Hispanic (*P*=.08)					
Yes	13 (9.4)	5 (5.6)	20 (11.0)	33 (12.0)	35 (16.3)
No	125 (90.6)	84 (94.4)	161 (89.0)	242 (88.0)	180 (83.7)
Relation group (*P*<.001)					
Single	33 (23.9)	32 (36.0)	59 (32.8)	124 (45.4)	131 (61.8)
Ever married	105 (76.1)	57 (64.0)	121 (67.2)	149 (54.6)	81 (38.2)
Parity (*P*=.73)					
Nulliparous	71 (51.5)	46 (51.7)	79 (43.6)	127 (46.2)	93 (43.5)
Primiparous	45 (32.6)	25 (28.1)	65 (35.9)	88 (32.0)	75 (35.0)
Multiparous	22 (15.9)	18 (20.2)	37 (20.4)	60 (21.8)	46 (21.5)
Age categories, years (*P* <.001)					
18 to 24	18 (13.0)	19 (21.3)	34 (18.8)	80 (29.1)	87 (40.5)
25 to 30	41 (29.7)	31 (34.8)	67 (37.0)	93 (33.8)	67 (31.2)
>30	79 (57.3)	39 (43.8)	80 (44.2)	102 (37.1)	61 (28.4)
Outcomes					
Total GWG[b] (*P*=.03, n=781)					
Exceeded recommended amount	59 (45.0)	39 (48.1)	64 (40.3)	132 (56.2)	70 (40.0)
Did not exceed recommended amount	72 (55.0)	42 (51.9)	95 (59.7)	103 (43.8)	105 (60.0
Rate of GWG (*P*=.09, n=795)					
Exceeded recommended rate	82 (62.6)	59 (71.1)	98 (59.4)	176 (73.0)	114 (65.1)
Did not exceed recommended rate	49 (37.4)	24 (28.9)	67 (40.6)	65 (27.0)	61 (34.9)

Demographics	Super user, n (%)	Medium user, n (%)	Consistent tracker, n (%)	Almost consistent or inconsistent tracker, n (%)	Nonuser, n (%)
GWG, kg (*P*=.03)[c], mean (SD)	13.66 (4.59)	14.37 (5.22)	13.59 (5.33)	14.87 (5.85)	13.29 (5.88)

[a]BMI: body mass index.

[b]GWG: gestational weight gain.

[c]Analysis of variance test results shown; all other *P* values provided in the table are chi-square *P* values.

Within the control arm participants there were similar demographic differences by patterns of usage as observed in the intervention arm participants. The demographic differences between the usage patterns in the control arm were driven by the no or minimal user; when low and medium users were compared there were no significant differences by demographics (Table 3). In addition to the demographic differences, parity was also significant within the control arm, where nulliparous women were more likely to be higher users of the website. There were no significant differences in GWG outcomes by control arm patterns of usage.

Given that there were demographic differences by GWG outcomes (Multimedia Appendices 1 and 2) and that there were demographic and GWG differences by patterns of usage (Tables 2 and 3), adjusted models were needed to examine the independent effect of usage patterns on weight outcomes (Table 4). In each of these models, the comparison group was participants who had the nonuser usage pattern. In the intervention arm, among participants with lower income and normal range BMI (stratum 1), the relative risk of excessive GWG was 1.92 times higher for an almost consistent or inconsistent tracker compared with the nonuser. An inconsistent tracker gained 2.48 kg more than a nonuser. Among participants with normal range BMI and higher income (stratum 2), the consistent trackers had 0.67 relative risk of excessive weekly GWG rate compared with nonusers, after adjusting for differences in BMI, age, race, parity, and gestational age at delivery. Among overweight and obese higher-income participants (stratum 4), the consistent trackers gained 2.78 kg less than nonusers.

We also examined GWG outcomes and usage patterns in the control arm (Table 5). In each of these models, the comparison group is participants who had the nonuser usage pattern. There is only one significant result in the control arm when looking at usage pattern and GWG, which was among overweight and obese lower-income control participants (stratum 3) where the low user usage pattern had a relative risk of excessive weekly GWG rate 1.35 times that of nonusers.

In addition to examining patterns of usage created through LCA, we combined the latent classes that emerged that included high usage of the active ingredient intervention features, which were theorized to have the greatest likelihood of reducing the risk of excessive GWG: the super user and the consistent tracker groups. Specifically consistent weight tracking loaded at probability of >0.70 in both the super user and the consistent tracker group. In these models, the comparison group is participants who were in the medium user, almost consistent or inconsistent tracker, or the nonuser groups (Table 6). Among participants with normal range BMI and higher income (stratum 2), consistent trackers and super users had reduced relative risk of excessive GWG amount (relative risk =0.64) and weekly rate (relative risk =0.72). They also gained 1.49 kg less in total GWG. Among overweight and obese higher-income participants (stratum 4), consistent trackers and super users had reduced relative risk of excessive GWG amount (relative risk =0.87) and gained 2.17 kg less compared with those who used the active ingredients less.

Table 3. Control arm: demographic and outcome differences by usage pattern (n=437).

Demographics	Mid or high user, n (%)	Low user, n (%)	No or minimal user, n (%)
No. of participants	164 (36.7)	157 (37.1)	116 (26.2)
Income (*P*<.001)			
Low income	54 (32.9)	52 (33.1)	62 (53.5)
Not low income	110 (67.1)	105 (66.9)	54 (46.5)
BMI[a] at screening (*P*=.06)			
Normal range BMI	100 (61.0)	92 (58.6)	55 (47.4)
Overweight BMI	51 (31.1)	42 (26.8)	46 (39.7)
Obese BMI	13 (7.9)	23 (24.6)	15 (12.9)
Strata (*P*=.002)			
Normal weight and lower income	27 (16.5)	28 (17.8)	31 (26.7)
Normal weight and higher income	73 (44.5)	64 (40.8)	24 (20.7)
Overweight or obese and lower income	27 (16.5)	24 (15.3)	31 (26.7)
Overweight or obese and higher income	37 (22.5)	41 (26.1)	30 (25.9)
Race (*P*<.001)			
Black	22 (13.4)	23 (14.6)	37 (31.9)
White	120 (73.2)	116 (73.9)	60 (51.7)
Other	22 (13.4)	18 (11.5)	19 (16.4)
Hispanic (*P*=.55)			
Yes	19 (11.6)	14 (9.0)	15 (12.9)
No	145 (88.4)	143 (91.0)	101 (87.1)
Relation group (*P*<.001)			
Single	53 (32.3)	52 (33.3)	66 (57.9)
Ever married	111 (67.7)	104 (66.7)	48 (42.1)
Parity (*P*=.005)			
Nulliparous	88 (53.7)	86 (54.8)	44 (37.9)
Primiparous	49 (29.9)	46 (29.3)	35 (30.2)
Multiparous	27 (16.4)	25 (15.9)	37 (31.9)
Age categories, years (*P*=.003)			
18 to <25	37 (22.6)	33 (21.0)	46 (39.6)
25 to <30	55 (33.5)	57 (36.3)	38 (32.8)
>30	72 (43.9)	67 (42.7)	32 (27.6)
Outcomes			
Total gestational weight gain (*P*=.62)			
Exceeded recommended amount	62 (43.7)	72 (49.3)	43 (45.3)
Did not exceed recommended amount	80 (56.3)	74 (50.7)	52 (54.7)
Rate of gestational weight gain (*P*=.54)			
Exceeded recommended rate	103 (70.6)	104 (71.2)	63 (65.0)
Did not exceed recommended rate	43 (29.4.1)	42 (28.8)	34 (36.0)
Gestational weight gain, kg (*P*=.17)[b], mean (SD)	14.48 (5.07)	14.19 (5.05)	13.21 (5.60)

[a]BMI: body mass index.

[b]Analysis of variance test results shown; all other *P* values provided in the table are chi-square *P* values.

Table 4. Intervention arm: Are usage patterns associated with gestational weight gain?

Usage patterns[a]	Excessive total GWG[b]			Excessive GWG rate			GWG		
	RR[c]	95% CI	*P* value	RR	95% CI	*P* value	Estimate	95% CI	*P* value
Stratum 1: normal range BMI[d] and low income (N=179)									
Super user[e]	0.74	0.20 to 2.74	.65	0.53	0.21 to 1.34	.18	−0.69	−3.80 to 2.41	.66
Medium user	1.51	0.67 to 3.41	.32	1.10	0.72 to 1.70	.65	2.27	−0.89 to 5.43	.16
Consistent tracker	1.61	0.89 to 2.91	.11	1.24	0.86 to 1.77	.25	1.79	−0.45 to 4.02	.12
Inconsistent tracker	1.92	1.18 to 3.14	.009	1.25	0.95 to 1.64	.12	2.48	0.63 to 4.33	.009
Stratum 2: normal range BMI and higher income (n=319)									
Super user	0.91	0.50 to 1.68	.77	0.85	0.59 to 1.22	.38	−1.22	−2.82 to 0.39	.14
Medium user	1.04	0.52 to 2.07	.91	1.12	0.77 to 1.61	.56	0.10	−1.67 to 1.88	.91
Consistent tracker	0.63	0.34 to 1.16	.14	0.67	0.46 to 0.98	.04	−1.22	−2.91 to 0.46	.15
Inconsistent tracker	1.33	0.79 to 2.25	.29	1.05	0.77 to 1.44	.75	0.47	−1.12 to 2.06	.57
Stratum 3: overweight or obese BMI and low income (n=172)									
Super user	1.34	0.92 to 1.95	.13	1.25	0.98 to 1.60	.07	0.55	−2.84 to 3.93	.75
Medium user	0.96	0.56 to 1.64	.87	0.95	0.62 to 1.45	.81	−0.58	−4.51 to 3.34	.77
Consistent tracker	1.24	0.81 to 1.89	.32	1.11	0.80 to 1.54	.52	1.10	−2.30 to 4.49	.53
Inconsistent tracker	1.02	0.70 to 1.50	.92	1.10	0.86 to 1.42	.45	0.44	−2.06 to 2.93	.73
Stratum 4: overweight or obese BMI and high income (n=228)									
Super user	0.96	0.72 to 1.30	.80	1.02	0.84 to 1.24	.83	−1.03	−3.59 to 1.53	.43
Medium user	1.13	0.85 to 1.51	.41	1.06	0.85 to 1.31	.60	−0.01	−2.84 to 2.82	.99
Consistent tracker	0.96	0.72 to 1.27	.76	1.01	0.83 to 1.23	.93	−2.78	−5.16 to −0.39	.02
Inconsistent tracker	1.17	0.92 to 1.48	.21	1.13	0.95 to 1.34	.16	0.35	−1.94 to 2.64	.77

[a]All models have been adjusted for age, race, parity, and BMI.

[b]GWG: gestational weight gain.

[c]RR: relative risk.

[d]BMI: body mass index.

[e]Relative risk of excessive GWG and mean GWG estimates (kg) are relative to subjects who were nonusers (reference group).

Table 5. Control arm: Are usage patterns associated with gestational weight gain?

Usage patterns[a]	Excessive total GWG[b]			Excessive GWG rate			GWG		
	RR[c]	95% CI	*P* value	RR	95% CI	*P* value	Estimate	95% CI	*P* value
Stratum 1: normal range BMI[d] and low income (n=86)									
Low user[e]	1.30	0.64 to 2.64	.47	1.07	0.69 to 1.67	.76	−0.05	−2.88 to 2.77	.97
Mid or high user	1.56	0.72 to 3.38	.26	1.25	0.79 to 2.00	.34	2.56	−0.10 to 5.22	.06
Stratum 2: normal range BMI and higher income (n=161)									
Low user	0.83	0.40 to 1.75	.63	0.97	0.63 to 1.50	.90	−0.29	−2.24 to 1.66	.77
Mid or high user	0.94	0.47 to 1.87	.85	1.13	0.75 to 1.72	.55	0.64	−1.36 to 2.64	.53
Stratum 3: overweight or obese BMI and low income (n=82)									
Low user	1.31	0.81 to 2.13	.28	1.35	1.00 to 1.82	.05	2.31	−0.79 to 5.40	.14
Mid or high user	1.11	0.67 to 1.82	.69	1.03	0.72 to 1.46	.89	1.39	−1.78 to 4.56	.39
Stratum 4: overweight or obese BMI and high income (n=108)									
Low user	1.34	0.90 to 2.00	.15	1.09	0.84 to 1.43	.52	0.54	−2.08 to 3.16	.69
Mid or high user	1.13	0.75 to 1.70	.56	1.12	0.86 to 1.47	.40	−0.44	−3.19 to 2.30	.75

[a]All models have been adjusted for age, race, parity, and BMI.

[b]GWG: gestational weight gain.

[c]RR: relative risk.

[d]BMI: body mass index.

[e]Relative risk of excessive GWG and mean GWG estimates (kg) are relative to subjects who were nonusers (reference group).

Table 6. Intervention arm: Are grouped usage patterns (super user and consistent tracker groups combined) associated with gestational weight gain after adjustment for demographics?

Usage patterns[a]	Excessive total GWG[b]			Excessive GWG rate			GWG		
	RR[c]	95% CI	*P* value	RR	95% CI	*P* value	Estimate	95% CI	*P* value
Stratum 1: normal range BMI[d] and lower income (n=179)[e]	0.92	0.59 to 1.44	.71	0.93	0.69 to 1.26	.65	−0.32	−2.08 to 1.43	.71
Stratum 2: normal range BMI and higher income (n=319)	0.64	0.45 to 0.90	.01	0.72	0.57 to 0.90	.004	−1.49	−2.44 to −0.54	.002
Stratum 3: overweight or obese BMI and lower income (n=172)	1.28	0.98 to 1.68	.07	1.14	0.94 to 1.38	.19	0.74	−1.56 to 3.05	.53
Stratum 4: overweight or obese BMI and higher income (n=228)	0.87	0.73 to 1.02	.09	0.94	0.84 to 1.06	.31	−2.17	−3.58 to −0.76	.003

[a]All models have been adjusted for age, race, parity, BMI, and timing variables.

[b]GWG: gestational weight gain.

[c]RR: relative risk.

[d]BMI: body mass index.

[e]Relative risk of excessive GWG and mean GWG estimates (kg) are relative to subjects who were either medium users, inconsistent trackers, or nonusers (reference group).

Discussion

Principal Findings

We applied a novel approach, LCA, to understand usage of website features included in a GWG eHealth intervention. We examined patterns of usage for both the intervention participants and the control arm participants. This approach is a unique methodological contribution to process evaluations for self-directed Internet-based interventions where the most appropriate measures of engagement are not yet well defined. Usage patterns for both intervention and control arm participants varied by demographic characteristics. Higher-income, older, white, and married women in both arms were more likely to be higher users of the website. In the control arm, where the content of the website was primarily informational, women who were having their first baby were greater users.

In the control arm, GWG outcomes did not differ by usage pattern. While this was expected because behavior change and weight management tools were not included on the control website, documenting that lack of effect by amount of use helps in interpreting the relationship between amount of use of features in the intervention arm and weight outcomes. The concern is that amount of use is associated with a personality type that will have better outcomes, no matter what the content of the intervention is. The control group results indicate that this concern is likely not relevant to this study.

In the intervention arm, GWG outcomes did differ by usage pattern. Among participants with lower income and normal range BMI (stratum 1), almost consistent or inconsistent trackers had a higher relative risk of excessive GWG and inconsistent trackers gained more weight during pregnancy compared with the nonuser usage pattern. Among participants with normal range BMI and higher income (stratum 2), the consistent trackers had a lower relative risk of excessive weekly GWG rate compared with nonusers. Among overweight and obese higher-income participants (stratum 4), the consistent trackers gained less weight during pregnancy than nonusers.

In order to better understand the patterns of usage and GWG outcomes, we examined 2 of the usage groups together that included most frequent usage of the active ingredients of the intervention, weight gain tracking and behavioral goal setting and self-monitoring. We compared super users and consistent trackers with the 3 usage groups that used less of the hypothesized active ingredients in the pregnancy intervention (medium users, almost consistent or inconsistent trackers, and nonusers). In the higher-income stratum (strata 2 and strata 4), higher users of the active intervention ingredients were associated with reduced risk of excessive GWG total and in the normal range BMI women (stratum 2) for weekly rate. Across BMI categories, total GWG (kilogram) was significantly lower in the super and consistent users compared with the medium users, almost consistent or inconsistent trackers, and nonusers.

Strengths and Limitations

The strengths of this study are as follows: the intervention's measures of usage are objectively measured by the website and as such there is no study staff reporting bias for the intervention use variables; a large randomized effectiveness trial with an economically and racially diverse sample; a theory-based and formative research-informed Internet-based intervention.

A limitation of this research is that consistent weight tracking and logging in to the website was low and was particularly low among lower-income participants, with only 25% of low-income participants in either the consistent tracker or super user usage patterns. This affects the ability to detect statistically significant differences in the GWG outcomes between groups defined by usage.

Implications

This study used a novel, data-driven approach to process evaluations that may be particularly helpful for self-directed Internet-based interventions on any topic. This approach may further the understanding of how self-directed Internet-based intervention tools are used and whether there are benefits associated with different patterns of use. The implications for this particular self-directed Internet-based intervention to prevent excessive GWG vary by socioeconomic status of the women. For higher-income women there was a reduction in GWG, but not necessarily a significant reduction in rate or excessive GWG for overweight or obese higher-income women. For lower-income women there were no detectable effects of usage on GWG. Future self-directed Internet-based interventions should consider best approaches for consistently engaging lower-income women when the success of interventions is anticipated to depend on consistent use.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Demographic differences by excessive gestational weight gain (intervention arm).

[PDF File (Adobe PDF File), 36KB - jmir_v19i1e6_app1.pdf]

Multimedia Appendix 2

Demographic differences by excessive gestational weight gain (control arm).

[PDF File (Adobe PDF File), 36KB - jmir_v19i1e6_app2.pdf]

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Abbreviations

AIC: Akaike information criterion
BMI: body mass index
FAQ: frequently asked question
GWG: gestational weight gain
LCA: latent class analysis

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Original Paper

Effects on Engagement and Health Literacy Outcomes of Web-Based Materials Promoting Physical Activity in People With Diabetes: An International Randomized Trial

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Abstract

Background: Developing accessible Web-based materials to support diabetes self-management in people with lower levels of health literacy is a continuing challenge.

Objective: The objective of this international study was to develop a Web-based intervention promoting physical activity among people with type 2 diabetes to determine whether audiovisual presentation and interactivity (quizzes, planners, tailoring) could help to overcome the digital divide by making digital interventions accessible and effective for people with all levels of health literacy. This study also aimed to determine whether these materials can improve health literacy outcomes for people with lower levels of health literacy and also be effective for people with higher levels of health literacy.

Methods: To assess the impact of interactivity and audiovisual features on usage, engagement, and health literacy outcomes, we designed two versions of a Web-based intervention (one interactive and one plain-text version of the same content) to promote physical activity in people with type 2 diabetes. We randomly assigned participants from the United Kingdom, Austria, Germany, Ireland, and Taiwan to either an interactive or plain-text version of the intervention in English, German, or Mandarin. Intervention usage was objectively recorded by the intervention software. Self-report measures were taken at baseline and follow-up (immediately after participants viewed the intervention) and included measures of health literacy, engagement (website satisfaction and willingness to recommend the intervention to others), and health literacy outcomes (diabetes knowledge, enablement, attitude, perceived behavioral control, and intention to undertake physical activity).

Results: In total, 1041 people took part in this study. Of the 1005 who completed health literacy information, 268 (26.67%) had intermediate or low levels of health literacy. The interactive intervention overall did not produce better outcomes than did

the plain-text version. Participants in the plain-text intervention group looked at significantly more sections of the intervention (mean difference –0.47, 95% CI –0.64 to –0.30, P<.001), but this did not lead to better outcomes. Health literacy outcomes, including attitudes and intentions to engage in physical activity, significantly improved following the intervention for participants in both intervention groups. These improvements were similar across higher and lower health literacy levels and in all countries. Participants in the interactive intervention group had acquired more diabetes knowledge (mean difference 0.80, 95% CI 0.65-0.94, P<.001). Participants from both groups reported high levels of website satisfaction and would recommend the website to others.

Conclusions: Following established practice for simple, clear design and presentation and using a person-based approach to intervention development, with in-depth iterative feedback from users, may be more important than interactivity and audiovisual presentations when developing accessible digital health interventions to improve health literacy outcomes.

ClinicalTrial: International Standard Randomized Controlled Trial Number (ISRCTN): 43587048; http://www.isrctn.com/ISRCTN43587048. (Archived by WebCite at http://www.webcitation.org/6nGhaP9bv)

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KEYWORDS

health literacy; digital intervention; diabetes; quantitative trial; physical activity

Introduction

Health literacy has been defined as "knowledge, motivation and competences to access, understand, appraise, and apply health information" [1]. The capacity to understand and apply health information depends not only on the capabilities of the individual, but also on the way in which health information is presented. Well-designed materials to support self-management of health can help to improve health literacy outcomes such as knowledge, motivation, confidence, and adherence [2,3]. Lower levels of health literacy are associated with poor illness management, health knowledge, health service use, and health and with higher mortality. Addressing the challenges posed by low health literacy in populations has been highlighted as an urgent priority in many countries [4].

Barriers to accessing support for self-management of chronic health problems include disability, cost, work or family responsibilities, and lack of transport [5]. Studies have shown that these barriers are more common among people with lower levels of education [6]. Web-based health interventions may help address this problem, as they can be conveniently accessed in the home and reach large numbers of people at low cost, thereby having the potential to reduce health disparities [7]. Access to and use of the Internet through a personal computer or mobile phone is rapidly becoming common among more sections of the population, with over 80% of the adult population now using the Internet in the countries participating in this study [8]. However, low health literacy levels may present barriers to understanding and applying health information obtained from the Internet [9-11]. Lower levels of eHealth literacy are also associated with lower levels of healthy behavior, such as physical activity [12]. Therefore, reducing the "literacy burden" of online health information is an important strategy in making support for self-management of chronic conditions more accessible.

To date, interventions to reduce the literacy burden and improve health literacy have included using simple language, audiovisual or pictorial formats, interactivity, and tailoring of content to individuals' needs (if the intervention is Web based). Reviews of the effectiveness of such interventions for the general public and mixed-patient populations [13-17] and for diabetes [18-20] suggest that these techniques show promise for some outcomes, but that overall the evidence for improving health literacy or reducing the literacy burden is weak and inconclusive, and it remains unclear exactly which elements of such interventions improve which outcomes.

This study addressed the evidence gap regarding how best to design Web-based materials for the growing population of patients with basic literacy and computer skills but lower levels of health literacy. We developed a Web-based intervention to promote physical activity in people with type 2 diabetes, following established best practice for designing accessible Web-based written content. We included a range of interactive elements (quiz, tailoring, a planner) and audiovisual modes of presentation, so that we could evaluate whether these improved usage and health literacy outcomes, particularly in those with lower levels of health literacy. We used our person-based approach to intervention development [21], carrying out iterative qualitative research with people with high and low levels of health literacy to gain feedback to improve accessibility and engagement [22].

This paper reports on a subsequent large international quantitative study comparing this Web-based intervention with a static, plain-text presentation of identical content. The study evaluated engagement and heath literacy outcomes in people with varied levels of health literacy. We measured engagement by objectively recorded intervention usage and self-reported user experience (website satisfaction and whether participants would recommend the website to others) [23]. The primary research question asked whether an interactive, tailored, and audiovisual Web-based intervention would lead to better engagement than a plain-text version of the same content. Secondary research questions asked (1) whether we could design a Web-based intervention that people with lower and higher levels of health literacy find engaging, (2) whether these materials could improve health literacy outcomes for people with lower levels of health literacy, and (3) whether the materials would also be effective for people with higher levels of health literacy.

Methods

Intervention Development

Healthy Living with Diabetes is a tailored Web-based intervention to motivate people with type 2 diabetes to increase their physical activity. The intervention was developed by a team of health researchers at the University of Southampton, United Kingdom, in collaboration with the Diabetes Literacy research consortium [24], patient representatives, and an international expert panel.

We developed 2 Web-based interventions using the LifeGuide software, an open access platform for developing Web-based behavior change interventions [25]. The first was a plain-text version of the intervention, and the second was an interactive version of the intervention. Both versions included the same content, which was written and designed to be accessible for people with lower levels of health literacy and to be engaging and novel. To enhance engagement, the intervention content contained novel and compelling information about the benefits of physical activity for people with type 2 diabetes. To enhance accessibility, we followed good practice guidelines for accessible Web-based design and presentation of written content [26-31] in both interventions.

We designed the interactive version to assess the additional impact that interactivity, audiovisual features, and tailoring may have on engagement with the intervention and health literacy outcomes in people with varied health literacy levels. Audiovisual aspects of the interactive intervention were positive images throughout, and a series of audiovisual sequences demonstrating lifestyle and physical activities (tailored to age and sex). The interactive features of the website consisted of a quiz, a physical activity planner, and tailored advice, feedback, and images based on user responses to questions (such as current physical activity levels, attitudes to physical activity, age, and sex).

We first developed the intervention in English for testing in the United Kingdom, and then adapted and translated it for testing in Austria, Germany, Ireland, Taiwan, and the United States. Researchers in the United States did not take part in this subsequent trial. We followed our person-based approach to intervention development [21,32] to enhance acceptability and feasibility from the earliest stages of intervention development through an in-depth understanding of the views and perspectives of our target users. Full details of the development and qualitative evaluation of the intervention, including screenshots of the intervention, have previously been published [22].

Design

We carried out a multisite randomized trial in the United Kingdom, Austria, Germany, Ireland, and Taiwan to compare the interactive Web-based materials versus a plain-text Web-based version of the intervention. The plain-text intervention contained the same content and structure as the interactive version, but all tailoring, interactivity, and audiovisual features were removed. Ethics and research governance approvals were granted by the University of Southampton and UK National Health Service (NHS) research ethics committees (number 13/LO/0316).

Participants and Procedure

Participants were invited to take part in the study if they were over 18 years old with a diagnosis of type 2 diabetes, had access to the Internet, were able to read the intervention language (English, German, or Mandarin), and give informed consent. We recruited participants from the United Kingdom, Austria, Germany, Ireland, and Taiwan between July 2014 and March 2015. Minor country differences in recruitment procedures were permitted to allow for differing health care systems and patient access. UK participants were recruited through 43 primary care practices specifically selected for being in areas of high deprivation in order to reach more people with low health literacy. Participants in Ireland and Taiwan were recruited opportunistically by health care professionals in diabetes outpatient clinics, and participants in Austria and Germany were recruited through national diabetes support group newsletters and advertisements placed on the Internet. Health care professionals in the United Kingdom, Ireland, and Taiwan screened potential participants to exclude patients with potential difficulties, including severe mental health problems, palliative care, recent bereavement, and inability to complete research measures (eg, learning disability, inability to read or speak an intervention language) before they were invited to the study.

Participants from all countries were presented with details of the study, research team contact details for more information, and a website URL where they could log in to the Web-based intervention on their own time. Participant information stated that we were comparing two types of webpages to see which was more helpful; it did not mention website features such as interactivity or audiovisual features. Participants were therefore blinded to what the differences between the 2 arms were. Consent was given online, and participants completed a very brief baseline questionnaire before being randomly assigned to 1 of the 2 groups (with a 50% ratio). Participants were then presented with either the interactive or plain-text Web-based materials, depending on randomization assignment. Participants were asked follow-up questions immediately after using the intervention. All recruitment and follow-up procedures (including full study information, obtaining informed consent, baseline and follow-up data collection, and randomization) were Web based using automated procedures carried out by the LifeGuide software [25].

Sample Size

We calculated the sample size a priori using the G*Power 3 (version 3.1.9.2) sample size calculation program [33]. We calculated that a minimum sample size of 676 participants in total would be required to detect a small difference (effect size, Cohen d=0.25) between the 2 groups on our primary outcome measure of objective intervention usage, with alpha=.05 and beta=.1.

Measures

Participants completed Web-based assessments at baseline (immediately before) and follow-up (immediately after using the intervention materials). We collected demographic variables

at baseline, consisting of age, sex, time since diabetes diagnosis, and age they left full-time education. Participants' levels of physical activity during the previous week were measured at follow-up using the International Physical Activity Questionnaire-Short Form (IPAQ-SF) self-administered questionnaire assessing the minutes spent doing vigorous and moderate activity and walking in the last 7 days [34]. We scored the IPAQ-SF using the recommended categorical scoring system [35], where participants are categorized as being either (1) inactive, (2) minimally active, or (3) highly active.

We measured engagement with the Web-based intervention by intervention usage and self-reported measures of engagement. Intervention usage was measured by the number of intervention sections completed, as total time spent on the intervention was likely to be confounded with format (plain text vs interactive). Both the interactive and plain-text intervention were designed to comprise 5 distinct sections: knowledge of physical activity benefits (with/without interactive quiz); advice on selecting physical activities (with/without tailoring); advice on planning physical activity (with/without interactive planner); success stories (with/without audiovisual presentation); access to further information about undertaking physical activity. All intervention usage data was automatically recorded by the LifeGuide software [25]. Self-reported measures of engagement at follow-up were a previously validated 3-item measure of satisfaction with Web-delivered advice [36], and a single item measuring whether participants would recommend the website to friends and family with diabetes, based on the NHS Friends and Family Test [37].

Health literacy outcomes were (1) diabetes knowledge, (2) patient enablement, and (3) attitude, behavioral control, and intention to undertake physical activity. Diabetes knowledge was measured by a 9-item knowledge quiz based on the intervention content. Patient enablement was measured by 3 items from the Patient Enablement Instrument [38] assessing participants' perceptions of their understanding of the benefits of physical activity for people with diabetes, their ability to cope with diabetes, and confidence in managing their health. Participants completed these measures immediately after viewing the intervention. Attitude, behavioral control, and intention to undertake physical activity were measured by 3 items drawn from the theory of planned behavior [39]. Participants completed these items at baseline (immediately before viewing the intervention) and follow-up (immediately after completing the intervention) in order to assess change. Responses were given on a 7-point Likert scale (ranging from disagree to agree). These 3 items were (1) "Increasing my level of physical activity would be good for me" (physical activity attitude), (2) "I would find it easy to increase my level of physical activity" (perceived behavioral control), and (3) "I plan to increase my level of physical activity" (physical activity intentions).

We measured health literacy at baseline by a validated single item: "How often do you have problems learning about your condition because of difficulty understanding written information?" [40]. On the basis of this measure, we identified participants as having high, intermediate, or low levels of health literacy. Measures were translated from English to German and Mandarin and checked by each country's research team for accuracy. All measures were optional apart from age and sex, which were essential for tailoring.

Analysis

We analyzed the data using IBM SPSS for Windows version 14.0 (IBM Corporation) and Stata statistical software Special Edition Release 2007 (version 13; StataCorp LP), following a prespecified data analysis plan developed with our statistician (BS) and approved by the whole Diabetes Literacy consortium. All comparisons of the plain-text and interactive versions of the website controlled for potential confounding effects of the covariates health literacy, education, age, sex, and illness duration. We allowed for clustering by country by including country as a random effect in the model.

Due to the small numbers of participants with low health literacy levels, we categorized health literacy as low/intermediate compared with high health literacy. To avoid undertaking too many between-country comparisons, analyses by country compared UK data with a pooled sample of all other countries, as the UK sample was the largest and the intervention materials were originally developed for testing in the United Kingdom, and then translated and adapted for other countries and cultures.

The primary research question asked whether an interactive, tailored, and audiovisual Web-based intervention can lead to better engagement than a plain-text version of the same content can. The primary analysis compared the number of intervention sections completed by participants randomly assigned to the interactive intervention versus the number completed by participants randomly assigned to the plain-text intervention to test the prediction that more sections of the interactive version of the Web-based intervention would be completed. We used linear regression to compare the mean difference between intervention groups. We then examined whether intervention usage was moderated by health literacy level or by country. For these analyses, we carried out linear regressions to look for group differences by health literacy level and country. Post hoc exploratory analyses of Web usage were carried out using visualization analyses to examine patterns of intervention usage. Intervention usage data were analyzed using the LifeGuide visualization tool [41] to explore patterns of intervention use. This tool enables researchers to visualize and compare which intervention features were viewed, for how long, and in what order, across all participants.

Secondary research questions asked whether people with high and low health literacy found the materials engaging, and whether the intervention improved health literacy outcomes in people with lower and high levels of health literacy. In order to answer these questions, we analyzed self-report measures of engagement (website satisfaction; recommending the website to others) and health literacy outcomes (diabetes knowledge; patient enablement; and change in attitude, behavioral control, and intention to undertake physical activity) using linear regression models and then assessed for potential moderator effects by heath literacy level and country.

Missing Data

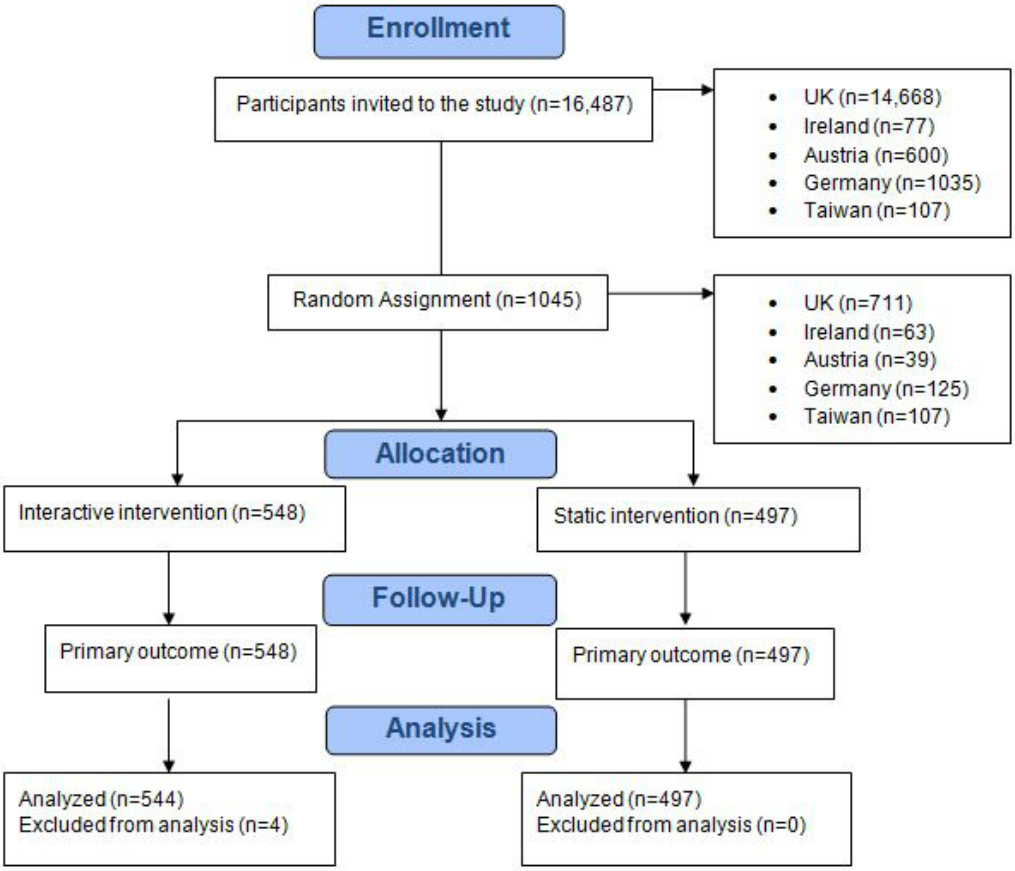
The main outcome for this study was intervention usage, which was automatically recorded by the intervention software for all participants and therefore had no missing data. We investigated levels of missing data for baseline and follow-up measures and compared the frequency of missing data between the 2 intervention groups. Levels of missing data were high for the diabetes knowledge quiz score (459/1041, 44.09% missing) and the single item measuring whether participants would recommend the intervention to others (231/1041, 22.19% missing data). We assumed that these were at random and applied a multiple imputation model of 100 imputations for missing secondary outcomes and key covariates. We present this analysis as a sensitivity analysis alongside the main analysis on complete cases.

Results

Participants

In total, 1045 participants from the United Kingdom, Austria, Germany, Ireland, and Taiwan participated in the study and were randomly assigned to view either the interactive intervention or the plain-text intervention. Of these, 4 participants used the Back button on their Internet browsers to be rerandomized and were consequently excluded, resulting in 1041 participants in the final analysis. We successfully measured the primary outcome, intervention usage, for 100% of randomly assigned participants. See Figure 1 for the Consolidated Standards of Reporting Trials (CONSORT) flow diagram.

Figure 1. Consolidated Standards of Reporting Trials (CONSORT) flow diagram.



Participant Characteristics

Participants in this study were predominantly male (662/1041, 63.59%), with a mean age of 62 years. On average, participants left full-time education before the age of 18 years and had been diagnosed with type 2 diabetes for 9.2 years (this ranged from just a few months to 50 years). The majority of participants (737/1005, 73.33%) had high levels of health literacy, while 268/1005 (26.67%) had intermediate or low levels of health literacy. A total of 835/1041 (80.21%) of participants completed the IPAQ-SF physical activity questionnaire. Most of these participants reported being inactive (561/835, 67.2%), while some reported being minimally active (190/835, 22.8%) and a minority reported being highly active (84/835, 10.1%). Participant characteristics were similar across both groups at baseline, with the only slight difference being higher health literacy levels in the interactive group. See Table 1 for participant characteristics by intervention group. Participant characteristics were similar by country (see Multimedia Appendix 1 for details).

Table 1. Participant characteristics in the 2 arms of the Web-based intervention promoting physical activity among people with type 2 diabetes.

Characteristic	Group	
	Plain-text (n=497)	Interactive (n=544)
Female, n (%)	182 (36.6)	197 (36.2)
Age in years, mean (SD)	61.5 (11.2)	62.4 (11.4)
Years since diagnosis, mean (SD)	9.1 (9.1)	9.5 (9.3)
Age when left full-time education, mean (SD)	17.8 (3.0)	17.8 (3.0)
Health literacy level (single-item measure), n (%)		
Low	37/478 (7.7)	30/527 (5.7)
Intermediate	105/478 (22.0)	96/527 (18.2)
High	336/478 (70.3)	401/527 (76.1)
Physical activity attitudes and intentions		
IPAQ-SF[a], mean (SD)	15.1 (3.5)	15.0 (3.7)
Highly active, n (%)	35/431 (8.1)	49/404 (12.1)
Minimally active, n (%)	106/431 (24.6)	84/404 (20.8)
Inactive, n (%)	290/431 (67.3)	271/404 (67.1)

[a]IPAQ-SF: International Physical Activity Questionnaire-Short Form.

Intervention Usage

The primary outcome in this study was Web-based intervention usage to test whether the interactive intervention led to better engagement than the plain-text version. Analysis of usage data found a significant difference in intervention usage between the 2 groups, with participants in the interactive intervention group being likely to complete fewer of the 5 intervention sections than were participants in the plain-text intervention group (mean difference –0.47, 95% CI –0.64 to –0.30, *P*<.001). Table 2 gives the results of intervention usage analyses.

Moderator analysis examined intervention usage by health literacy level. Participants with higher levels of health literacy were significantly more likely to complete more sections of the intervention (mean difference 0.25, 95% CI 0.05-0.45, *P*=.02; Table 3).

Table 2. Results of analysis of intervention usage as determined by number of sections completed, and results of self-reported measures of engagement and moderator analyses of self-reported engagement, by intervention group.

Analysis	Intervention group		Univariate difference		Multivariate difference[a]		Multivariate difference[a] based on 100 imputations	
	Plain text	Interactive	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value
Intervention usage								
No. of sections completed, mean (SD)	4.5 (1.3)	4.0 (1.5)	–0.47 (–0.64 to –0.30)	<.001	–0.49 (–0.67 to –0.31)	<.001	N/A[b]	N/A
Measures of engagement								
Satisfied with website, mean (SD)	4.1 (2.0)	4.1 (1.9)	0.03 (–0.24 to 0.30)	.82	0.05 (–0.22 to 0.33)	.70	0.08 (–0.19 to 0.35)	.54
Would recommend to others, n (%)	281/419 (67.1)	248/391 (63.4)	0.85 (0.64 to 1.14)	.28	0.85 (0.62 to 1.15)	.29	0.78 (0.58 to 1.05)	.10

[a]All analyses controlled for possible confounding by age, sex, time since diagnosis, age when the participant left education, health literacy, and for clustering by country.

[b]N/A: not applicable.

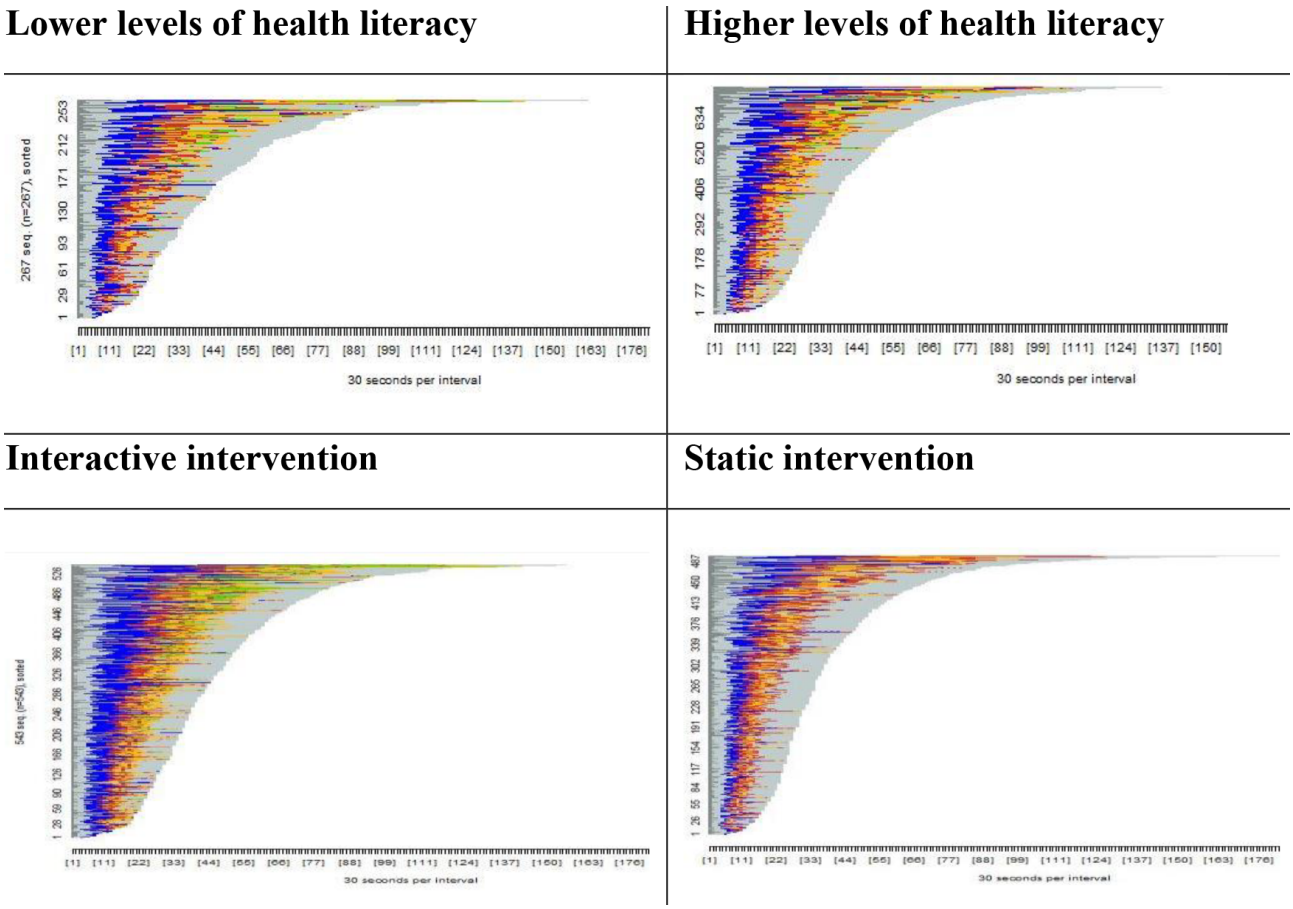
Table 3. Results of analysis of intervention usage as determined by number of sections completed, and results of self-reported measures of engagement and moderator analyses of self-reported engagement, by health literacy level.

Analysis	Health literacy level		Univariate difference		Multivariate difference[a]		Multivariate difference[a] based on 100 imputations	
	Lower	High	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value
Intervention usage								
No. of sections completed, mean (SD)	4.1 (1.5)	4.3 (1.4)	0.25 (0.05 to 0.45)	.02	0.28 (0.08 to 0.48)	.01	N/A[b]	N/A
Measures of engagement								
Satisfied with website, mean (SD)	4.1 (2.0)	4.1 (2.0)	–0.03 (–0.34 to 0.29)	.87	0.05 (–0.27 to 0.37)	.76	0.04 (–0.28 to 0.35)	.82
Would recommend to others, n (%)	139/195 (71.3)	372/591 (62.9)	0.70 (0.48 to 0.97)	.04	0.64 (0.44 to 0.93)	.02	0.69 (0.48 to 1.01)	.05

[a]All analyses controlled for possible confounding by age, sex, time since diagnosis, age when the participant left education, health literacy, and for clustering by country.

[b]N/A: not applicable.

Figure 2. Visualization of intervention usage by health literacy level and intervention. Blue: time spent on quiz; yellow: time spent on physical activity planner; red: time spent on reading personal tips; green: time spent on audiovisual sequences.



We carried out exploratory analyses to examine whether intervention usage differed by country (comparing the United Kingdom versus the other participating countries). Patterns of usage were similar in the United Kingdom and the other countries. See Multimedia Appendix 2 for details of intervention usage by country. Extensive visualization analyses of usage in the whole sample revealed no difference in how the intervention was used by health literacy level, age, sex, time since diagnosis, physical activity level, or change in physical activity attitude. Visualization analyses outputs illustrate intervention usage for the selected sample over time (in 30-second intervals). Visualization analyses comparing usage of the interactive intervention and the static intervention revealed that the interactive group spent more time on the quiz (represented by blue in Figure 2) and the physical activity planner (represented by yellow), while the static intervention group spent more time reading personal tips (represented by red). These differences could be explained by the interactive nature of the quiz and

planner adding to the time taken to complete them, while the lack of tailoring in the static intervention increased the reading burden for the personal tips section (since all tips were presented rather than just those tailored to the users). Similarly, we did not include audiovisual sequences (represented by green) in the static intervention and these are therefore represented only in the visualization of usage of the interactive intervention. See Figure 2 for visualization of intervention usage by health literacy level and intervention.

Self-Reported Measures of Engagement

The self-reported measures of engagement were website satisfaction and a single item measuring whether participants would recommend the website to others. We used these items to address the secondary research question asking whether Web-based materials can be developed to be engaging to people with low and high levels of health literacy. There were no significant group differences, with participants in both groups reporting high levels of website satisfaction and the majority of participants in both groups reporting that they would be likely to recommend the website to others. Table 2 and Table 3 give details of these results.

We carried out exploratory analyses to evaluate whether self-reported measures of engagement varied by health literacy level. Participants with lower health literacy were significantly more likely to recommend the website to friends or family with diabetes (mean difference –0.70, 95% CI 0.48-0.97, *P*=.04), although this difference was no longer significant following 100 imputations (mean difference 0.69, 95% CI 0.48-1.01, *P*=.05). There were no significant differences in website satisfaction, with participants with all levels of health literacy reporting high levels of satisfaction. See Table 3 for details. Moderator analysis found that the same pattern of results occurred in the UK data compared with other countries. See Multimedia Appendix 3 for details of moderator analyses by country.

Health Literacy Outcomes

Secondary research questions asked whether the Web-based materials could improve health literacy outcomes in people with low health literacy and be effective for people with higher levels of health literacy. The health literacy outcomes in this study were (1) diabetes knowledge, (2) patient enablement, and (3) change in attitude, behavioral control, and intention to undertake physical activity. There was a significant group difference in participants' diabetes knowledge, with participants in the interactive group scoring significantly higher than the plain-text intervention group (mean difference 0.80, 95% CI 0.65-0.94, *P*<.001). The diabetes knowledge measure had a ceiling effect with a large proportion of participants from both groups scoring highly. When comparing participants who answered all the questions correctly with those who got 1 or more wrong, the group difference was maintained and the interactive group was nearly 7 times more likely than the plain-text group to have answered all the questions correctly (mean difference 6.5, *P*<.001, 95% CI 4.4-9.4). There were no significant group differences in patient enablement, with participants in both groups reporting feeling more enabled as a result of using the intervention materials. Details of these results are given in Table 4.

Table 4. Health literacy outcomes by intervention group.

Outcome	Intervention group		Univariate difference		Multivariate difference[a]		Multivariate difference[a] based on 100 imputations	
	Plain text	Interactive	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value
Diabetes knowledge, mean (SD)	8.0 (1.1)	8.8 (0.5)	0.80 (0.65 to 0.94)	<.001	0.78 (0.63 to 0.92)	<.001	0.74 (0.50 to 0.88)	<.001
Diabetes knowledge score of 9 vs lower score, n (%)	124/303 (40.9)	228/279 (81.7)	6.5 (4.4 to 9.4)	<.001	6.9 (4.6 to 10.3)	<.001	4.90 (3.35 to 7.17)	<.001
Patient Enablement Instrument, mean (SD)	7.5 (3.1)	7.6 (3.0)	0.08 (–0.33 to 0.49)	.70	0.02 (–0.40 to 0.43)	.93	0.17 (–0.25 to 0.58)	.44

[a]All analyses controlled for possible confounding by age, sex, time since diagnosis, age when the participant left education, health literacy, and for clustering by country.

Moderator analyses explored these results by health literacy level. There was a trend for people with higher levels of health literacy to score higher on the Patient Enablement Instrument (multivariate mean difference 0.53, 95% CI 0.04-1.02, *P*<.03), although this was no longer significant following 100 imputations (mean difference 0.40, 95% CI –0.09 to 0.88, *P*<.11). There were no significant health literacy differences in diabetes knowledge acquired, with both groups scoring highly. See Table 5 for details. Moderation analyses by country showed a similar pattern of results for the United Kingdom compared with other countries; see Multimedia Appendix 4 for details.

Participants were asked about their attitudes and intentions toward physical activity at baseline and again at follow-up, enabling an analysis to establish whether the score had changed within each group. In both intervention groups, and across all health literacy levels, the score at follow-up was significantly higher than at baseline, indicating that participants from all groups had more positive attitudes and intentions toward physical activity after viewing the intervention materials. Table 6 shows the results of this analysis.

Table 5. Moderator analyses of health literacy outcomes by health literacy levels.

Outcome	Health literacy level		Univariate difference		Multivariate difference[a]		Multivariate difference[a] based on 100 imputations	
	Lower	High	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value
Diabetes knowledge, mean (SD)	8.2 (1.1)	8.4 (0.9)	0.16 (–0.02 to 0.35)	.09	0.13 (–0.05 to 0.30)	.16	0.13 (–0.06 to 0.32)	.18
Diabetes knowledge score of 9 vs lower score, n (%)	73/132 (55.3)	270/434 (62.2)	1.33 (0.90 to 1.97)	.16	1.31 (0.83 to 2.07)	.25	1.27 (0.84 to 1.92)	.26
Patient Enablement Instrument, mean (SD)	7.3 (2.8)	7.7 (3.1)	0.39 (–0.09 to 0.87)	.11	0.53 (0.04 to 1.02)	.03	0.40 (–0.09 to 0.88)	.11

[a]All analyses controlled for possible confounding by age, sex, time since diagnosis, age when the participant left education, and for clustering by country.

Table 6. Change in attitude behavioral control and physical activity intentions from baseline to follow-up across all groups and literacy levels.

Outcome	Plain text group		Interactive group		Lower health literacy		High health literacy	
	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value	Mean (95% CI)	*P* value
Physical activity attitude	0.10 (0.02-0.18)	.01	0.22 (0.11-0.34)	<.001	0.15 (0.02-0.27)	.02	0.15 (0.07-0.23)	<.001
Perceived behavioral control	0.34 (0.24-0.45)	.001	0.35 (0.22-0.47)	<.001	0.33 (0.17-0.49)	<.001	0.34 (0.24-0.43)	<.001
Physical activity intention	0.35 (0.24-0.45)	<.001	0.49 (0.35-0.63)	<.001	0.27 (0.10-0.44)	.002	0.46 (0.35-0.56)	<.001

Discussion

Principal Findings

The main finding of this study was that the interactive intervention overall did not produce better outcomes than those obtained by a plain-text version of the intervention. Participants in the plain-text intervention group showed higher levels of engagement by completing more sections of the intervention, although this did not lead to better health literacy outcomes, and participants in the interactive intervention group had better diabetes knowledge.

Health literacy outcomes significantly improved following the intervention to a very similar extent in both groups. These significant changes were reflected across all health literacy levels and all countries, with participants reporting increased beliefs in the benefits of physical activity, greater confidence in undertaking physical activity, and a stronger intention to increase physical activity as a result of the intervention. Given the low levels of physical activity reported by our sample, these changes in attitude to physical activity are positive, and it is encouraging that we observed these changes in those with lower levels of health literacy, since low self-confidence for physical activity has been shown to be a key mediator of the association between low health literacy and inactivity [42]. Diabetes knowledge was higher in the interactive group, suggesting that the interactive quiz format may have been useful for learning new information. Both interactive and plain-text intervention groups reported high levels of enablement as a result of viewing the intervention materials, and both intervention groups were likely to recommend the intervention to friends or family with diabetes.

Analysis by health literacy level revealed few differences. Participants with high levels of health literacy completed more sections of the intervention, but this did not lead to better health literacy outcomes. Participants with high health literacy reported higher levels of enablement, and participants with lower health literacy were more likely to recommend the intervention to others, but these differences were not significant after correcting for missing data. Despite these minor group differences, there are encouraging signs that the intervention design was accessible and helpful for people with all health literacy levels. These findings are consistent with evidence from previous research that interventions designed to be accessible for people with lower health literacy can be suitable for people with higher health literacy [15,22,43]. Participants with all health literacy levels reported high levels of enablement and were likely to recommend the intervention to friends or family members with diabetes. We observed similar patterns of results in the United Kingdom compared with other countries, suggesting the translated and adapted materials were equally effective. A detailed description and illustrations of the intervention have previously been published [22].

However, more work is needed to engage hard-to-reach populations in Web-based interventions. Despite deliberately sampling in socially deprived populations, we attracted surprisingly few people with lower levels of health literacy.

Limitations

This study did not succeed in recruiting many participants with very low levels of health literacy, and the results can therefore not be generalized to this group. It is also important to note that the results only refer to our version of interactivity, and others may be able to produce more engaging interactive materials. This study was not powered for examining interactions, and all subgroup analyses were exploratory and should be interpreted with caution. There were minor recruitment differences between countries, which should be taken into account when interpreting response rates. We did not undertake longer-term follow-up and therefore do not know the extent to which the immediate

intervention effect will endure in this population. Since this study did not include a control group, we cannot draw firm conclusions regarding the effectiveness of the Web-based intervention content, since changes in attitudes before and after viewing the content could in theory have been due to other factors.

Conclusion

In this study, a good, clear design and person-based intervention development [21,32] to establish an in-depth understanding of the views and perspectives of target users appears to have been more important than interactivity and audiovisual presentation when developing accessible digital health interventions to improve health literacy outcomes. This approach also seems able to be adapted for successful use in different counties and cultures. The finding that the same materials can be equally engaging for people with high and lower levels of health literacy is important, since the need to tailor or target interventions for different sectors of the population increases the complexity of interventions and could reduce their cost effectiveness. Consequently, well-designed digital communication materials that have been developed and evaluated for accessibility with a range of users may be sufficient as a means of filling unmet needs for improving health literacy. Looking to the future, more needs to be done to encourage and support intervention providers to develop Web-based materials that can benefit people with limited health literacy.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Participant characteristics by country.

[PDF File (Adobe PDF File), 31KB - jmir_v19i1e21_app1.pdf]

Multimedia Appendix 2

Moderator analysis of intervention usage by country.

[PDF File (Adobe PDF File), 19KB - jmir_v19i1e21_app2.pdf]

Multimedia Appendix 3

Moderator analyses of self-reported engagement by country.

[PDF File (Adobe PDF File), 20KB - jmir_v19i1e21_app3.pdf]

Multimedia Appendix 4

Moderator analyses of health literacy outcomes by country.

[PDF File (Adobe PDF File), 21KB - jmir_v19i1e21_app4.pdf]

Multimedia Appendix 5

CONSORT-EHEALTH checklist V1.6.2 [44].

[PDF File (Adobe PDF File), 678KB - jmir_v19i1e21_app5.pdf]

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Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
IPAQ-SF: International Physical Activity Questionnaire-Short Form
NHS: National Health Service

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Original Paper

Variations in Facebook Posting Patterns Across Validated Patient Health Conditions: A Prospective Cohort Study

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Abstract

Background: Social media is emerging as an insightful platform for studying health. To develop targeted health interventions involving social media, we sought to identify the patient demographic and disease predictors of frequency of posting on Facebook.

Objective: The aims were to explore the language topics correlated with frequency of social media use across a cohort of social media users within a health care setting, evaluate the differences in the quantity of social media postings across individuals with different disease diagnoses, and determine if patients could accurately predict their own levels of social media engagement.

Methods: Patients seeking care at a single, academic, urban, tertiary care emergency department from March to October 2014 were queried on their willingness to share data from their Facebook accounts and electronic medical records (EMRs). For each participant, the total content of Facebook posts was extracted. Using the latent Dirichlet allocation natural language processing technique, Facebook language topics were correlated with frequency of Facebook use. The mean number of Facebook posts over 6 months prior to enrollment was then compared across validated health outcomes in the sample.

Results: A total of 695 patients consented to provide access to their EMR and social media data. Significantly correlated language topics among participants with the highest quartile of posts contained health terms, such as “cough,” “headaches,” and “insomnia.” When adjusted for demographics, individuals with a history of depression had significantly higher posts (mean 38, 95% CI 28-50) than individuals without a history of depression (mean 22, 95% CI 19-26, *P*=.001). Except for depression, across prevalent health outcomes in the sample (hypertension, diabetes, asthma), there were no significant posting differences between individuals with or without each condition.

Conclusions: High-frequency posters in our sample were more likely to post about health and to have a diagnosis of depression. The direction of causality between depression and social media use requires further evaluation. Our findings suggest that patients with depression may be appropriate targets for health-related interventions on social media.

(J Med Internet Res 2017;19(1):e7) doi:10.2196/jmir.6486

KEYWORDS

Facebook; depression; natural language processing; social media

Introduction

More than two billion individuals worldwide have social media accounts [1]. Many, including 71% of adult Internet users in the United States, have a Facebook account, and 70% of users report utilizing the platform on a daily basis [2]. The digital divide is also narrowing because social media users are increasingly diverse, representing all strata of gender, race, age, income, and education [2]. Although social media is still evolving, the scope of human engagement with social media tools is vast, suggesting that these tools may be used to glean meaningful insights about human health and behavior. For example, prior work has shown that language used on social media can be used to predict county-level heart disease, track public sentiment around vaccines, and predict disease outbreak [3-6]. To identify the patient groups and disease entities most appropriate for targeting via social media interventions, we sought to examine differences in posting quantity on social media across health conditions.

In a given year, patients may only spend a few hours with clinicians in a physical, face-to-face context [7]. This amount of contact is limited in comparison to the vast majority of time that patients spend outside the confines of the doctor's office. The concept of "automated hovering" proposes the development of initiatives to follow patients' routine, everyday behaviors (eg, diet, exercise, and medication adherence) in a manner that is welcomed and convenient for patients for the purpose of improving health outcomes [7]. Given that Facebook's daily active user base is more than a billion people worldwide, this presents an opportunity to consider the potential for health intervention in the social media sphere [8].

Within public health, social media platforms are increasingly being explored as an avenue for health-related interventions. These interventions have included using Twitter to support smoking cessation efforts, Facebook to encourage physical activity in college students, and online forums to enhance emotional support among cancer patients [9-11]. Less focus has been on which diseases and which cohorts of patients will be the most receptive to social media interventions. Patients within disease groups who are already sufficiently engaged with social media may be the most likely to respond to social media interventions. Alternatively, due to the personal use of these tools, health interventions through these platforms may not be welcomed at all.

In this study, we focused on posting frequency and content on a social media platform (Facebook) as one particular measure of social media activity. We sought to (1) describe variability in social media use across a cohort of social media users within a health care setting and explore the language topics correlated with frequency of use, (2) evaluate the differences in the quantity of social media postings across individuals with different disease diagnoses, and (3) determine if patients could accurately predict their own levels of social media engagement to evaluate the ability to use self-report of social media usage as a proxy for actual use. This work has the potential to inform which patient groups may be most accessible for social media interventions.

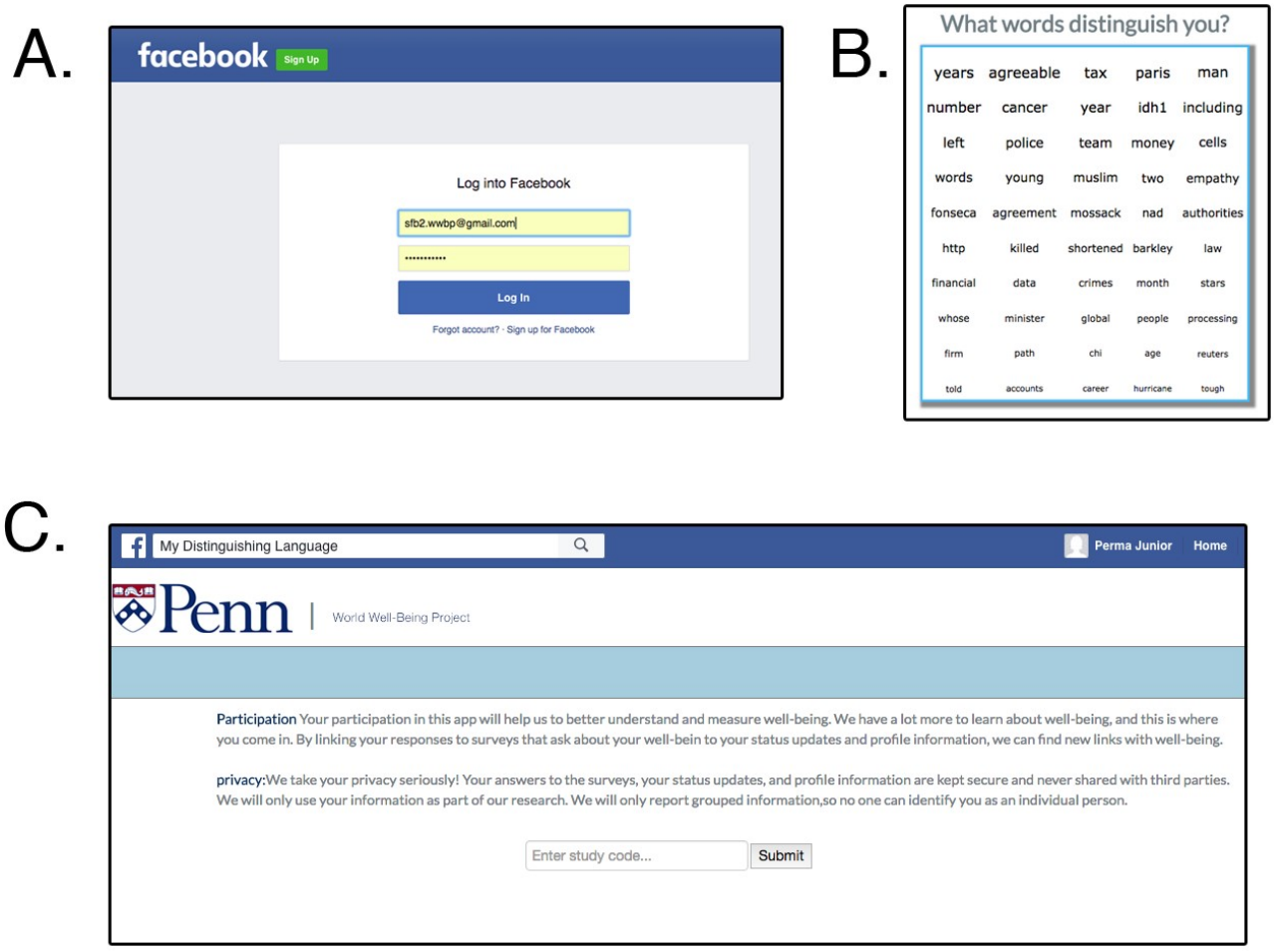
Methods

Study Design

This was a prospective study of patients seeking care in a single, urban, adult emergency department (ED) from March to October 2014. The study was approved by the Institutional Review Board at the University of Pennsylvania. Patients were excluded if they had severe trauma, were younger than 18 years, in respiratory distress, or had evidence of other severe illness. Patients were asked if they used Facebook. If patients responded affirmatively, they were asked about their willingness to participate in a study about social media. They were then told that the study entailed "sharing" data from their Facebook accounts (eg, statuses, photos, likes, demographics) and their electronic medical records (EMRs) with health researchers.

Participants willing to share their Facebook data underwent a thorough consent procedure. (A thorough analysis of sharer versus nonsharer subsets can be found in Padrez et al [12].) A written consent form was reviewed with a research assistant. A copy of the written consent was then given to the patient. The document explained the types of information that would be extracted from the patient's social media and EMR data. Patients willing to share their Facebook information were then directed to log in to their Facebook accounts and add a Facebook "plug-in" app related to this study. Before adding the plug-in, another agreement screen appeared detailing the information that would be automatically extracted by the research team. This app was designed for internal research use by the research team using Facebook's public "Graph" application programming interface (API) with the primary purpose of extracting status updates and limited account information [13]. A secondary function gives feedback to the user about their most frequently used language on Facebook relative to the general population. A screenshot of this Facebook app can be seen in Figure 1. The app only requires a Facebook account and is not tied to a specific browser or operating system.

Figure 1. Screenshots of data collection from the Facebook app. (A) illustrates the log-in page for the app, (B) illustrates a language description task for users, and (C) illustrates part of the consent and privacy process for the study.



Assessing Variability in Social Media Use Across a Cohort

To assess Facebook use across the study cohort, we used an automated process to extract data from each participant's Facebook account using the previously described Facebook app. We extracted the following variables from each user's Facebook account: number and content of status updates, and number of friends. For each participant, the total number of Facebook posts was extracted over 6 months prior to study enrollment.

Medical and social media data were stored on servers compliant with the Health Insurance Portability and Accountability Act at the University of Pennsylvania in accordance with protocols approved by the Penn Institutional Review Board.

Assessing Language Most Commonly Associated With High- and Low-Posting Frequency

To distil the language of our sample into a smaller feature space, we used a natural language processing technique; specifically, we used an unsupervised clustering algorithm, latent Dirichlet allocation (LDA) [14] implemented in the MALLET package [15]. LDA assumes that each document (in our case, each Facebook status post) is a mixture of "topics," in which each word is produced by one of the unobserved topics. The LDA algorithm automatically finds the maximum likelihood word-topic assignment, and produces topics that are clusters of words that tend to co-occur in documents; these can be days of the week or more abstract groups, such as profanity or words related to food and drink. The parameter for number of topics was chosen prior to any statistical analyses based on visual inspection with the goal of balancing topic coherence (specificity) with coverage of themes used in our Facebook post sample (sensitivity).

Assessing Variability in Social Media Use Across Disease Diagnoses

Demographic variables (age, race, and sex) were extracted from the patient's EMR. Using *International Classification of Diseases, Ninth Revision* (*ICD-9*) codes extracted from the EMR, we identified the top eight prevalent conditions in our sample based on each patient's available historical EMR (years 1997-2014). In addition, during enrollment, patients completed the Patient Health Questionnaire-2 (PHQ-2), a two-question depression screen [16].

Assessing Accuracy of Perception of Social Media Posting

During enrollment, participants were surveyed about their perceived frequency of posting on social media [2]. Patients were grouped into four categories based on their reported

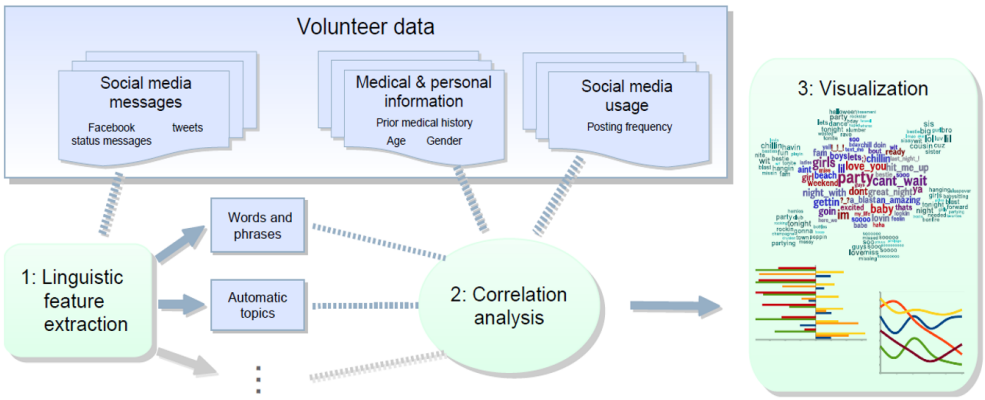
frequency of posting (≥3 times daily, 1-3 times daily, every few days, about once per week or less).

Statistical Analysis

Language and Posting Frequency

After deriving 500 topics, including the probability of each word given each topic, from our sample of Facebook status messages, we applied the topic models to each participant's complete Facebook posting history, giving us a distribution over the 500 topics for each participant. These made up our independent language variables. Each topic was correlated with a given outcome (eg, membership in the top-posting quartile), controlling for age, sex, and race. To determine the significance of a topic, each language variable (topic) was standardized and separately used as an independent variable in a linear regression to predict each outcome. Linear regression with a binary dependent outcome variable was employed to preserve interpretability of the coefficient; standardized linear regression coefficients are analogous to Pearson product moment correlation. Ordering of results did not change running the same analyses with logistic regression. Control variables (categorical age, race, sex) were binarized (eg, isFemale, isAgeBin1, isAfricanAmerican) and used as additional independent variables to extract the specific predictive power of the language variable. We obtained the standardized regression coefficient for the language variable (hereafter referred to as β), calculated *P* based on degrees of freedom, and then corrected for multiple comparisons (across 500 topics) using the Benjamini-Hochberg method [17]. Statistically significant topics were then presented as clusters of related words associated with posting frequency. For example, we specifically examined age-, race-, and sex-adjusted topics by quartiles of posting frequency. See Schwartz et al [18] for additional details on the language correlation analysis outlined here, as well as Figure 2 for an outline of this process.

Figure 2. Steps in language correlation analyses (adapted from Schwartz et al [17]). Broadly, step 1 involves deriving independent language variables from the aggregated participant Facebook language data. In step 2, language topics are correlated with other participant characteristics. In step 3, world clouds and other figures are created to visualize the language-characteristic correlations.



Posting Frequency and Diagnoses

Because the number of posts for each participant over time was not normally distributed, a log transformation was performed prior to analysis. To compare differences in quantity of Facebook posts across demographics and health conditions, we used the two-sample *t* test for binary variables and one-way ANOVA for variables with three or more categories. To further elaborate differences in posting between individuals with and without each disease condition, we employed an analysis of covariance (ANCOVA) adjusting for the covariates of sex, age, and race. For purposes of presentation, all transformed means are presented as the antilog (ie, data transformed back into their original form). These analyses were performed using SAS statistical software version 9.4 (SAS Institute, Cary, NC, USA).

Perception of Social Media Use

The mean number of actual posts was calculated within each category of perceived posting frequency and compared across groups using a one-way ANOVA. Projected number of posts was interpolated for each category based on the description over time (eg, a perception of posting 1-3 times daily over 6 months equates to an estimated total of 180-540 total posts in that time period).

Results

Enrollment and Demographics

A total of 1433 patients agreed to participate in a study related to social media and health. Of those, 1008 (70.34%) agreed to share their social media (eg, Facebook) and EMR for this study. Of these, 250 had accounts with inaccessible data. Of the remaining 748 participants, we excluded 53 (7.1%) participants who solely utilized Twitter and did not report having Facebook accounts. Among the 695 Facebook sharers, the mean age was 28.6 (SD 8.9) years, 74.0% (514/695) were female, and 70.4% (489/695) self-identified as African American/black. See Table 1 for statistics on the sample reported here.

Table 1. Facebook posts in the 6-month period prior to enrollment and demographics of participants (N=695).

Demographic	n	Mean (95% CI)[a]	*P* value
Sex			
Female	514	27 (24-32)	.006
Male	181	18 (15-23)	
Race			
African American/black	489	27 (24-32)	.04
White	141	19 (14-25)	
Other race	65	20 (13-31)	
Age (years)			
18-29	437	28 (24-33)	.02
30-39	173	20 (16-26)	
40-49	60	23 (15-35)	
>49	25	12 (6-23)	
Facebook friend count			
Q1 (874-4800)	173	40 (31-51)	<.001
Q2 (483-873)	175	22 (17-28)	
Q3 (295-482)	175	26 (21-34)	
Q4 (13-294)	171	16 (12-21)	
Posting frequency			
≥3 times daily	154	51 (40-66)	<.001
1-3 times daily	161	42 (33-53)	
Every few days	176	25 (20-32)	
Once per week or less	204	9 (7-11)	

[a]All analyses were performed using $\log_{10}$ of Facebook posts. Values transformed back for presentation purposes.

Variability in Social Media Use Across a Cohort

The mean number of posts in the previous 6 months was 25 (IQR 7-89), which equates to a mean of one post per week. The mean number of posts in the previous month was 4 (IQR 1-15), which similarly equates to a mean of one post per week. Because mean frequency of posting was consistent across the two time periods (1 month and 6 months prior to enrollment), we present data for the number of posts over the 6-month period prior to study enrollment. Table 1 illustrates the differences in posting frequency across demographics in our sample. Women posted a mean 27 (95% CI 24-32) posts compared to a mean 18 (95% CI 15-23) posts by men (*P*=.006). Participants older than 49 years had fewer mean Facebook posts (mean 12, 95% CI 6-23) compared to younger (age 18-29) participants (mean 28, 95% CI 24-33, *P*=.02). Across racial groups, patients identifying as African American had the highest posting mean (mean 27, 95% CI 24-32, *P*=.04).

Language of High-Frequency Users

To further characterize the differences in high- and low-frequency users, we developed topic word clouds using LDA. Figure 3 shows that the language topics most highly correlated with being in the highest quartile of Facebook posters (>90 posts in 6 months) related to health and illness. For example, the language topic most correlated with the highest quartile of posters (β=0.240) contained the words “sleep,” “wide,” “sleepy,” “insomnia,” and “wake.” The second-most correlated topic (β=0.214) contained the words “throat,” “sick,” “nose,” “hurt,” and “sore.” The third-most correlated language topic (β=0.183) contained the words “hurt,” “tummy,” “stomach,” “head,” and “bad.” The topics most negatively correlated with posting frequency (β=-0.174) contained language related to “wishes,” “birthday,” “special,” “wishes,” and “celebration.”

Variability in Social Media Use Across Disease Diagnoses

We examined differences in posting quantity across *ICD-9* health conditions with the highest prevalence (n>50) in our sample (Table 2).

Figure 3. Language of high- and low-frequency Facebook posters. (a) The blue text bubbles illustrate the language topics most positively correlated with participant posting frequency and (b) the green text bubbles illustrate the language topics most negatively correlated with participant posting frequency.

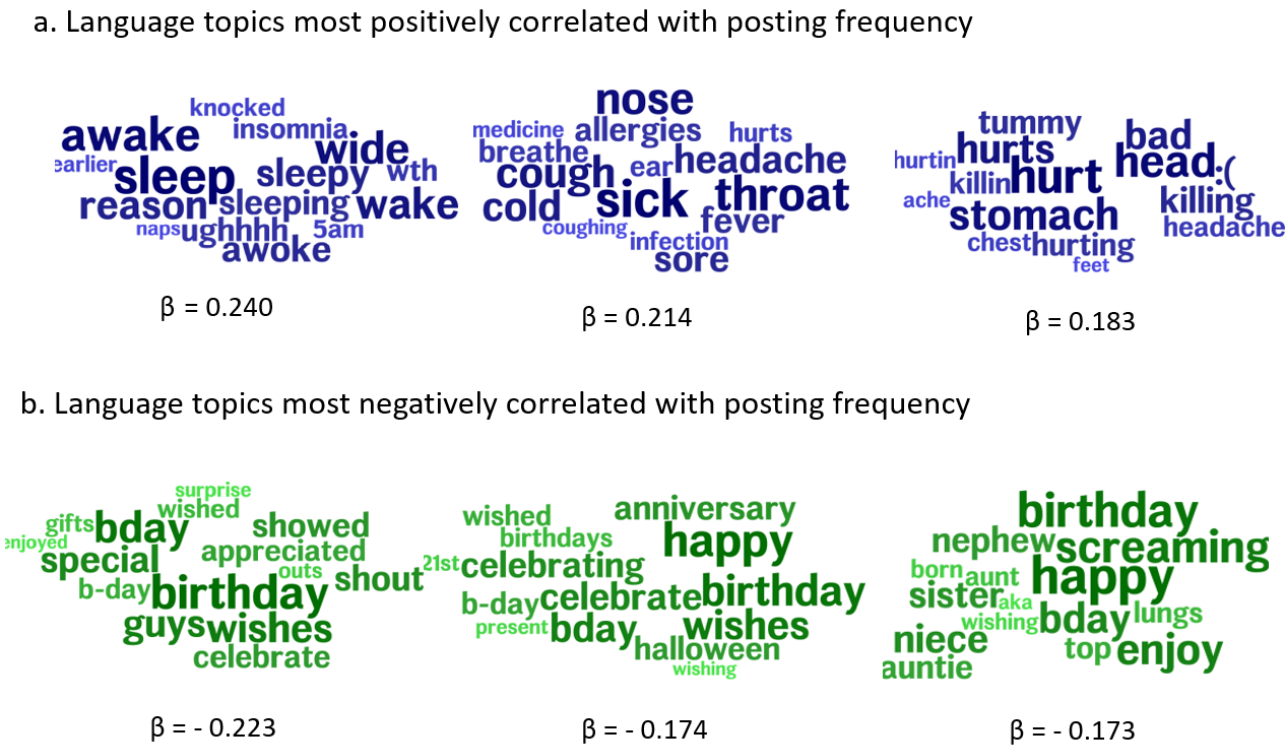


Table 2. Prevalence of most common conditions from the electronic medical record within our participant sample (N=695).

Condition	n (%)
Headaches	272 (39.1)
Back pain disorders	243 (35.0)
Anemia	177 (25.5)
Depression	134 (19.3)
Asthma	134 (19.3)
Neoplasm	108 (15.5)
Hypertension	98 (14.1)
Diabetes	66 (9.5)

We also compared posting quantity differences based on the results of the depression screen within the ED. Among patients who screened positive for depression in the ED, the mean number of posts was 38 (95% CI 27-52), which was notably higher than the postings of individuals who did not screen positive for depression (mean 23, 95% CI 20-26, *P*=.003). Individuals with a history of depression or asthma in their past medical history also had higher mean Facebook postings compared to individuals without a history of depression (depression: mean 38, 95% CI 29-50; no depression: mean 22, 95% CI 19-22, *P*=.001) or asthma (asthma: mean 34, 95% CI 24-45; no asthma: mean 25, 95% CI 20-26, *P*=.02). There were no significant differences in Facebook posting frequencies between patients with and without the following conditions: hypertension, diabetes, headaches, back pain, anemia, and cancer. After using an ANCOVA model to control for age, race, and sex, the depression screen and depression medical history were the only health outcomes that showed significant differences in mean posting quantities between patients with and without a disease (Table 3).

Table 3. Unadjusted and adjusted (sex, race, age) mean[a] Facebook posts in the 6 months prior to enrollment by presence or absence of highly prevalent *International Classification of Diseases, Ninth Revision* codes in the electronic medical record.

Health condition	n	Unadjusted mean posts		Adjusted mean posts	
		Mean (95% CI)	*P* value	Mean (95% CI)	*P* value
Depression screen					
Positive	120	38 (27-52)	.003	37 (27-49)	.005
Negative	575	23 (20-26)		23 (20-26)	
Depression					
Yes	134	38 (29-50)	.001	38 (28-50)	.001
No	561	22 (19-26)		22 (19-26)	
Asthma					
Yes	134	34 (25-45)	.02	31 (23-41)	.11
No	561	23 (20-26)		23 (20-27)	
Headaches					
Yes	272	29 (24-35)	.05	28 (23-34)	.69
No	423	22 (19-26)		23 (19-27)	
Anemia					
Yes	177	23 (18-30)	.57	22 (17-29)	.36
No	518	25 (22-29)		26 (22-30)	
Diabetes					
Yes	66	26 (17-40)	.73	29 (19-43)	.46
No	629	25 (21-28)		24 (21-28)	
Hypertension					
Yes	98	26 (18-37)	.78	30 (21-42)	.27
No	597	25 (21-28)		24 (21-27)	
Neoplasm					
Yes	108	24 (17-34)	.94	26 (19-36)	.69
No	587	25 (22-28)		24 (21-28)	
Back pain					
Yes	243	25 (20-31)	.96	25 (20-31)	.96
No	452	25 (21-29)		25 (21-29)	

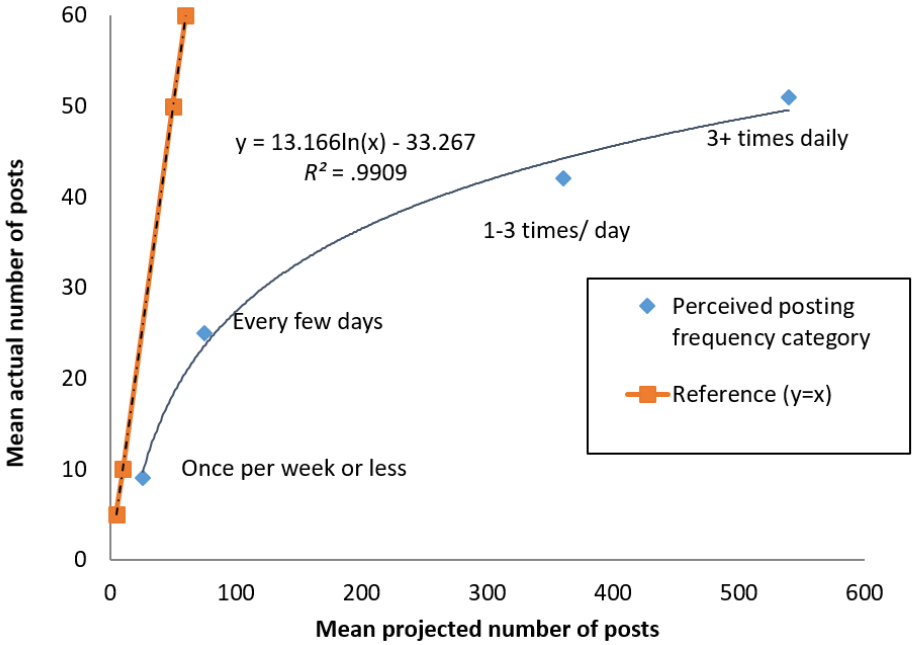
[a]All analyses were performed using $\log_{10}$ of Facebook posts. Values transformed back for presentation purposes.

Perception of Posting Frequency

Within the sample, 154 of 695 (22.1%) participants reported posting on Facebook three or more times per day, 154 of 695 (22.1%) reported posting one to three times per day, 176 of 695 (25.3%) reported posting once every few days, and 204 of 695 (29.3%) reported posting once a week or less. There was no significant variation in self-reported posting frequency based on gender, race, or age.

Participants who reported posting on Facebook more frequently did, in fact, have more Facebook posts. For example, in the 6 months prior to enrollment, among participants who reported posting three or more times daily, the mean total posts was 51 (95% CI 40-66) compared to mean 42 (95% CI 33-53) posts in the one to three times daily category, mean 25 (95% CI 20-32) posts in the every few days category, and mean 9 (95% CI 7-11) posts in the once per week or less category. The difference in mean posting frequency across the four posting frequency groups was significant over the 6 months prior to enrollment ($P<.001$). Figure 4 illustrates the logarithmic relationship between mean actual posting amount and mean projected posting amount based on the four categories of perceived posting quantity.

Figure 4. Actual versus projected mean number of posts by perceived posting frequency.



Discussion

Our study had four major findings: (1) there was significant variation in Facebook posting frequency within our patient sample; (2) high-frequency posters wrote about topics related to health; (3) when controlling for demographic variables, there were significant differences in Facebook posting quantities between individuals who screened positive for and/or had a clinical diagnosis of depression; and (4) patients are relatively good predictors of their Facebook posting frequency over time.

Variation in Social Media Posting

We found that there was significant variation in Facebook posting frequency within our patient sample. These differences may allow us to identify and distinguish health-related characteristics that are specific to subsets of patients based on their levels of social media use.

High-Frequency Posters Write About Topics Related to Health

The language topics most correlated with the highest quartile of users in our sample indicate that high-frequency users communicate about health and disease on Facebook profiles. This suggests that there may be further insights to be gained from studying the language of social media within this high-posting population. By contrast, among the low-frequency posters, the topics of “birthday” and “celebration” indicate that this subset of the sample is primarily posting on Facebook in response to being prompted by the Facebook platform (ie, to wish someone a happy birthday). The language of low-frequency posters may be less rich for identifying potential health interventions.

Depression and High-Posting Frequency

Our study suggests that posting frequency was associated with depression, but not with other disease diagnoses. Individuals screening positive for depression symptoms are more likely to post more frequently on Facebook, regardless of the content of their posts. As such, depression and other mental health conditions may be ideal candidates for pursuing social media interventions. We know that social media platforms are being mined for insights about health and disease with the potential for meaningful interventions [19,20]; in fact, Facebook recently introduced an online tool to help identify individuals at high risk for suicide [21].

There could be several explanations for our finding that high-frequency posting seemed to be more common in those with positive depression symptoms or a diagnosis of depression. In fact, our results provide an extension to a growing body of literature on this topic. Previous work by Bessière et al [22] showed that increased use of the Internet for the purpose of connecting with friends and family is associated with decreased rates of depression. However, work by Sagioglou and Greitemeyer [23] showed that increased Facebook usage, although distinct from total Internet use, correlated with negative mood. In contrast, other reports showed no association between time on social networking sites and PHQ-9 score [24]. Work by Hampton et al [25] suggested that high-frequency exposure to digital media may cause users to be more aware of stressful events in the lives of others, indirectly causing higher stress levels in the user, termed the “cost of caring” [26]. Other work by Steers et al [27] suggests that increased time on Facebook causes people to feel depressed due to comparative feelings of inadequacy. Our work is distinct within this growing body of literature in that we used a validated EMR, as opposed to self-report, to identify patient mental health conditions.

It is unclear at this point what direction the depression-posting relationship entails. Individuals in the developing stages of depression may be posting on Facebook with greater frequency as a means to reach out to a social network, escape a sense of isolation, or maintain connectivity. Conversely, it is possible that high-frequency activity on Facebook or any other virtual connectivity platform may contribute to underlying depression.

Either way, knowing that a user is a high-frequency poster may be a useful signal to indicate appropriate screening for depression.

Patients Predict Their Own Social Media Use

Accuracy of patient self-reported activity is often either unreliable or unknown in other domains of medicine [28-30]. If social media usage is ever deemed to be a risk factor for the development or presentation of an illness, our findings suggest that patients may provide reliable information regarding their own usage.

Limitations

This study has several limitations. Findings are reported from a convenience sample of primarily young, predominantly black women who enrolled via a single, urban, academic medical ED. These demographics are not nationally representative, but our sample did represent a target population with high rates of chronic disease. We also limited our analyses to Facebook, although we recognize that social media encompasses a broad range of ever-evolving online platforms. We also recognize that "posting" is merely one proxy of social media engagement because most people silently observe online activity without tangibly contributing, which is harder to observe and track [31].

Conclusion

Posting frequency on Facebook varied across demographics and health conditions. In our sample, individuals with depression were more likely to post more content on Facebook than those who were not depressed, suggesting that depression may be an ideal disease target for intervention on social media. Furthermore, the language of high-frequency posters illustrates that patients do post about health. Patients are relatively accurate assessors of their own social media posting habits.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface
ED: emergency department
EMR: electronic medical record
ICD-9: International Classification of Diseases, Ninth Revision
LDA: latent Dirichlet allocation
PHQ: Patient Health Questionnaire

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Original Paper

IntelliCare: An Eclectic, Skills-Based App Suite for the Treatment of Depression and Anxiety

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Abstract

Background: Digital mental health tools have tended to use psychoeducational strategies based on treatment orientations developed and validated outside of digital health. These features do not map well to the brief but frequent ways that people use mobile phones and mobile phone apps today. To address these challenges, we developed a suite of apps for depression and anxiety called IntelliCare, each developed with a focused goal and interactional style. IntelliCare apps prioritize interactive skills training over education and are designed for frequent but short interactions.

Objective: The overall objective of this study was to pilot a coach-assisted version of IntelliCare and evaluate its use and efficacy at reducing symptoms of depression and anxiety.

Methods: Participants, recruited through a health care system, Web-based and community advertising, and clinical research registries, were included in this single-arm trial if they had elevated symptoms of depression or anxiety. Participants had access to the 14 IntelliCare apps from Google Play and received 8 weeks of coaching on the use of IntelliCare. Coaching included an initial phone call plus 2 or more texts per week over the 8 weeks, with some participants receiving an additional brief phone call. Primary outcomes included the Patient Health Questionnaire-9 (PHQ-9) for depression and the Generalized Anxiety Disorder-7 (GAD-7) for anxiety. Participants were compensated up to US $90 for completing all assessments; compensation was not for app use or treatment engagement.

Results: Of the 99 participants who initiated treatment, 90.1% (90/99) completed 8 weeks. Participants showed substantial reductions in the PHQ-9 and GAD-7 (P<.001). Participants used the apps an average of 195.4 (SD 141) times over the 8 weeks. The average length of use was 1.1 (SD 2.1) minutes, and 95% of participants downloaded 5 or more of the IntelliCare apps.

Conclusions: This study supports the IntelliCare framework of providing a suite of skills-focused apps that can be used frequently and briefly to reduce symptoms of depression and anxiety. The IntelliCare system is elemental, allowing individual apps to be used or not used based on their effectiveness and utility, and it is eclectic, viewing treatment strategies as elements that can be applied as needed rather than adhering to a singular, overarching, theoretical model.

Trial Registration: Clinicaltrials.gov NCT02176226; http://clinicaltrials.gov/ct2/show/NCT02176226 (Archived by WebCite at http://www.webcitation/6mQZuBGk1)

(J Med Internet Res 2017;19(1):e10) doi:10.2196/jmir.6645

KEYWORDS

mHealth; eHealth; mobile health; depression; anxiety

Introduction

Psychological treatments, although effective in treating depression and anxiety [1,2] and preferred to psychopharmacological treatments by two-thirds of patients in primary care [3-6], are inaccessible by up to 75% of people due a variety of barriers including lack of availability of services, time constraints, transportation problems, and cost [7,8]. Furthermore, due to the high prevalence of both depression and anxiety disorders, we will likely never be able to meet the demand for services with standard one-on-one intensive treatments [9].

To overcome these barriers and meet treatment needs, a wide variety of Web-based treatments have been developed and shown to be highly effective in the treatment of depression and anxiety, particularly when coupled with some human support to promote adherence and enhance outcomes [10,11]. These programs, leveraging the strengths of computer-accessed Web programs in providing information, have strong psychoeducational components along with some interactional components that function much like worksheets [12].

Substantially less is known about the use of mobile phone apps for the treatment of anxiety and depression [13]. The use of mobile phones is rapidly increasing around the world, with 72% of Americans using mobile phones in early 2016—up from just 35% in early 2011 [14]. People use their phones for a variety of functions including supporting their health. A recent US national survey indicated that more than half of mobile phone users (58%) have downloaded at least one health-related mobile app [15], and more than half of outpatient psychiatry patients report wanting to use mental health apps [16].

A key challenge is designing apps to be useful and usable. The use of mobile phones and mobile phone apps tends to differ considerably from the use of desktop computers and websites with considerations ranging from screen real estate to where and when they are used. Although websites can be designed to be responsive and accessible via multiple devices, including mobile phones, if interactional styles remain highly didactic this approach fails to consider the unique affordances and challenges of using mobile phone apps [17]. For example, apps that require lengthy engagement times, or that have deeper navigation to provide multiple features do not fit well with how people use mobile apps. Typically, popular apps serve singular purposes, such as searching for restaurants or businesses, managing flights, or posting pictures. People tend to use apps in very short bursts of time, sometimes frequently [18,19]. Thus, apps tend to use simple interactions, are quick to use, and support a single or limited set of related tasks.

This creates a number of problems for the design of interactive apps aimed at improving mental health. Most apps provide psychoeducation via text or video, or simply facilitate logging symptoms or mood, requiring the bulk of treatment to be conducted elsewhere, such as face-to-face or through computer interfaces [20,21]. Given that for many people mobile phones represent their only access to the Internet [14], mobile phone intervention apps that do not require other devices will be important for broader dissemination. Furthermore, solutions that are independent of other treatment sources and use the app and mobile phone as the platform to enable new digitally enabled services can help provide a more distinct option from traditional approaches to mental health service delivery. Indeed, psychoeducational or curricular approaches tend to lean heavily on content and concepts from psychotherapy developed for face-to-face therapy, such as cognitive-behavioral therapy [22], which results in a skeuomorph, tunneling the vision of developers to the exclusion of innovation and limiting the options for consumers [23]. To address these challenges, we designed IntelliCare using the Behavioral Intervention Technology (BIT) Model as a framework [24] to be elemental, skills-based, and eclectic, and more consistent with a frequent, dynamic style of real-world interactions rather than a weekly, didactic model drawn from face-to-face practices.

IntelliCare is *elemental* in that it is a suite of apps, each supporting a single skill or using a single interactional style to support acquisition of a set of skills with a focused theoretical aim related to depression or anxiety (eg, goal setting, cognitive restructuring, exposure). This is consistent with the US Institute of Medicine's report outlining a framework for establishing evidence-based standards for psychosocial interventions, which recommended identifying effective treatment elements [25]. IntelliCare is *skills-based*, emphasizing in-the-moment practice of new skills over psychoeducational or curricular approaches. Most IntelliCare apps prioritize "doing" over knowledge acquisition. Thus, the user is prompted to *do* the task right at the beginning of the interaction. For most apps, there is no explanation prior to engagement. Apps were designed to make the interaction as intuitive as possible. Minimal didactic content relegated to a "Help" section in almost all apps. Apps are designed for brief, frequent interactions to be used in-the-moment, consistent with prevailing mobile phone use patterns using common interaction elements (eg, logging, checklists, reminders, simple gamification). IntelliCare is *eclectic*, as current evidence-based behavioral and psychological strategies come from diverse theoretical frameworks (eg, acceptance and commitment therapy, cognitive-behavioral therapy, positive psychology, problem-solving therapy). This is consistent with a growing movement arguing that treatment elements should be applied based on patient variables and preferences, rather than the theoretical orientation from which they evolved [26,27]. Therefore, the IntelliCare app suite is intended to be a framework that is extensible and modifiable.

Most of these apps have been available on the Google Play store since September 2014. A recent paper describing the first 10,131 downloads showed good use, with the mean app launch rate ranging from 3.1 to 17.0, and mean time from first to last launch ranging from 13.0 to 25.3 days, depending on the app [28]. However, evaluation of clinical benefit from that sample was lacking. Since the initial Google Play deployment, another app,

BoostMe, was added after extensive user research and usability testing, which focused on behavioral activation [29].

In addition to evaluating clinical efficacy, the other major departure between the Google Play store deployment and this study is the inclusion of coach support. The addition of a coach to support treatment and adherence with the program is important, given that coaching appears to improve outcomes with mobile interventions [30]. Although it is true that many stand-alone apps exist in app marketplaces, many offerings are beginning to include human support (eg, Coach.me, Ginger.io, Joyable, Lantern). Many human support models have been developed in the context of more psychoeducational programs, for example, [31,32]. Our objective was to develop and evaluate a lean, low-effort coaching protocol aimed at efficiently promoting use and positive outcomes that would be consistent with the interactional style of these apps.

The primary aim of this single-arm pilot study was to evaluate the change in depression and anxiety, as well as app use, during 8 weeks of IntelliCare supported by low-intensity coaching.

Methods

Participants

Participants were recruited from March 2015 to March 2016 from a variety of sources including the Minnesota-based health care system, HealthPartners, online (eg, ResearchMatch, Craigslist, Reddit, clinicaltrials.gov, social media advertising) and community (eg, print advertisements posted on public transportation, media) advertising, and clinical research registries. Recruitment materials informed participants that the study was examining the use of mobile phone apps to teach self-management skills for depression and anxiety.

Participants were included in this single-arm field trial if they exhibited depressive symptoms indicated by a score of 10 or higher on the Patient Health Questionnaire-9 (PHQ-9) [33], or anxiety symptoms indicated by a score of 8 or higher on the Generalized Anxiety Disorder-7 (GAD-7) questionnaire [34]; were 18 years of age or older (age 19 if in Nebraska, given age of consent); could speak and read English, living in the United States; and owned and were familiar with an Internet-ready Android mobile phone with data and text plans. The PHQ-9 and GAD-7 closely match the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria for major depressive disorder and generalized anxiety disorder, respectively. Furthermore, these measures are widely used in primary care settings and useful for identifying and monitoring depression and anxiety in clinical and general populations [35-37]. Thus, these inclusion criteria are similar to what might be expected to identify people at need for real-world deployments of similar treatment options. Participants were excluded if they had any visual, hearing, voice, or motor impairments that would prevent completion of study procedures; met diagnostic criteria for a severe psychiatric disorder (eg, bipolar disorder, psychotic disorder, dissociative disorder) or any other diagnosis for which this trial was either inappropriate or dangerous; exhibited severe suicidality including having ideation, a plan, and intent; had initiated or changed antidepressant or antianxiolytic pharmacotherapy in the previous 14 days; or had used any of the IntelliCare apps for more than 1 week in the last 3 months.

Procedures

The IntelliCare field trial was approved by the Northwestern University institutional review board and monitored by an independent data and safety monitoring reviewing board. People interested in participating completed an initial Web-based or telephone screener and, if eligible to continue, were sent the consent form. Once signed, the consent form was reviewed over the telephone with research staff to ensure understanding, after which people received an eligibility assessment consisting of a phone interview and Web-based questionnaires. People meeting eligibility criteria were offered participation in the field trial. As part of the field trial, participants received 8 weeks of coaching aimed at helping them use the IntelliCare app suite, and received additional assessments at weeks 4 and 8. Participants were compensated for completing all assessments and could earn up to US $90. Payment was not tied to app use or engagement in coaching.

IntelliCare Apps

The IntelliCare program consisted of 14 apps in total, including 13 clinical apps designed to improve symptoms of depression and anxiety through efficacious treatment strategies, and the “Hub” app, which coordinates a user’s experience with the clinical apps [28]. A description of each clinical app can be found in Table 1.

Table 1. Description of IntelliCare apps.

App	Behavioral strategy	Description
IntelliCare Hub		Manages messages and notifications from the other apps within the IntelliCare collection.
Aspire	Personal values and goal setting	Guides user to identify the values that guide one's life and the actions (or "paths") that one does to live that value. Helps keep track of those actions throughout the day and supports the user in living a more purpose-driven and satisfying life.
Day to Day	Psychoeducation and prompts	Delivers a daily stream of tips, tricks, and other information throughout the day to boost the user's mood. Prompts the user to work on a particular theme each day and every week; learn more about how to effectively cultivate gratitude, activate pleasure, increase connectedness, solve problems, and challenge one's thinking.
Daily Feats	Goal setting	Encourages the user to incorporate worthwhile and productive activities into the day. Users add accomplishments to the Feats calendar, where they can track their positive activity streaks and level up by completing more tasks. Helps motivate users to spend their days in more meaningful, rewarding ways to increase overall satisfaction in life.
Worry Knot	Emotional regulation and exposure	Teaches the user to manage worry with lessons, distractions, and a worry management tool. Provides a guided tool to address specific problems that a user cannot stop thinking about and provides written text about how to cope with "tangled thinking." Presents statistics about progress as the user practices coping with worry, gives daily tips and tricks about managing worry, and provides customizable suggestions for ways to distract oneself.
ME Locate	Behavioral activation	Provides a personal map for finding and saving user's mood-boosting locations. Assists the user in finding and remembering these places to help them make plans, maintain a positive mood, and stay on top of responsibilities.
Social Force	Social support	Prompts the user to identify supportive people in their lives, and provides encouragement for the user to get back in touch with those positive people.
My Mantra	Self-affirmations and positive reminiscence	Prompts the user to create mantras (or repeatable phrases that highlight personal photo strengths and values and can motivate one to do and feel good) and construct virtual albums to serve as encouragement and reminders of these mantras.
Thought Challenger	Cognitive reframing	Guides the user through an interactive cognitive restructuring tool to examine thoughts that might exaggerate negative experiences, lead one to be overcritical, and bring down one's mood. Teaches the user to get into the habit of changing perspective and moving toward a more balanced outlook on life.
iCope	Proactive coping	Allows the user to send oneself inspirational messages and reassuring statements, written in their own words, to help the user get through tough spots or challenging situations.
Purple Chill	Relaxation	Provides users with a library of audio recordings to relax and unwind. Teaches a variety of relaxation and mindfulness practices to destress and worry less.
MoveMe	Exercise for mood	Helps the user select exercises to improve mood. Provides access to curated exercise videos and to written lessons about staying motivated to exercise. Allows the user to schedule motivational exercise time for oneself throughout the week.
Slumber Time	Sleep hygiene	Prompts the user to complete sleep diaries to track sleep. Provides a bedtime checklist intended to clear one's mind before going to sleep. Provides audio recordings to facilitate rest and relaxation. Features an alarm clock function.
Boost Me	Behavioral activation	Encourages users to select and schedule positive activities ("boosts") when they notice a drop in mood and to track positive activities they note positively impacting their mood. Includes animated mood tracking for pre or post positive activities, calendar integration, and suggested activities that are auto-populated based on past mood improvement.

The apps prioritize the use of an interactive tool to help the user learn skills and engage in the treatment strategy. These tools are typically either on the first screen or accessible directly from it, thereby requiring little navigation. Tools are designed to be intuitive, requiring few instructions, and each app contains brief "tips" on the home screen to guide users through their first interaction with a new tool. Any didactic or psychoeducational material is usually available under the "Help" menu, usually in a template form that includes the following topics: (1) Why use this app, (2) How can this app help me, (3) How to use this app, (4) How often to use this app, (5) What might get in the way of using this app, and (6) Call to Action or What to do now. The clinical apps are available for free download on the Google Play Store.

The Hub app provides a number of organizing functions for users. It consolidates notifications, so those who have multiple IntelliCare apps have a single notification view, and all IntelliCare apps are listed and can be downloaded through the Hub app. The Hub app also provides recommendations for new apps (2 per week). In this trial, weekly recommendations for new apps were made randomly to support the development of the recommendation engine. Once the planned recommender engine is completed, app recommendations will be derived from algorithms of patterns of use data to identify apps that the person

will most likely use and find useful. Participants were also free to explore and download apps on their own. Participants were not restricted in the number of apps they could have on their phone or use at any given point in time. However, for this trial, participants were guided to choose 1 or 2 apps to focus on per week to provide them with an opportunity to build proficiency in these 1 or 2 skills. To support this model, the Hub app also contains a feature that allows users to identify 1 or 2 of the IntelliCare apps as "primary," meaning they are the main treatment focus for a given week, with the goal of having them try a variety of apps during the study period and learn several skills that help them accomplish their goals. Apps identified as primary are highlighted on the app's home screen.

Coaching Protocol

The coaching protocol was based on aspects of the Efficiency Model of BIT Support [38] and supportive accountability [39]. Coaching was aimed primarily at encouraging participants to try the apps recommended to them through the Hub app. Coaches also answered questions about how to use the tools found in the apps and the rationale behind the skills taught by the apps, encouraged application of skills in daily life, and provided some technical support as needed. Coaching began with an initial 30- to 45-minute engagement phone call to establish goals for mood and anxiety management, ensure the participant could download the Hub app from the Google Play store, introduce the suite of available mobile phone apps, build rapport, and set expectations for the coach-participant relationship. Thereafter, participants received 1-2 texts per week from their coach to provide support, offer encouragement, reinforce app use, and check-in on progress or challenges. Coaches also responded to all participant-initiated texts within 1 working day. Coaches were trained and monitored by one of the authors (KNT) and had at least a bachelor's degree.

The coaches had a dashboard that provided information about the IntelliCare apps on each participant's phone, including which apps were installed, when they were downloaded, each time an app was used, and which apps were selected as "primary" in the Hub app. The dashboard also included an short message service (SMS) messaging tool, a section for brief notes, and an alert indicating when no IntelliCare app had been used for 3 days, prompting coaches to check in.

Coaches were explicitly prohibited from making any recommendations about which apps to use, primarily because the aim of developing a recommender system required for that use and app selection reflect users' intentions and actions. Thus, the major focus in the early part of the trial was on encouraging engagement with the IntelliCare system, but not influencing which app or how frequently any particular app was used. This balance proved difficult to manage, resulting in confusion among participants about how they should use the IntelliCare system and the role of coaches (this information came from participant feedback interviews used for quality improvement) and difficulty on the part of coaches in how to manage participants' confusion. Minor clarifications and adjustments were made to coaching protocol to try to address these issues; however, approximately halfway through the field trial, a somewhat more substantive modification was made to address these concerns. The protocol was changed such that coaches made a clear recommendation during the engagement call that participants focus on learning 1 new app per week, and this was reinforced by checking via a text asking which app they selected (even though this was usually visible on the dashboard). Coaches were instructed to encourage participants to first review the recommended apps and then explore the list of apps on their own when deciding which app to focus on for the week. If the participant reported being unsure about which app to choose, or directly asked the coach for a recommendation, coaches were then able to provide suggestions for specific apps. A 10-minute phone call at week 4 was also offered to check in on participant experiences with utilization of the program and any relevant concerns with the coaching.

Coaches

Coaches (N=4) had at least a bachelor's degree in psychology or a related field. Coaches received a detailed coaching manual, as well as training in the principles of coaching and motivational interviewing strategies. Coaches were also required to use the IntelliCare apps daily over several weeks during the training period and encouraged to continue to use the apps to maintain fluency with various aspects of treatment. Coaches also received 30-60 minutes of individual supervision per week, and also attended weekly group supervision including ongoing training didactics. Training and supervision were provided by one of the authors (KNT), who also authored the coaching manual.

Assessment and Measurement

At baseline, prospective participants were screened and characterized using the Mini International Neuropsychiatric Interview (MINI). The MINI [40], a structured interview, was administered over the telephone by trained clinical evaluators who were supervised by a PhD level psychologist. Demographic information was collected via a self-report survey. Questions about pharmacotherapy and psychotherapy use were added shortly after the trial began, and 2 participants were not administered these questions. This explains the different denominator used for these results. Depression and anxiety were measured at baseline, week 4, and week 8 using the PHQ-9 and GAD-7, respectively. All assessment data were collected and managed using REDCap electronic data capture tools hosted at Northwestern University [41].

App use data from app launch and use logs were collected passively. An app use session is defined as a sequence of user-initiated actions or events separated by less than 5 minutes between events. A new app launch is defined as a new activity after 5 min of no activity (we note that some apps have audio or video content that may last longer than 5 min, in which case the running content is counted as activity). The length of an app use session is the time from first launch or use of an app to the last event in a session.

Statistical Analyses

Baseline demographic and clinical characteristics were reported as frequency and percent for categorical variables and median and interquartile range (IQR) for continuous variables. Outcome measures over time were reported as means and standard deviations. Baseline characteristics were compared between

participants meeting preliminary screening criteria and participants ultimately enrolled using a 2-sample *t* test for continuous variables and a chi-square test for categorical variables. Linear mixed-effects models were used to evaluate continuous PHQ-9 and GAD-7 scores over time and associations between participant demographic characteristics. Generalized linear mixed-effects models were used to evaluate symptom remission (PHQ-9<10 and GAD-7<8) over the study period. Participants completing at least two follow-up assessments were included in the analysis of primary outcomes. Usability of the IntelliCare apps were reported using frequencies and means. Session frequency over the course of the study period was evaluated using generalized linear mixed-effects regression models assuming a normal distribution. Differences in total app use sessions and total app time across participant demographic characteristics were assessed using the nonparametric Wilcoxon rank-sum test. All analyses were performed using SAS, version 9.4 (Cary, NC, USA).

Results

Participants

A total of 105 participants consented and were enrolled in the field trial. Of those enrolled, 6 participants did not respond to attempts to initiate treatment. An additional 3 participants did not complete any follow-up assessments after the baseline assessment, resulting in final analytic samples of 99 participants with usability data and 96 participants with at least two outcomes assessments. The flow of patients through the study is displayed in Figure 1.

Baseline characteristics of participants can be found in Table 2. The depression criterion of a PHQ-9 total score ≥10 was met by 78.1% (82/105) enrolled participants. The criterion for anxiety of a GAD-7 total score >8 was met also met by 78.1% (82/105) participants, and 60% (63/105) met criteria for both depression and anxiety.

Figure 1. CONSORT Diagram of participant flow.

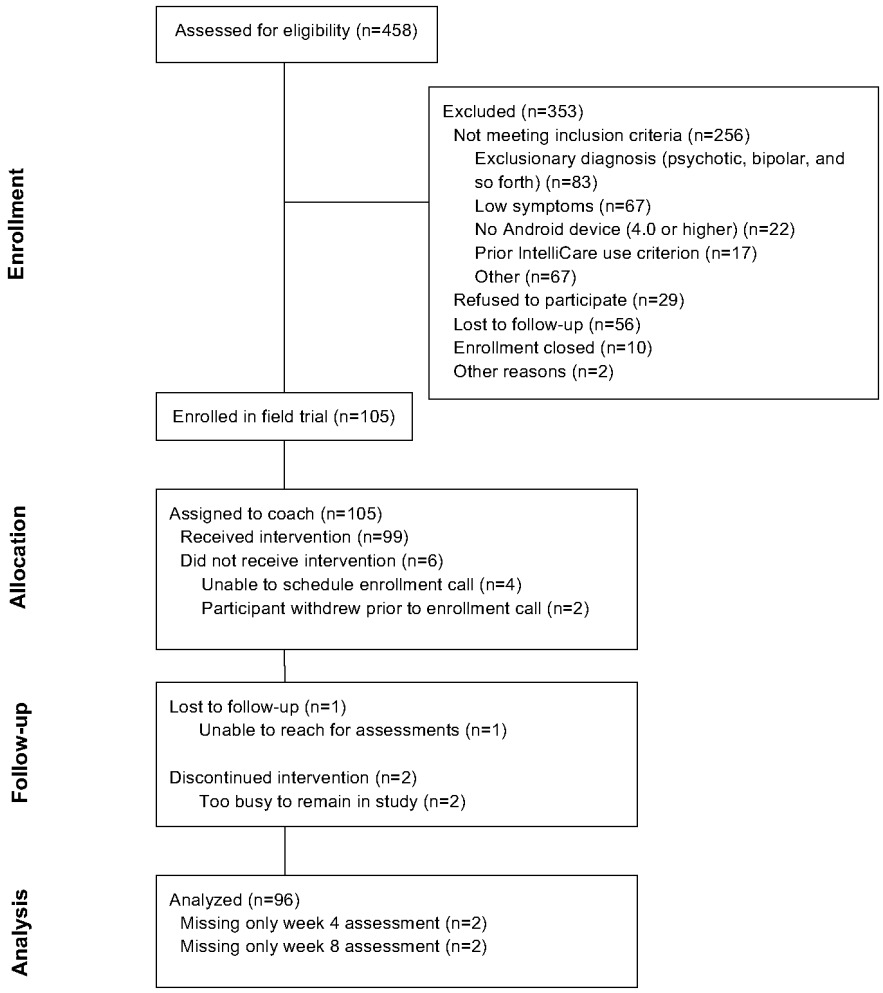

Table 2. Sample characteristics (N=105).

Demographics	Median (IQR[a]) or n (%)
Age (years), median (IQR)	36 (27-50)
Gender, n (%)	
Female	80 (76.2%)
Male	25 (23.8%)
Ethnicity, n (%)	
Not Hispanic or Latino	99 (94.3%)
Hispanic or Latino	5 (4.8%)
Declined to report	1 (1.0%)
Race, n (%)	
Black or African American	8 (7.6%)
American Indian or Alaska Native	1 (1.0%)
Asian	6 (5.7%)
White	88 (83.8%)
More than 1 race	1 (1.0%)
Declined to report	1 (1.0%)
Marital status, n (%)	
Single	35 (33.3%)
Married or domestic partner	38 (36.2%)
Separated	1 (1.0%)
Divorced	13 (12.4%)
Widowed	3 (2.9%)
Living with significant other	15 (14.3%)
Education, n (%)	
Some high school	1 (1.0%)
Completed high school or GED[b]	4 (3.8%)
Some college	20 (19.1%)
2-year college (Associate)	16 (15.2%)
4-year college (BA, BS)	37 (35.2%)
Master’s degree	22 (21.0%)
Doctoral degree	4 (3.8%)
Professional degree (MD, JD)	1 (1.0%)
Employment status, n (%)	
Employed	76 (72.4%)
Unemployed	11 (10.5%)
Disability	8 (7.6%)
Retired	5 (4.8%)
Other	5 (4.8%)
Number of hours per week spent working, median (IQR)	40 (7-40)
Income, median (IQR)	
Current total yearly household income	US $63,000 (30,000-100,000)
Current total yearly personal gross income	US $35,000 (15,000-58,000)

Demographics	Median (IQR[a]) or n (%)
Treatment, n (%)	
Psychotherapy	23 (21.9%)
Pharmacotherapy (n=103)	66 (64.1%)
Recruitment source	
HealthPartners Healthcare System	38 (36.2%)
Web or social media	16 (15.2%)
ReearchMatch	11 (10.5%)
Other	40 (38.1%)

[a]IQR: interquartile range.

[b]GED: general educational development.

Table 3. Means and standard deviations of outcome measures.

Outcome	Baseline n=96	Week 4 n=94	Week 8 n=94	Pre or post effect size (Cohen d)	*P* value
PHQ-9[a], mean (SD)	12.5 (4.3)	8.4 (4.1)	6.4 (4.3)	1.4	<.001
GAD-7[b], mean (SD)	10.9 (4.5)	7.1 (3.9)	5.8 (4.0)	1.2	<.001
PHQ-9 >10, n (%)	76 (79.2%)	36 (38.3%)	21 (22.3%)	N/A[c]	<.001
GAD-7 >8, n (%)	74 (77.1%)	42 (44.7%)	28 (29.8%)	N/A	<.001

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

[b]GAD-7: Generalized Anxiety Disorder-7

[c]N/A: not applicable.

Pharmacotherapy was used by 64% (66/103) of participants, 22% (23/103) reported engaging in psychotherapy, (17% (18/105) reported using both pharmacotherapy and engaging in psychotherapy, and 30% (32/105) were untreated at baseline. There were no significant relationships between treatment status (pharmaco- or psychotherapy) and PHQ-9 or GAD-7 (*P*>.52). Among participants who met preliminary screening criteria (n=244), those who were enrolled (n=105) did not differ significantly from those not enrolled (n=139) on demographic data including age (*P*=.46), gender (*P*=.66), ethnicity (*P*=.55), race (*P*=.12), or score on PHQ-8 (*P*=.97) or GAD-7 (*P*=.96).

Outcomes for Depression and Anxiety

Descriptive statistics for outcome measures over time are summarized in Table 3 for participants completing at least two assessments.

Significant improvements were seen across the entire sample for both PHQ-9 (*P*<.001) and GAD-7 (*P*<.001). Among participants meeting entry criteria for depression, significant reductions were present on both the PHQ-9 (*P* ≤.001) and the GAD-7 (*P* ≤.001). Similarly, among participants meeting entry criteria for anxiety, significant reductions were present on both the PHQ-9 (*P* ≤.001) and the GAD-7 (*P* ≤.001).

At the end of the treatment, 37% (35/105) of participants met criteria for full remission or no symptoms of depression (PHQ-9<5), 40% (38/105) met criteria for recovery or mild symptoms (PHQ-9=5-9), and 22% (21/105) continued to meet criteria for referral for treatment (PHQ-9≥10). Similarly, 42% (39/105) of participants met criteria for full remission or no symptoms of anxiety (GAD-7<5), 45% (42/105) met criteria for recovery or mild symptoms (GAD-7=5-9), and 14% (13/105) continued to meet criteria for referral for treatment (GAD-7≥10).

Neither baseline PHQ-9 nor GAD-7 were significantly related to changes in depression or anxiety severity, or concurrent treatment with psychotherapy or pharmacotherapy (*P* s>.19). There were no significant relationships between gender, education, ethnicity, or use of psychotherapy or antidepressants in either the PHQ-9 or GAD-7 outcomes (*P* s=.10-.79). There was a significant effect of age on GAD-7 total score, with greater age being associated with improved anxiety (*P*=.01), although age was not associated with PHQ-9 scores (*P*=.20).

App Usage

Trial participants initiated an average of 191.4 (SD 139.2; median 180) IntelliCare treatment app sessions during the 8 weeks of the trial. Of the 99 participants who initiated the treatment, 96.0% (95/99) continued to use the apps at week 5 and 90.1% (90/99) continued through week 8. Table 4 reports the mean and median number of treatment app sessions by study week, which did not change significantly over time (*P*=.10).

Table 4. Mean number of treatment app use sessions by study week.

Week	n used	Mean (SD)	Median	Interquartile range	Minimum	Maximum
1	98	20.09 (15.63)	15	10-26	0	105
2	97	22.79 (16.76)	20	11-31	0	81
3	97	24.1 (20.21)	20	10-31	0	124
4	94	25.33 (20.68)	20	10-37	0	100
5	94	26.07 (20.41)	23	12-35	0	103
6	91	26.25 (23.66)	21	7-41	0	117
7	89	23.44 (22.27)	18	6-37	0	126
8	90	23.3 (25.57)	14	8-30	0	163

Table 5. Mean frequency of individual treatment app and Hub app use sessions.

App	n used	Mean (SD)	Median	Interquartile range	Minimum	Maximum
Day to Day	78	34.4 (48.3)	14	1-50	0	230
Daily Feats	73	25.8 (32.1)	17	0-39	0	217
Slumber Time	72	18.3 (21.3)	13	0-27	0	109
Purple Chill	81	17.8 (17.9)	13	3-28	0	77
My Mantra	62	15.4 (21.8)	6	0-26	0	100
Thought Challenger	82	13.4 (16.3)	8	2-17	0	70
Aspire	73	13.0 (15.2)	9	0-17	0	68
iCope	70	11.7 (20.6)	4	0-11	0	125
Boost Me	68	10.1 (11.1)	7	0-14	0	47
Move Me	74	9.9 (12.8)	5	0-14	0	67
Worry Knot	74	9.2 (10.6)	7	0-12	0	55
Social Force	56	6.9 (11.1)	2	0-9	0	60
Me Locate	51	5.5 (8.5)	1	0-9	0	42
Total	99	195.4 (141)	182	95-263	9	844
Hub app	99	107.32 (71.29)	92	51-152	6	372

The average length of use for each session was 1.4 min (SD 3.9; median 18 seconds). The Hub app was launched an average of 107.3 (SD 71.3; median 92) times over the 8 weeks.

There were no significant relationships between age, education, employment status, gender, race, or ethnicity and the number of treatment app sessions or the length of time spent in the apps (P=.18-.68). There were significant effects of age, gender, and antidepressant medication on total time spent using the apps. Older patients tended to use the apps for a longer time than younger patients (P=.003), as did women (P=.03) and participants using medications (P=.01). Additionally, there was a marginal effect for engagement in individual psychotherapy (P=.055) or pharmacotherapy (P=.054) with those in treatment spending more time in the apps.

Table 5 shows the mean frequency of individual treatment app and Hub app use sessions over the 8 weeks of treatment.

Eight (8.1%) participants downloaded 5 or fewer of the IntelliCare Treatment apps, 60 (60.6%) downloaded between 6 and 10 apps, and 31 (31.3%) downloaded 11-13 apps. The Hub app was launched at least six times by all participants who initiated treatment over the study period.

Coaching

Among the 99 participants who initiated treatment, 97% (96/99) continued to participate in coaching at week 5, and 93% (92/99) continued through the end of the trial. Because some texts were broken into more than 1 SMS transmission, we report here on days when texts were sent, rather than number of texts, to avoid inflating results. On average, coaches sent texts to participants on 22.2 (SD 4.7) study days (39.6%) over the 8 weeks of treatment. Participants sent texts to their coach on an average of 16.7 (SD 5.8) study days (29.9%). All 99 participants who initiated treatment received an engagement call, lasting on average 39.1 (SD 7.7) minutes. The first 34 participants did not receive an offer for a midpoint follow-up call. In response to

participant feedback interviews indicating some confusion around procedures, expectations, and the role of the coach, a second call was offered to participants beginning with the 35th person enrolled, which lasted on average 12.8 (SD 8.5) minutes.

After the change in the coaching protocol, participants no longer commented on confusion surrounding the role of coaches. There was no significant difference in outcomes on the PHQ-9, GAD-7, number of app sessions, or total time on IntelliCare apps between participants receiving the initial and revised coaching protocols (P=.33-.90).

App Use Before and After the Trial

Because IntelliCare apps were freely available on the Google Play Store, we examined the number of people who had used apps prior to enrolling in the study. Of the 99 who initiated treatment, 33.3% (33/99) had used at least one of the apps for an average of 16.6 days (SD 11.2; median 15) prior to enrollment. There was no significant difference in outcomes on the PHQ-9, GAD-7, number of app sessions, or time using apps (P=.29-.93) between those with prior exposure to the IntelliCare apps and those without.

After completion of the study, 33.7% (29/99) people continued to use the IntelliCare apps 2 weeks later, 20.9% (18/99) at 1 month, 22% (19/99) between months 1 and 2, and 23.2% (20/99) beyond 2 months.

Safety

There were no adverse events (eg, suicide attempts, psychiatric hospitalizations).

Discussion

Principal Findings

In this pilot feasibility study, the IntelliCare apps and coaching showed large reductions in symptoms of depression and anxiety. These improvements were largely consistent across many demographic variables, although outcomes were slightly worse for those who reported receiving disability slightly better for older participants. Outcomes were unrelated to whether or not the participant was receiving psychotherapy or antidepressant medications during the treatment.

App usage was substantial, with an average of 195 app launches per participant over the course of 8 weeks of treatment. This is considerably higher than has been reported for other apps that have ranged on the order of 15-22 launches in total [21,42]. There are several likely reasons for this. First, the design of the IntelliCare suite is markedly different from other apps. Most of the IntelliCare apps are intended to be used frequently and briefly; other apps that have been described in the literature do not necessarily have the same frequency expectations. In addition, IntelliCare is a suite of apps, in which people are expected and encouraged to swap apps in and out of their use rotation, thereby maintaining novelty and engagement. Finally, while the use statistics for IntelliCare apps downloaded "in the wild," without a coach or participation in a study, were also much higher than is typically seen [28], use statistics in this study were far higher than even those, which was likely the result of our use of low-intensity coaching. Given coaching required only around 40-50 min of call time per subject, along with a small amount of time for composing and sending text messages, IntelliCare has the potential to be very cost-effective.

Novel Treatment Design

The approach used here differs substantially from previous mHealth and eHealth interventions for depression or anxiety in several ways. First, IntelliCare apps are very interactive, emphasizing the application of skills through in-app actions. Most eHealth interventions for depression or anxiety have used psychoeducational approaches, and mobile phone approaches have tended to use the phone primarily for symptom and mood monitoring, leaving primary treatment to clinicians or websites [20,21,43]. These interventions attempt to provide understanding for the user as part of an effort to persuade the person to engage in a new treatment behavior (eg, engaging in positive behaviors or thought restructuring). The IntelliCare apps place the action (eg, goal setting, checklists, reminders, logging, and so forth) at the beginning of the interaction. Most IntelliCare apps have only limited explanation of why the action would be useful, most of which is relegated to the Help section. Thus, users download the app and begin with the exercise, not the explanation. Essentially, IntelliCare operates from the assumption that doing is learning. Understanding will come from doing, and it is not necessary that everyone have the same understanding for the exercise to be useful.

The interactions supporting skills training were designed to be brief and frequent. Given there is little to no explanation, interactions are designed to be as intuitive as possible. With mean app session lengths of 1 minute, median app session rates of 17 seconds, and mean weekly app use frequencies of 21-29, with no drop-off over time, that goal appears to have been achieved.

IntelliCare was designed to be eclectic. Apps draw from a variety of theoretical orientations, and users are encouraged to identify apps they perceive as useful and consistent with their goals rather than following a particular conceptual model. Indeed, 95% of participants used 5 or more apps during the study, supporting the notion that users are willing to use multiple apps even when they are not necessarily organized by a therapy orientation. In this way, approaches that construct metaphorical toolboxes through digital tools might be a good way to present potential options and allow individual users to tailor treatment and select options that fit their own interests and need, for example, [44,45]. Furthermore, the Hub app was used frequently, supporting the idea that that apps or interfaces that help organize these toolboxes might help improve user experience across such apps.

Future Research

A longer-term goal for IntelliCare is to develop a recommender system that will be able to use passively collected data, such as app usage, to identify and recommend apps that are likely to be acceptable and useful to the individual. Thus, while the recommendations offered through the Hub app in this study were random, the Hub app is intended to provide recommendations that are of value to the user. Rather than basing such recommendations on rules derived from a

psychological orientation, recommendations will be based on accumulating knowledge from the entire population of app users. Such a system could be modifiable and extensible, identifying apps that are underperforming so that they can be removed from the system and accommodate the introduction of new apps. Thus, while the focus of this study has been largely on the apps within the IntelliCare system, the longer-term vision for IntelliCare is as a platform that can use available data acquired from the suite of apps to monitor efficacy and provide evidence-based recommendations. The theoretical underpinnings for such a system have been described elsewhere [46] and are the focus of ongoing research.

Coaching Protocol

This field trial used a coaching protocol aimed at encouraging efficient use of the apps [39,47]. This protocol was developed with 2 aims in mind. First, the literature generally suggests that human support enhances adherence and perhaps outcomes for digital interventions [10]. Our open deployment on Google Play suggested that, compared with many health apps [38], IntelliCare apps appear to be relatively engaging, with mean number of uses ranging from 3.1 to 17.0, and mean time from first to last launch ranging from 13.0 to 25.3 days, depending on the app [28]. This field trial found use rates that far exceeded those rates; however, it is difficult to compare these 2 sets of findings because the Google Play deployment analyzed data from anyone who downloaded the app, while this study selected participants with significant symptoms and sufficient motivation to be in a research study. Additionally, the coaching protocol aimed to ensure sufficient use of a variety of the apps that could help support analytics necessary to develop a recommendation engine.

It is interesting to note that changes made to the coaching protocol during this field trial had no observable impact on symptoms or app usage. This is notable because the user feedback interviews conducted for quality improvement at the end of the study indicated that participants were much clearer about the role of the coaches after this change in the coaching protocol. This impression was also mirrored by greater clarity among coaches in their role.

Finally, this is the first study we are aware of that has evaluated a freely available digital intervention in a coached form, and thus shed light on the relationship between digitally enabled services and the apps or tools available on app stores that support them. About a third of participants had prior exposure to the apps, and a third continued to use them after the end of coaching. Those who used apps prior to engaging with the study and treatment may have been evaluating the apps before committing to the treatment and study, and indeed some people found their way to the study through the apps. This suggests that apps may serve both as an initial point of evaluation for potential patients, as well as a conduit through which services can be provided. This is very consistent with marketing practices for digitally enabled services generally, and apps and websites designed for the possibility of both self-guided and human-supported consumer experiences that are becoming increasingly more frequent in the mental health space.

Limitations

A number of limitations should be noted in considering these results. First, because this was a single-arm trial, we cannot rule out the possibility that the improvement in depression and anxiety, although impressive, was due to factors other than IntelliCare. For example, it is possible that we recruited a sample that was likely to improve anyway. Second, if the IntelliCare system did in fact have a positive impact, we cannot disentangle the effects of the coaching and the apps. Third, the coaching protocol was not constructed under ideal circumstances, as coaches' role encouraging the use of the overall system conflicted in practice with the prohibition from influencing participants' use of specific apps. Fourth, it is possible that study compensation contributed to treatment adherence. We believe this is unlikely, given participants were clearly informed that compensation was for completion of assessments only, and the university's payment processing system results in delays of up to 2 months for payments. Finally, the apps are currently available on Android only, and this user base and their use of apps might be different from users of other platforms. Our team plans iOS development, which will address this shortcoming.

Conclusions

These shortcomings notwithstanding, this study showed clear support for a novel mHealth system for providing mental health treatment. Although other groups, such as the National Center for Telehealth and Technology, have developed multiple mental health apps covering diverse treatment strategies, targets, and populations (eg, Breathe2Relax, CBT-i Coach, Moving Forward, Positive Activity Jackpot, PTSD Coach, T2 Mood Tracker), IntelliCare represents the first effort to make a unified, consolidated app experience. Novel features of the IntelliCare system include that it is elemental, allowing individual apps to be used or not used based on their effectiveness and utility and it is eclectic, viewing treatment strategies as elements that can be applied as needed rather than based on 1 theoretical model. The future of mHealth is likely not to rest on a singular approach, or a singular app. Therefore, it is necessary to consider platforms that can consolidate efforts across a variety of apps such as IntelliCare.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

IntelliCare: Selected Annotated Screenshots.

[PDF File (Adobe PDF File), 1MB - jmir_v19i1e10_app1.pdf]

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Abbreviations

BIT: behavioral intervention technology
GAD-7: Generalized Anxiety Disorder-7
IQR: interquartile range
MINI: Mini International Neuropsychiatric Interview
PHQ-9: Patient Health Questionnaire-9
SMS: short message service

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Original Paper

Translating E-Mental Health Into Practice: What Are the Barriers and Enablers to E-Mental Health Implementation by Aboriginal and Torres Strait Islander Health Professionals?

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Abstract

Background: With increasing evidence for the effectiveness of e-mental health interventions for enhancing mental health and well-being, a growing challenge is how to translate promising research findings into service delivery contexts. A 2012 e-mental health initiative by the Australian Federal Government (eMHPrac) has sought to address the issue through several strategies, one of which has been to train different health professional workforces in e-mental health (e-MH).

Objective: The aim of the study was to report on the barriers and enablers of e-MH uptake in a cohort of predominantly Aboriginal and Torres Strait Islander health professionals (21 Indigenous, 5 non-Indigenous) who occupied mainly support or case management roles within their organizations.

Methods: A 3- or 2-day e-MH training program was followed by up to 5 consultation sessions (mean 2.4 sessions) provided by the 2 trainers. The trainer-consultants provided written reports on each of the 30 consultation sessions for 7 consultation groups. They were also interviewed as part of the study. The written reports and interview data were thematically analyzed by 2 members of the research team.

Results: Uptake of e-MH among the consultation group was moderate (22%-30% of participants). There were significant organizational barriers to uptake resulting from procedural and administrative problems, demanding workloads, prohibitive policies, and a lack of fit between the organizational culture and the introduction of new technologies. Personal barriers included participant beliefs about the applicability of e-MH to certain populations, and workers' lack of confidence and skills. However, enthusiastic managers and tech-savvy champions could provide a counter-balance as organizational enablers of e-MH; and the consultation sessions themselves appear to have enhanced skills and confidence, shifted attitudes to new technologies, and seeded a perception that e-MH could be a valuable health education resource.

Conclusions: A conclusion from the program was that it was important to match e-MH training and resources to work roles. In the latter stages of the consultation sessions, the Aboriginal and Torres Strait Islander health professionals responded very positively to YouTube video clips and apps with a health education dimension. Therapy-oriented apps and programs may fit less well within the scope of practice of some workforces, including this one. We suggest that researchers broaden their focus and definitions of e-MH and give rather more weight to e-MH's health education possibilities. Developing criteria for evaluating apps and YouTube videos may empower a rather greater section of health workforce to use e-MH with their clients.

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KEYWORDS

e-mental health; indigenous populations; Aboriginal and Torres Strait Islander peoples; professional supervision; professional consultation; service implementation; health education; mobile apps

Introduction

A National E-Mental Health Strategy

e-Mental Health (e-MH) is gaining traction, nationally and internationally, as a way to increase access to mental health services and deliver treatment in a cost-effective manner [1]. Research suggests that for some common mental health problems, e-MH treatments can be just as effective as face-to-face treatments [2], although in service delivery contexts, considerable variability is reported [3,4].

Drawing on the reported positive impacts of e-MH and the potential to increase access to mental health services for all Australians [5], the Australian Federal government developed a national e-MH strategy [6]. One element of this was the development of a national Web-based therapy service, the MindSpot Clinic [4,7]. Another element was the e-Mental Health in Practice (eMHPrac) project, an initiative to provide health professional training in both patient-facing and provider-facing e-MH interventions.

E-Mental Health in Practice

The Australian government established eMHPrac initially as a 3-year project (2013-16), recognizing that, in order to translate e-MH from research to clinical practice, health provider training was a prime requirement. Since the e-MH role of health providers (eg, general practitioners vs psychologists) tends to differ (eg, appropriate referral vs providing guided self-help), separate arms of the project were established to train 3 groups of health providers: GPs, allied health professionals, and health professionals providing services to Aboriginal and Torres Strait Islander peoples. This study focused on the experiences of a group of Aboriginal and Torres Strait Islander health professionals who were providing services to Aboriginal and Torres Strait Islander peoples.

Aboriginal Mental Health

The extent of mental ill health and psychological distress in Aboriginal and Torres Strait Islander communities has been well documented and closely linked to intergenerational trauma and to current levels of disadvantage and disengagement [8]. Aboriginal and Torres Strait Islander adults are almost 3 times more likely to experience high or very high levels of psychological distress than other Australians; have high rates of substance abuse; and have 2-5 times the rate of suicide compared with other Australians [9-11]. Indigenous citizens of other westernized countries (eg, Native Americans, Inuit, Maori) also experience high degrees of psychological distress and historical trauma [12-14], which suggests the possible relevance of our project for other Indigenous peoples.

Availability and Potential of e-MH for Indigenous Peoples

e-MH research with Indigenous peoples has been hampered by a lack of culturally appropriate e-MH resources. At the start of our project, there were already many Web-based therapy programs and apps available for majority cultures and a large body of outcome studies. In contrast, there have still not been, to our knowledge, any e-MH therapy outcome studies for Indigenous peoples from any country.

When we started the study, the availability of e-MH therapy resources for Australia's Indigenous peoples was restricted to just one Indigenous-specific app, Stay Strong, which could be downloaded onto iPads. Stay Strong is a strength-based app with specific Indigenous content and imagery [15], which has been designed for health workers to use with Indigenous clients. For a Youtube video demonstration of Stay Strong, see [16]. Stay Strong uses cognitive behavioral principles to (1) set SMART goals, (2) build social support, and (3) identify and change behaviors that are either enhancing or diminishing mental health. An earlier paper-and-pencil version of Stay Strong had proved to be valuable in working with Aboriginal and Torres Strait Islander clients [15]. The iPad version had previously received strong endorsement from our local advisory groups and learning circles and from Northern Territory health professionals and community members as acceptable and appropriate [17,18]. Hence, Stay Strong was included as a core part of the training program.

Provision of Training in Culturally Appropriate e-MH for Aboriginal and Torres Strait Islanders

With regard to culturally appropriate e-MH training, there has been an initial eMHPrac report from a Northern Territory training program showing that practitioners reported gains in knowledge, skills, and confidence in use of Stay Strong when comparing pre- and immediate posttraining measures [19]. The study was consistent with other reports in the literature showing that one-off workshops can influence practitioner knowledge and attitudes [20]. However, to date, no study has addressed day-to-day e-MH implementation with Indigenous peoples in Australia or elsewhere.

Several other studies have suggested that "low-intensity interventions" delivered by health providers without specialist knowledge of psychological therapies may potentially be useful, if delivered in a culturally appropriate way [15,21-23]. Hence, the current training included Aboriginal health providers with limited knowledge of psychological therapies.

The Importance of Follow-Up Supervision or Consultation Sessions

A burgeoning literature on the impact of one-off workshops now suggests that training without follow-up supervision, consultation, or reflection is largely ineffective in influencing therapist behavior and patient outcomes [24-26]. Therefore, for best results, it appears that follow-up consultation or supervision should be offered if practitioners are to gain maximum benefit from training programs.

Accordingly, for our study, Aboriginal and Torres Strait Islander health providers who received a 2- or 3-day training in e-MH strategies (the R U Appy program) were offered monthly follow-up consultation sessions to reinforce learning from the training program. The distinction between consultation and clinical supervision is that consultation focuses on the further development of specific intervention techniques, and is usually provided by experts who are external to an organization; while clinical supervision usually focuses on the practitioner's clinical

work with specific patients, and is often provided by a senior staff member internal to the organization [25].

A dual consultation model with one Aboriginal and one non-Aboriginal consultant-trainer was developed for our project to provide both e-MH expertise and cultural safety. This was based on a proposal from a recent study of issues affecting supervision and support for the Aboriginal and Torres Strait Islander mental health workforce [27].

Purpose of the Study

Ultimately, the goal of training health professionals in e-MH is to facilitate the uptake of e-MH amongst Aboriginal and Torres Strait Islander peoples. As a first step, the aim of our study was to provide a qualitative evaluation of the impact of e-MH training plus follow-up consultation sessions with Aboriginal health providers. To our knowledge, this is the first study, in Australia or elsewhere, which has provided extended e-MH training/consultation to Indigenous health professionals, and then examined the enablers and barriers of implementation.

Methods

Intervention: Training Plus Follow-Up Consultation Sessions

Training

A total of 50 providers of health and community services for Aboriginal and Torres Strait Islander peoples attended either a 3-day (n=43) or a 2-day (n=7) R U Appy e-MH training in one of the 2 locations (Lismore or Tweed Heads) in northern New South Wales. The aim of the R U Appy training program was to improve awareness, confidence, and competence in the use of e-MH resources. The design of the program (workshops plus consultation sessions) was guided by the extensive involvement of local advisory groups, learning circles, and a regional Aboriginal and Torres Strait Islander Health Council [28]. R U Appy training was strongly oriented toward experiential learning, featuring a hands-on approach for using iPads to search the Internet and download and use apps. One of the 3 training days was specifically devoted to training health providers in the Aboriginal-adapted app, Stay Strong. One participant had used the paper-based version of Stay Strong, but none had previously used the app.

Follow-Up Consultation Sessions

At the completion of the R U Appy workshop program, the trainees were invited to join a skills-based consultation group. Those wishing to attend were assigned a group based on either geographic location or organization-specific groupings. For example, where there were several participants from the one organization, an organization-specific group was formed (4 groups), and the sessions were held in the premises of the organization. Alternatively, participants from different organizations working in the same region formed "location-specific" groups (3 groups) and agreed on a specific meeting place.

Participants and managers were provided with the rationale for the consultation sessions and encouraged by the R U Appy trainers to attend following the training. Some participants were actively supported by their managers to attend both workshops and consultations; other managers viewed the consultation sessions as optional for their staff. Equally, some workers were very keen to participate in consultation sessions; others, for various reasons, had little interest or capacity to attend (further exploration of these issues is the subject of a parallel study currently underway).

The consultation sessions were formulated as a skills-based follow-up to the R U Appy training, drawing on research indicating the importance of consultation or supervision for embedding new skills [29,30]. They were conducted monthly for each group by the 2 e-MH trainers. One was a male psychologist specialized in e-MH, and the other a female Aboriginal Mental Health Worker undertaking an undergraduate degree in psychology. The initial consultation sessions were primarily focused on embedding Stay Strong skills; later sessions were adapted to meet other needs of participants (see Results).

Data Collection

The study data were the consultant-trainers' (SD, KH) written reports on each of the 30 consultation sessions that they conducted. Immediately following each supervision session, a report was written by SD and then checked by KH. The consultant-trainers were asked to record: who was present, whether they had appropriate technology, and how many participants had used Stay Strong or another e-MH resource with clients. The session reports also contained details of session activities, session observations, and participant reports of experiences that had facilitated or hindered their learning. These reports were then emailed to the research team (JS and JBL) that reviewed the content and systematically stored the reports (see Multimedia Appendix 1 for an example of a consultant-trainer session report). The consultation sessions were loosely structured to enable the participants to direct the sessions according to their specific needs. As such, the consultants' reports did not follow a structured reporting schedule; rather they described the different or divergent group experiences.

At the completion of the consultation sessions, the research team conducted a semistructured interview with the consultant-trainers (see Multimedia Appendix 2 for the interview guide). The purpose of the interview was to allow more detailed exploration of key issues emerging from their reports. The primary focus of the interview was on consultant observations about participants' interest, confidence, and use of e-MH resources and the factors that impeded or facilitated their learning. The interview was digitally recorded and transcribed verbatim for data analysis (see next section).

Data Analysis

At the end of the 6-month consultation period, the session reports were collated in date order for each of the 7 consultation groups and compiled into 1 document. One member of the research team (JS) conducted the initial thematic analysis of the session reports, following best practice guidelines to explicate "motivations, experience, and meaning" [31]. The

process involved reading the 30 field note reports several times to develop broad categories, and then rereading the dataset and assigning code names to the emerging themes. Subsets of the data were then read again to check the relevance of the code names.

In order to enhance rigor and validity, a second researcher (JBL) randomly selected 6 of the field note reports and repeated the process. Comparison of the 2 categorizations revealed consistency across categories and agreement on codes and key themes. Once categorization of the reports was completed, a similar process was then undertaken with the interview transcript.

A review of both datasets (reports and interview transcript) indicated that all the themes identified in the reports were represented in the analysis of the interview transcript. Further themes were identified in the analysis of the interview, as this dataset contained a more detailed and nuanced description of the consultation process. A combined thematic map was developed linking the two datasets (see Figure 1).

As a further check on the validity of the analysis, the thematic map, the quotations and examples, and the interpretation of the data were reviewed by the consultant-trainers. This review indicated that the data and themes were found by both consultant-trainers to be wholly consistent with their experience.

In the Results section:

1. The quotes in italics are those of the consultant-trainers.

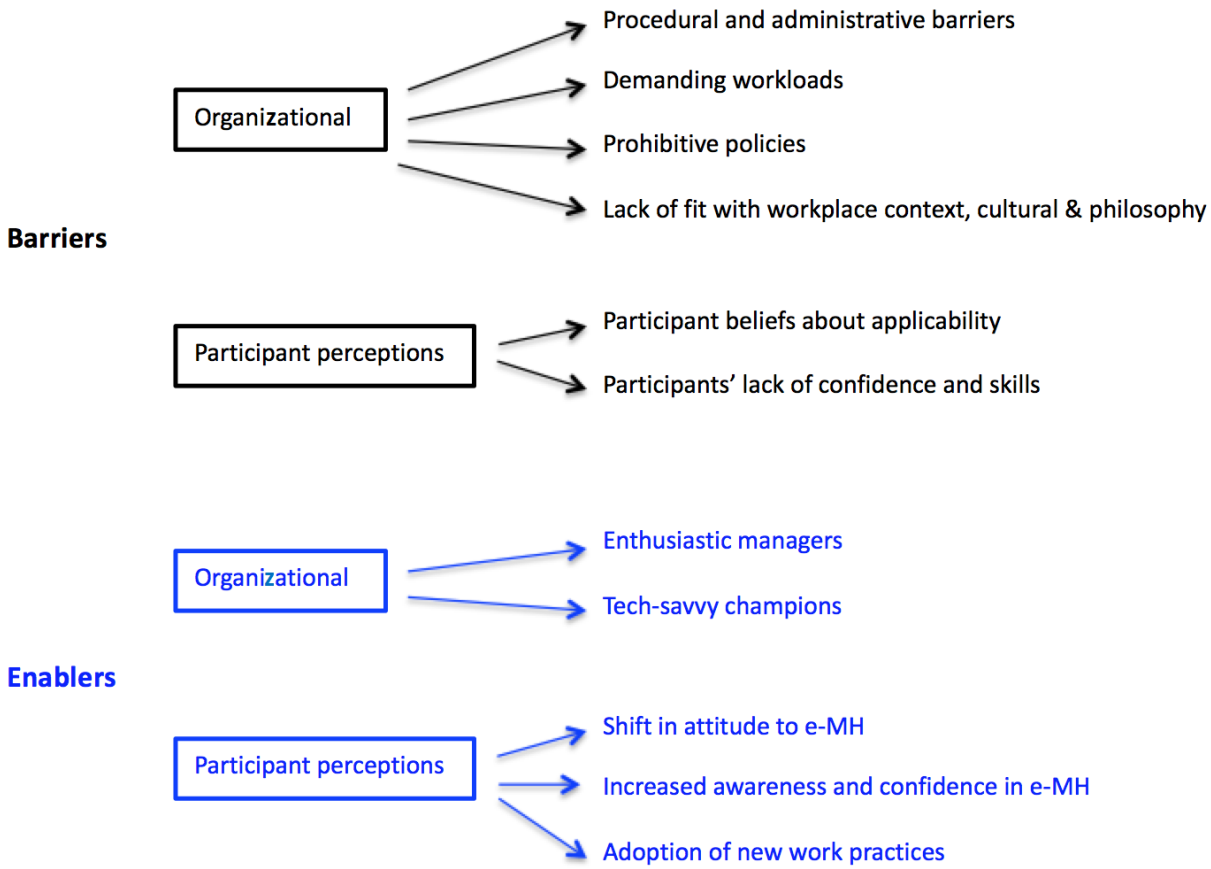
2. Double quotation marks are used to represent the health professionals' "voice" as quoted by the consultant-trainers.

3. CTR refers to quotes taken from the consultant-trainers' reports.

4. CT1 and CT2 refer to quotes from the interviews with them.

The study received ethics approval from the Aboriginal Health and Medical Research Council (NSW) AHMRC-HREC 955/13 and the Northern NSW Local Health District NCNSW-HREC 076.

Figure 1. Barriers and enablers to the uptake of e-mental health practices by Aboriginal and Torres Strait Islander health professionals.



Results

Participants

Twenty-eight of the 50 health providers, who attended the 2- or 3-day R U Appy training program in northern New South Wales, elected to attend the consultation sessions. Twenty-two R U Appy participants were not able to attend consultation sessions or chose not to. Two of 28 consultation study attendees were excluded from our analysis as they were not seeing clients at the time of the consultation sessions. Of the 26 health professionals in our study, 14 were females and 12 males. Twenty-one were Aboriginal and Torres Strait Islanders, and 5

were from non-Aboriginal backgrounds. Participants were drawn from 10 organizations: Aboriginal-specific nongovernmental organizations (NGOs) (3), generalist NGOs (6), and government health services (1). The mean consultation group size was 4.0 people (range 2-7). The mean number of consultation sessions attended was 2.4 sessions (range 1-5).

Participants had a variety of job titles, mainly describing support or case management roles (eg, youth worker, indigenous services worker, drug and alcohol worker, family development worker, well-being coordinator, Aboriginal health education officer, mental health support worker, and healthy lifestyle worker). Most had obtained certificates or diplomas from industry training programs (eg, Certificate in Primary Health Care); 2 had undergraduate Bachelor degrees, one of whom also had a Master degree. None of the participants had qualifications in a mainstream health profession (eg, nurse, psychologist, social worker), or specialist training in an evidence-based psychological therapy.

Usage of e-MH Resources

The study protocol and initial consultation sessions were focused on building Stay Strong skills. However, after 2-3 sessions, it became apparent to the consultant-trainers that some participants were not able to gain regular access to iPads with Stay Strong; other participants noted that Stay Strong did not fit with their work contexts, and wanted to broaden the focus of consultation sessions to a wider range of well-being resources (not specifically "mental health") such as specific Aboriginal health education resources, YouTube videos, and a broader range of apps. These observations led the R U Appy team to adapt the protocol to better meet the needs of participants, with consultation content becoming largely participant-determined. This change in emphasis was a key factor in maintaining group engagement.

The consultants' reports illustrated that 23% (6/26) had used Stay Strong with 1 client (or more) over the period of the consultation sessions; only 1 participant was using Stay Strong regularly with clients. Also, 31% (8/26) reported using other e-MH resources (YouTube, other apps) between consultation sessions.

Enablers and Barriers to the Uptake of e-MH

The main themes that emerged from the analysis of the consultation notes and interview were clearly identifiable as (1) the barriers and (2) the enablers to the uptake of e-MH. Figure 1 summarizes the barriers and enablers.

Barrier 1: Organizational

The consultant-trainers noted that the participants were hampered in various ways by organizational issues and structures that prevented the uptake of e-MH. These organizational barriers included procedural and administrative obstacles, demanding workloads, and entrenched and obstructive IT policies within the workplace.

Procedural and Administrative Barriers

In some services, the lack of procedures to manage iPad security and storage blocked accessibility to the devices:

> *We had some organizations where we would go to a consultation session and a person would say, "I still haven't loaded (the Apps) onto the iPad and we can't quite get to them because they are locked in a bottom draw"* [CT1]

In other organizations, the management of the iPads was the responsibility of senior staff who were often too busy to address the IT requirements:

> *(The worker) has been knocking on the manager's door to progress the IT side, which is to get (the app) downloaded onto the iPad, but (the worker) is getting drowned out by the other more immediate needs of the organization* [CT1]

The consultants described these issues by stating that the workers were often "caught up in an administrative mousetrap" [CT1].

In some situations, it was the dearth of basic procedures to guide the management of new technologies that stymied implementation:

> *(The worker said) "I've got the iPad and I'm keen to download (the App), but the person who bought the iPad and set it up left the organization and we don't know the code to get into the iPad...the critical piece of information has gone with someone else"...there can be real enthusiasm, but the challenges of technology can jump up quite quickly* [CT1]

The consultants reported numerous technological hurdles experienced by the health professionals as they attempted to engage with new technologies and specifically with iPads. Many of these obstacles stemmed from a lack of technological capability within the organization. For instance, managers or team leaders with responsibility for the iPads may not be tech savvy themselves:

> *We are also asking (managers who have not attended training) if they know how to use an iPad...how to turn it on, do they have an iTunes account … (some people think) you just turn it on and it's there* [CT2]

Demanding Workloads

The consultants reported that, in many services, demanding workloads left the workers with little or no opportunity to incorporate new skills into their existing work practices:

> *Another stumbling block is the sheer busy-ness that people have in their work lives...they are too busy to include (e-MH)* [CT1]

Consultants also commented that the high turnover of staff in some organizations was problematic:

> *As an organization, they're certainly taking it on, I think the fly in the ointment was just that...we lost maybe half or three quarters of the staff that went through the training…so there was a knowledge/experience leak from the training* [CT1]

Prohibitive Policies

The consultants also reported that several health professionals worked in government-funded services where the organizational policies prohibited purchase and use of new technologies:

> *Their workplace don't have iPads so using e-technologies is made difficult … (they were) frustrated with being sent to training but then not being able to apply the tools back at work* [CTR]

(The workers said):

> *"it's a great app, but we're not going to be able to do it because management's just not going to give us the resources to do it"* [CTR]

Lack of Fit With Workplace Context, Culture, and Philosophy

Some workers perceived a "lack of fit" between e-MH resources and their current work practice. For instance, Stay Strong, which was valued and used by some workers, did not fit with the work contexts of others:

> *(Some workers) don't feel that the nature of their contact with clients, which is usually crisis driven and concerned with meeting immediate living needs, gives the opportunity to use the app (Stay Strong)* [CTR]
>
> *(The workers reported that they are) dealing with very fundamental needs as an organization...finding housing, getting their forms sorted out, dealing with them being safe (and) keeping peoples' heads above water, practically* [CT1]

The culture and philosophy of the organization also impacted on the uptake of e-MH resources. For some workers, technology was perceived to reduce human connection:

> *(These workers) principally value face-to-face contact with clients and the "human connection"...they want to "connect with the person" and assist them to connect emotionally to those around them. Technology was still viewed as an impediment to this* [CTR]
>
> *(Another worker reported to the consultants that) "it's hard to engage with our clients at the best of times, let alone trying to show them a website to use"* [CTR]

Barrier 2: Participant Perceptions

In addition to organizational barriers, the consultants reported that the workers' perceptions about e-MH resources also posed barriers to their uptake.

Participant Beliefs About Applicability

Another view reported by the consultants related to generational beliefs about technology:

> *(Workers said) it's more for the younger generation, and we're dealing mainly with workers that were in the older section* [CT2]
>
> *(Some workers said) older clients feel uncomfortable with technology as it's not part of their everyday experience* [CTR]

Participants' Lack of Confidence and Skills

The consultants noted that, for some health professionals, a perceived lack of confidence and skills using new technologies hindered uptake:

> *The workers that weren't feeling 100% confident using iPads would say, "if I'm clumsy, then that takes away that rapport with the client"* [CT2]
>
> *What I found (was) if they didn't feel confident with using the app they refused to use it within clients...If they couldn't do it within themselves, why should they have to get a client to do it?* [CT2]

Collectively, these issues highlighted the complexity involved in the implementation of e-MH, particularly for organizations that had limited resources and limited expertise with new technologies.

Enabler 1: Organizational

Enthusiastic Managers

The consultants reported how the influence of enthusiastic managers significantly enhanced the workers' interest and opportunity to engage with e-MH resources. For instance, the manager of one service attended the 3-day R U Appy workshops and participated in the consultation sessions:

> *(Although) he had limited experience with technology, he identified the importance and value of his organization staying abreast of these technologies so as to remain in touch with younger clients and the organization as a whole growing into a more technologically-driven world* [CTR]

The consultants also reported that a number of managers were supportive and had purchased iPads specifically to enable staff to develop e-MH skills and competency:

> *It helped having the service (manager) on board...some services had purchased iPads and…were keen to be using more e-technologies* [CT2]

Tech-Savvy Champions

One organization had a "tech-savvy champion" who enthusiastically embraced e-MH resources and inspired others to do so:

> *He acted as a champion in his organization and was encouraging other staff members to get involved … one idea he had was having a staff-client day that was specifically orientated towards practicing with the Stay Strong app* [CT1]

Enabler 2: Positive Experience of the Consultation Sessions

Building Skills and Confidence to Use New Technologies

Many workers began the R U Appy training with little or no experience of using new technologies. Through the consultation process, the consultants described how some workers surprised

themselves by developing skills in using new technologies and moved from being "dinosaurs" to "e-explorers":

> *She was very adamant (stating) "I'm a dinosaur, and I can't use these things" … she's gone from (being) a dinosaur to "oh my god, I've learned how to do this"* [CT2]

> *(Another worker) was like, "oh my God, I'm a dinosaur," and at the end of the training, low and behold, he went and bought himself an iPad, and sits on Facebook and is willing to do the Stay Strong app. He was another one that had done a big turnaround* [CT2]

Shift in Attitude to New Technologies

Associated with the development of new skills, the consultants also described how some workers changed their views from "technology is bad" to "technologies can be helpful":

> *People would come with quite strong ideas around technology, (they) can see a lot of detriments associated with technology use...bullying online, young people being exposed to information and things through their devices that can be quite harmful. For a lot of health workers, it's an intrusion on society that's been quite damaging. I think it was quite enlightening (for them) to see that there had been a lot of resources developed that are aimed to assist and support people and that they can take advantage of this technology (for the) people they work with* [CT1]

> *They didn't realize how many resources are actually out there. So they've gone from hardly knowing anything, to "wow," (all the) YouTube clips and different apps and websites* [CT2]

The consultants also reported having "complex conversations" with workers during the consultation sessions "(about) how (technology) fits with their work environment, how it fits with how they engage with people" [CT1]. They described one particular worker's experience during the consultation process in shifting his understanding about the potential relevance of new technologies in his work with younger clients:

> *(A worker) and I were having a conversation about how the youth have a good way of emotional expression on text, rather than face-to-face conversations. As we were having that conversation, (another worker) started thinking of (a young client) that he could actually use technology with, and get him to build a rapport with this young one, because he (the young client) was so technologically savvy* [CT2]

The consultants noted the various views expressed by the health professionals about their motivation to become tech-savvy. For some, it was the view that

> *"technology is becoming part of everyday life."* [CTR]

For others, engaging with technology was important in order to

> *"guide and educate people in the healthy use of technologies"* [CTR]

and as workers, the importance

> *"to participate with technology in order to not be left behind"* [CTR]

Seeing e-MH as a Health Education Resource

Responding to participants' expressed needs for apps for different purposes and contexts, the consultants introduced a range of different e-MH resources into the consultation sessions, tailoring them to the specific interests of the different consultation groups. A feature of the consultation sessions was the opportunity for workers to learn how to search for and assess resources that were relevant to their work context:

> *(It's been about) becoming aware of the resources that are out there...that was certainly a big impact...thinking a bit more critically about the role that technology plays in the lives of their clients, and then how they may be able to interface with that in a way that actually supports them in the work that they're doing with clients* [CT1]

Many of the health professionals worked in the drug and alcohol field and found some of the new technologies to potentially offer a valuable adjunctive educational tool:

> *Having something else to explain what an addiction looks like and then having a library of YouTube clips that you could refer to and have a different way of engaging…it's a different way of having a discussion about that issue* [CT1]

> *We showed them some of the YouTube clips of what an addiction can look like. (Workers) took that on board and could see how they could use that within their service...how the brain works, if you're taking a drug what it can do to a brain* [CT2]

YouTube, as a medium, was seen as particularly valuable for Aboriginal and Torres Strait Islander clients. One of the consultants remarked:

> *Aboriginal people, (are) so visual, that having those YouTube clips we can actually connect to that visual stuff, and go, oh, that's exactly what you're talking about, we know that feeling* [CT2]

Discussion

Principal Findings

As research evidence for the value of e-MH resources accumulates, attention is gradually turning to strategies for e-MH implementation in health service contexts [4,32,33]. For our study, we designed a training plus consultation program to teach e-MH skills to Aboriginal and Torres Strait Islander health and community professionals, drawing on best practice implementation science [25,34]. A previous study had identified the potential value of culturally appropriate consultation or supervision sessions to follow up training for Aboriginal health providers [27]. However, our study is the first to follow up Aboriginal and Torres Strait Islander health providers over 6

months, and examine the enablers and barriers to e-MH implementation. Furthermore, no reports of training plus follow-up consultation sessions with Indigenous health workers from other countries are available.

Among those who attended consultation sessions, interest in e-MH was strong and the consultation sessions were well received and appreciated. Stay Strong, the only Indigenous-specific app available at the time of the training, was well accepted by our participants, mirroring reports from Northern Territory community members [18], but it was only used by a minority of workers (6/26) even after training plus consultation. However, interest in other e-MH resources grew as the sessions developed. In particular, Aboriginal and Torres Strait Islander workers expressed interest in apps and YouTube videos, which could be used for health education and information purposes. Eight out of 26 workers started to use apps and e-MH resources other than Stay Strong with clients.

While the translation-to-practice impact of the training and consultation might be perceived as only moderate, qualitative session-by-session analysis of the consultation sessions reveals that there were good reasons why uptake was relatively low. Organizational impediments played a major role in determining whether participants adopted e-MH practices, as has been noted in e-MH studies with non-Indigenous health providers [35]. Our participants reported difficulties in accessing iPads, passwords, and iTunes accounts; pressing needs of other work and relegation of e-MH to low priority; and high staff turnover. Organizational culture, orientation, and individual factors also had an impact [35,36]: one organization and its staff saw technology as a barrier to human connection; others were largely responding to crises and contexts where e-MH might have been inappropriate, or viewed e-MH as valuable only for young people. The perception of "fit" with the work environment, work roles, clients, and the culture of the organization was central to workers' willingness to adopt e-MH [37]. However, organizations could exert a positive impact too. Managers who supported e-MH and tech-savvy champions in the organization tended to influence other workers in their organization and provide enhanced access to e-MH resources.

The qualitative analysis indicated that the consultation sessions had a positive influence in a number of ways. They enhanced curiosity and interest in e-MH, facilitated exploration, increased skills in some participants, and created major shifts in attitude toward e-MH. Despite this, some workers simply did not feel confident enough in their skills to use e-MH resources and thought that their clumsiness might affect rapport with clients.

Conceptualizing the Results

Perhaps the most interesting impact of the consultation sessions was the change of tack taken by the consultants around the third session when they realized that, for some organizations and health providers, there was a lack of fit between the Stay Strong app and workers' roles and organizational cultures. To grasp this point, it is important to understand that only 2 of the participants had university-level training, and none were in a specialized mental health profession (eg, psychologist, social worker, or physician). For most Aboriginal and Torres Strait Islander health providers in our region, their scope of practice was restricted to an educational role or a support worker or case management role rather than a therapy role.

Once the consultant-trainers recognized that Stay Strong lay outside of many participants' scope of practice, they found that participants' interest was piqued by the possibility of using apps and YouTube clips for health education and information purposes (see Multimedia Appendix 3 for examples). The health providers were genuinely excited at this prospect as there is high usage of mobile phones in the Aboriginal and Torres Strait Islander population [38], and a perception that their clients are often very "visual" (see last comment in Results section).

Reynolds et al have recently developed conceptual model to understand the value of different e-MH resources for different types of health worker [37]. The model helps to shed light on why Stay Strong may have been favored by some workers but not by others, and why educational YouTube clips and apps were strongly favored by this cohort. The model makes important distinctions between the different roles of workers (eg, nonclinical, case management, coaching, therapist) and the relative value of different e-MH resources to them. An implication of the model (p. 7) is that Stay Strong may be most suited to workers who have mental health skills appropriate for coaching or therapist roles. However, the majority of the Aboriginal and Torres Strait Islander health workers in our cohort had more of a support or health education role than a coaching or therapist role. What the Reynolds et al model suggests is that the most appropriate e-MH role for this workforce is to provide e-MH information and health education resources for their clients, which is exactly what the cohort in our study responded to best.

As Reynolds et al also made clear, the vast majority of e-MH research has been directed toward evaluating the impact of Web-based therapy programs. Little consideration has been given to evaluating other e-MH resources or workforce roles. Our study highlights the potential value that Indigenous and non-Indigenous health providers in support worker roles may have in using relevant mental health resources on YouTube and social media for health educational purposes, as has been successfully demonstrated in other health-related contexts [39,40]. However, the quality of such resources does need to be carefully assessed. Therefore, we suggest that much more attention be given to developing agreed criteria for evaluating apps and YouTube videos [41-43], which may play a valuable role in health service delivery in the future.

Limitations

We recognize that this study had a number of limitations. Reliance on consultant-trainers' reports and the interview was both a strength and a limitation: a strength because observations were recorded immediately after sessions for all 30 consultation sessions, but a limitation because these observations were "second-hand" —the consultants rather than the participants were recording the participants' experiences. Consequently, these observations may be subject to perceptual bias on the part of the consultants. Another issue was that we did not accurately record who was using what e-MH resources other than Stay Strong prior to training and prior to the consultation sessions. We believe that only 2 of the participants had any previous

interest or exposure to any form of e-MH, but this was not recorded.

Unfortunately we were unable to determine e-MH usage beyond the consultation sessions and follow up those health professionals who only attended 1 or 2 sessions, as further follow-up lay outside our ethics approval. It is therefore possible that the e-MH usage figures from the consultants' reports may underestimate eventual usage as some participants may have started to use e-MH resources after they had ceased to attend consultation sessions.

Conclusions

This study highlights the importance of broadening our conception and definition of e-mental health resources, which, until now, has been largely restricted to Web-based therapy programs. A growing health education literature featuring Internet-based materials, and our own study, suggest that e-mental health resources should encompass other Web-based materials (eg, apps, YouTube videos) that may promote social and emotional well-being, and can be used by a variety of different workforces that do not necessarily have a clinical role [37]. In the present case, it is suggested that for Aboriginal health providers who do not have specific health professional qualifications and are in support worker or health education roles, training in the use of health promotional e-MH resources may be rather more valuable than training in Web-based therapy programs or apps that require a coaching role. The study also highlights the importance of preparatory work with organizations that plan to send their staff to e-MH training (see the organizational checklist provided by Puszka et al [36]). Trainer-consultants need to work with these organizations to acquire necessary e-MH resources before training programs and enable their staff to attend post-training consultation sessions. This extends to such basic planning as ensuring staff have access to resources such as iPads, Androids, and iTunes accounts [36].

What we are learning is that, when it comes to translation into practice, the devil is in the detail. What is seen as valuable "on the ground" is not necessarily what is seen as valuable by university researchers. Consumer and service provider involvement is vital if e-MH is to fulfill its undoubted promise [32], particularly in disadvantaged communities such as Aboriginal and Torres Strait Islander communities [28,44].

To summarize, we suggest that the training plus consultation model was successful in enhancing engagement and usage of e-MH resources. However, a number of organizational and personal barriers to implementation also emerged. To increase efficacy, e-MH resources for Indigenous communities needs to be not only culturally relevant, but role- and organizationally relevant. In the context of Australian Indigenous health providers, role and organizational relevance means broadening the scope of e-MH resources from a focus on e-therapy to a focus on health promotion in the form of health education and information resources.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

A deidentified example of a consultant-trainer session report (names changed).

[PDF File (Adobe PDF File), 20KB - jmir_v19i1e1_app1.pdf]

Multimedia Appendix 2

Interview guide with the consultant-trainers.

[PDF File (Adobe PDF File), 14KB - jmir_v19i1e1_app2.pdf]

Multimedia Appendix 3

Examples of health education and information resources explored in consultation sessions.

[PDF File (Adobe PDF File), 27KB - jmir_v19i1e1_app3.pdf]

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Abbreviations

CT1: consultant-trainer 1
CT2: consultant-trainer 2
CTR: consultant-trainer report
e-MH: e-mental health
eMHPrac: e-Mental Health in Practice
NGO: nongovernmental organization

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Original Paper

Identifying Topics for E-Cigarette User-Generated Contents: A Case Study From Multiple Social Media Platforms

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Abstract

Background: Electronic cigarette (e-cigarette) is an emerging product with a rapid-growth market in recent years. Social media has become an important platform for information seeking and sharing. We aim to mine hidden topics from e-cigarette datasets collected from different social media platforms.

Objective: This paper aims to gain a systematic understanding of the characteristics of various types of social media, which will provide deep insights into how consumers and policy makers effectively use social media to track e-cigarette-related content and adjust their decisions and policies.

Methods: We collected data from Reddit (27,638 e-cigarette flavor-related posts from January 1, 2011, to June 30, 2015), JuiceDB (14,433 e-juice reviews from June 26, 2013 to November 12, 2015), and Twitter (13,356 “e-cig ban”-related tweets from January, 1, 2010 to June 30, 2015). Latent Dirichlet Allocation, a generative model for topic modeling, was used to analyze the topics from these data.

Results: We found four types of topics across the platforms: (1) promotions, (2) flavor discussions, (3) experience sharing, and (4) regulation debates. Promotions included sales from vendors to users, as well as trades among users. A total of 10.72% (2,962/27,638) of the posts from Reddit were related to trading. Promotion links were found between social media platforms. Most of the links (87.30%) in JuiceDB were related to Reddit posts. JuiceDB and Reddit identified consistent flavor categories. E-cigarette vaping methods and features such as steeping, throat hit, and vapor production were broadly discussed both on Reddit and on JuiceDB. Reddit provided space for policy discussions and majority of the posts (60.7%) holding a negative attitude toward regulations, whereas Twitter was used to launch campaigns using certain hashtags. Our findings are based on data across different platforms. The topic distribution between Reddit and JuiceDB was significantly different (P<.001), which indicated that the user discussions focused on different perspectives across the platforms.

Conclusions: This study examined Reddit, JuiceDB, and Twitter as social media data sources for e-cigarette research. These mined findings could be further used by other researchers and policy makers. By utilizing the automatic topic-modeling method, the proposed unified feedback model could be a useful tool for policy makers to comprehensively consider how to collect valuable feedback from social media.

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KEYWORDS

electronic cigarettes; topic modeling; Latent Dirichlet Allocation; social media; infodemiology

Introduction

Electronic cigarettes (e-cigarettes) have become increasingly popular in recent years. As a new type of nicotine delivery system, e-cigarettes, as defined by the US Food and Drug Administration (FDA), are battery-operated products designed to deliver nicotine, flavor, and other chemicals in aerosol form [1]. Although the FDA has expressed concern about e-cigarettes because they are not fully studied, the market has experienced tremendous growth. The sales of e-cigarette products were £3.9 billion globally, and £1.7 billion in the US, according to data from Euromonitor International [2]. The growth rate was estimated to be 24.2% per year through 2018 [3]. The fast market development has led to ongoing discussions and debates about the use of e-cigarettes, prompting significant research interests and policy concerns [4-6].

Many e-cigarette studies have used the survey method to collect information on the pattern of usage [7-16]. The survey sample was usually the general population [8,11,13-16] or current or former smokers [7,9,10,12]. The survey method included Internet survey [7,9,10,11,13,14,16], telephone survey [8], mail-in survey [15], and interview [12]. Some surveys only drew samples from one country, such as the United States [10,15,16], United Kingdom [7,9], and the Czech Republic [12], but others used international samples [8,11,13,14]. The survey questions included e-cigarette awareness, use, harm and benefit perception, and preferences. Other demographic information and smoking status were collected as well. The survey method provided evidence to lay a solid scientific foundation for public health legislation. However, surveys are usually time and money consuming. Social media, as a new channel to access to user-generated content, provides opportunities to collect large volumes of data conveniently.

The rapid growth of online communities and social media provides a new approach in collecting evidence for policy-making processes. Large social media platforms, including Facebook, Twitter, YouTube, and Reddit, enable new channels for e-cigarette users to share information and experiences. These platforms have provided efficient methods of information access for health surveillance and social intelligence [17,18]. E-cigarettes, as an emerging substitute for combustible cigarettes, are broadly studied from the perspective of social media as well. Vapor shop owners rely heavily on social media or other online communities to promote e-cigarette products by offering price discounts, specials, and loyalty programs [19].

More insights were generated from studies based on specific social media platforms. For example, one study found that the vast majority of e-cigarette information on YouTube promoted their use and depicted it as socially acceptable [20]. Another study discovered that e-cigarette-related videos usually highlighted e-cigarettes' economic and social benefits [21]. Hua and colleagues [22] studied YouTube videos and found e-cigarette users' puff duration was approximately twice as long as puff duration for conventional smokers. Twitter also appeared to be an important marketing platform for e-cigarettes [23]. Marketing strategies and locations of use were studied and identified from e-cigarette-related tweets [24]. Cole-Lewis and colleagues [25] conducted a thorough content analysis of e-cigarette-associated tweets and identified possible trends of e-cigarette usage growth. Topic modeling was used to examine tobacco-related tweets [26]. A supervised machine learning technique was used on Twitter data to predict the themes of posts, with fairly sound accuracy [27].

E-cigarettes are also discussed on forums. Reddit, one of the most comprehensive forums on the Internet, was used as a source to identify vulnerable populations [28] and e-liquid categories [29]. In addition to Reddit, data from three e-cigarette forums, Electronic Cigarette Forum, Vapers Forum, and Vaper Talk, were used to analyze e-cigarette-related symptoms [30]. Chen and colleagues [31] extracted contextual factors and conducted topic-modeling techniques on data from Reddit and other forums to study e-cigarette and hookah use. Social media platforms are often linked; thus, combined analyses of social media is interesting. Recently, a research paper examined the marketing strategies of leading e-cigarette brands on multiple social networking sites including Twitter, Facebook, Google+, and Instagram, providing a first step in understanding multiple social networking site marketing [32]. Their findings showed that studying the user-generated content from multiple social media platforms could be of great importance to understand the e-cigarette market's status quo.

Moreover, we have noticed that different social media platforms have different characteristics, both for posts and users. For instance, Reddit is essentially an online bulletin system that includes all kinds of discussions [33]. As one of the most popular forums in the world, Reddit has comprehensive content about e-cigarette topics, including policy discussions, experience sharing, and promotions. Twitter, on the other hand, is efficient at information transmission. Using the retweeting mechanism, information spreads quickly through the network. In comparison, JuiceDB is a relatively new platform focusing only on e-juice product reviews [34]. The contents are limited to flavor discussions. Studying e-cigarette topics on different platforms and conducting cross-platform analysis would be of great significance because it will provide insights into how consumers and policy makers can make good use of social media to track e-cigarette-related content and adjust their decisions and policies. New e-cigarette research angles could also be generated with the help of technical tools from information science. In this research, we are interested in automatically identifying topics behind massive posts, which could be used to provide real-time support to policy makers. Furthermore, our paper aims at exploring the possibility of combining the results from multiple platforms. We provide valuable insights from the data and propose an automatic approach to generate these insights.

Methods

Data Collection and Preprocessing

In a previous study, we collected data from Reddit [29]. A total of 34,051 e-cigarette flavor-related posts were collected from Reddit from January 1, 2011, to June 30, 2015. In practice, there was some noise in the posts due to semantic ambiguity. We considered words not related to e-cigarettes as noise and eliminated posts that only contained noise keywords. For instance, the Apple watch is an electronic product produced by Apple Inc. Thus, the posts only containing the keyword "Apple watch" should not be covered in our analysis. Finally, a total of 27,638 unique e-cigarette flavor-related posts were identified for analysis.

Data from JuiceDB were collected by using its public application program interface (API). We collected 14,433 JuiceDB e-liquid reviews from June 26, 2013 to November 12, 2015. The dataset was comprised of reviews on e-liquids including overall rating, subrating of e-liquid components, and detailed comments.

We also collected some data from Twitter. We created crawling agents and simulated human behavior in the searching page of Twitter to retrieve historical data from January 1, 2010 to June 30, 2015. We used the keywords "e cigarettes," "electronic cigarettes," "ecigarettes," "ecigs," "smoking electronic cigarettes," "smoking ecigarettes," and "smoking ecigs" in the searches and collected 353,984 tweets. Compared with Reddit, Twitter is good at information transmission, which makes it an important platform for advertising and social media campaigns. Results from the Reddit dataset showed that the e-cigarette ban debate was an interesting discussion topic. "E-cig ban" and "e-cigarette ban" were general keywords describing the topic. Thus, we used these keywords to collect data and analyze the detailed discussion topic on Twitter. Some tweets were not written in English. They were collected because they used English hashtags that contained the keywords. In order to analyze English tweets only, we filtered out other tweets by using a stop words list to detect the most probable language the tweet was written in. Finally, we collected 13,356 tweets that were valid for analysis.

Data Analysis

We used natural language processing (NLP) and Latent Dirichlet Allocation (LDA), which are information science techniques, to analyze the data. "Natural language" means the language used by humans, whereas processing means using computers to understand natural language input [35]. By enabling the use of automated methods that represent the relevant information in the text with high validity and reliability, NLP facilitates tasks such as information retrieval, analysis, and prediction in health areas [36]. Because it is difficult and time consuming for users to manually handle the huge amounts of reviews or posted data, we needed to use NLP techniques to help the computers understand the meaning of human languages. Specifically, we used basic NLP methods, including tokenization, stop words, and stemming, to process the contents of reviews and posts with the help of the Python Natural Language Toolkit (NLTK) package [35].

LDA is a generative model for unsupervised topic modeling that automatically discovers hidden topics from a set of documents, such as posts, reviews, or tweets in this study, each of which contains a bag of words [37]. The algorithm generates a given number of topics for a specific set of documents. Each document is considered to be a mixture of several topics, and a topic is characterized as a distribution of words [37]. By understanding the topic distributions among documents and the word distributions among topics, hidden information in the text could be found automatically. We used the Python package gensim to conduct LDA analysis [38]. The data processing steps are shown in Multimedia Appendix 1. Multimedia Appendix 2 shows the details of our LDA-based e-cigarette topic analysis model.

Practically, it was challenging to determine the number of topics in the LDA method. We used the hierarchical Dirichlet process (HDP-LDA) to evaluate our decision, which was also supported by the Python gensim package [39]. In the HDP-LDA model, the number of topics could be unbounded and learned from the data. We estimated the probability weight associated with each topic using the Reddit dataset. Finally, we decided to use five topics in the analysis.

The output of LDA in this study was a set of topics and the main words associated with each topic. For example, 13,356 tweets were treated as the input after preprocessing by the NLP tools. After LDA processing, five topics with associated words were summarized from these tweets. Consider each of the topics as a group. Every post belonged to one of the groups based on the words it contained.

Results

Dataset Analyses

We performed LDA on the three datasets. The number of topics for each dataset was set to five. For a specific topic, the top 20 associated keywords are listed in Table 1.

Table 1. Top five topics and keywords for posts from Reddit, JuiceDB, and Twitter.

Platform and topic	Keywords[a]
Reddit	
1. Individual trades and vendor promotions	Liquid, size, mini, sold, brand, shipping, free, cream, retail, price, sample, purchase, list, prices, items, high, left, love, prefer, natural
2. Flavor-related experiences and sentiments	Juice, flavor, good, flavors, vape, taste, great, juices, well, sweet, liquid, tastes, menthol, love, tank, nice, pretty, coffee, hit, find
3. E-liquid components	Strawberry, flavor, VG, juice, vanilla, cream, custard, thanks, vapor, banana, PG, flavors, TFA, apple, mL, milk, 12 mg, bottles, menthol, 30 mL
4. Relationship with traditional tobacco products	Tobacco, nicotine, vaping, smoking, cigarette, people, smoke, ecig, quit, products, health, product, year, electronic, know, companies, pack, stop, addiction, quit
5. Personal experiences and questions	Time, know, well, feel, best, love, long, pretty, thought, start, find, want, favorite, give, question, experience, idea, hear, start, thanks
JuiceDB	
1. Throat hit and vapor production	Throat hit, VG, vape, coil, tank, cloud, use, RDA, PG, vapor, max VG, liquid, dripper, high, drip, vapor production, price, higher, 50/50, 6 mg
2. Fruit and cream flavors	Sweet, like, strawberry, exhale, flavor, nice, get, really, fruit, fruity, vape, cream, inhale, taste, candy, good, tart, well, menthol, little
3. Cream, tobacco, and seasonings flavors	Sweet, like, creamy, rich, exhale, custard, cinnamon, get, tobacco, nice, vanilla, inhale, good, banana, cream, really, caramel, vape, smooth, hint
4. Product promotion and recommendation	Try, vape, bottle, great, juice, order, favorite, recommend, best, flavor, day, love, time, first, adv, go, would, price, amaze, definite
5. Vaping experiences	Like, steep, try, taste, really, get, good, vape, would, bottle, don't, much, first, got, smell, think, bit, better, still, even
Twitter	
1. Euecigban	Euecigban, eu, save, tobacco, stop, smoke, live, vaper, help, swof, try, want, people, million, smoker, please, go, via, need, product
2. New York and noecigban	Vape, smoke, Twitter, come, pic, health, public, nyc, euecigban, cig, ad, noecigban, like, via, citi, call, propose, look, tobacco, news
3. General discussion of e-cigarette ban	Vape, smoke, vote, blog, post, huge, electroniccigarette, consequence, citi, include, council, new, school, report, fda, house, county, harm, propose, cig
4. Petition	Sign, vape, health, flavor, RT, want, tobacco, petitition, euecigban, say, please, support, sale, regulate, us, minor, use, propose, govern, plane
5. Noecigban and freevape	Vape, public, noecigban, vaping, sale, smoke, place, bill, minor, freevape, new, indoor, use, would, cig, call, consider, New York, lawmaker, wale

[a] PG: propylene glycol; RDA: rebuildable dripping atomizer; RT: retweet; TFA: the flavor apprentice; VG: vegetable glycerin.

Reddit Dataset Analysis

The first topic was about purchasing e-cigarette products. It contained vendor promotions and advertisements, but also individual trading information. The keywords included product descriptions and prices. Topic 2 was flavor-related experiences and sentiments. People discussed their vaping experience with specific flavors and expressed their sentiment or evaluation. Topic 3 was the discussion of e-liquid components. It is known that e-liquid consists of vegetable glycerin (VG), propylene glycol (PG), nicotine, and flavors [40], most of which showed up in this topic. Topic 4 was about the relationship between e-cigarettes and traditional tobacco products. E-cigarettes were promoted as a substitute product for traditional cigarettes. Some smokers were seeking a comparison of e-cigarettes and traditional cigarettes to decide whether to switch from smoking to vaping. From the keywords, we knew that people were concerned about nicotine and addiction problems. The final topic was about personal experience and questions. The keywords included some verbs that describe the behavior of using e-cigarettes, such as "start," "find," or "want."

JuiceDB Dataset Analysis

The outcome of LDA on JuiceDB reviews was quite different. JuiceDB is a specific platform only for e-liquid reviews and the LDA results supported this. The top five topics were narrower and more focused on e-liquids (Table 1).

Topic 1 referred to throat hit and vapor production, which were two major features of the e-cigarette vaping experience. Topics 2 and 3 were discussions of specific flavors. From the previous study, we knew that fruit and cream flavors were the most popular, which was supported by the result that these two flavors made up one topic and other flavors were a separate topic [29]. Topic 4 was related to product promotion and recommendation.

Reviews could be written for different purposes, such as individual experience sharing or advertorial promotion. The last topic was vaping experience, the same as the last topic from the Reddit results.

Twitter Dataset Analysis

The LDA performance on the Twitter data was even more specific because we focused on the tweets related to e-cigarette bans. Almost all tweets had a URL link that brought noise to the LDA analysis. Thus, we built the LDA model after removing URL links.

Twitter is famous for its hashtag system. The hashtag is a word coming after a hash (#) sign. It is used as a label to tag the tweet to a specific group so that users can easily find and share information in a specific community. Some of the keywords (Table 1), such as "euecigban," "noecigban," "electroniccigarette," and "freevape," were actually hashtags, and they were especially designed for social media campaigns. We observed that the topics from the LDA results were quite similar to one another. Some of the keywords, such as "euecigban," "noecigban," and "New York," were present in several topics. However, topics still had their own characteristics. Topics 1, 2, and 5 were related to campaigns debating e-cigarette ban regulations. Topic 3 was a general discussion of e-cigarette bans. It had "school," "house," and "FDA" as keywords. Topic 4 was about petitions of the social media campaign. We saw the words "petition," "support," "sign," and "us" as the typical keywords. The word "RT" represents "retweet," which indicates the fast information transmission in the petition.

Comprehensive Analysis Across Platforms

The preceding results described different topics for different social media platforms. Generally speaking, Reddit is a comprehensive forum so the topics are more general and broader compared to JuiceDB, which is a specific platform for e-liquid reviews. The data from Twitter showed that this social media was used as a platform for campaigns. We summarize the topics in these three platforms and present our insights for policy makers. In total, there were four types of topics: promotions, flavor discussions, experience sharing, and regulation debates.

Promotions

Promotion as a topic included trading among e-cigarette users and sales from vendors to users. For instance, on Reddit, one example of a vendor promotion to users was:

> *Wednesday Purple Drank, Banana Berry Milkshake, AND Hot Cider Donut Giveaway! Coupon code inside for 15% off ALL liquids! | Vapor Trails NW.*

JuiceDB had promotions as well. However, the vendor promotions on JuiceDB were written in the format of user reviews because JuiceDB did not accept advertisements. For example:

> *Mountain Dew-inspired flavor. I have been using this juice for a few days now and it's actually really good! Tastes pretty close to the real Mountain Dew flavor. It's not exactly the same flavor as the drink but it is VERY close. I recommend it!*

Trading among users was another important type of e-cigarette promotion. It was common to see these posts on Reddit because the titles usually started with want to trade (WTT), want to sell (WTS), and want to buy (WTB). For example:

> *WTT/WTS: Avid and MBV Juice, Also a Kanger Aerotank + full 5 pack of coils.*

Among all the posts, 1636 posts had WTS in their title, 895 posts were labeled as WTT, and 431 posts were WTB posts.

Reddit, as a comprehensive platform, provides a promotion platform for both vendors and individual users. Of 27,638 posts, 2962 (10.72%) are related to trading, which indicates that there exists some secondhand e-cigarette transaction channels, raising new challenges for regulation and surveillance. Teenagers, for example, could acquire e-cigarette products easily from such channels, which decreases the effectiveness of the FDA's proposed e-cigarette ban policy. The existence of secondhand markets introduces other possible problems as well. Without regulations and standards, the product safety is not guaranteed, raising potential risks for users. More than half of the trading posts were on the supply side, which indicates that e-cigarette users tend to be capricious about preference. This phenomenon provides evidence for the necessity of further investigation.

Reddit and JuiceDB both provided detailed descriptions of e-cigarette products. Moreover, some posts linked these two platforms together. For instance, the posts in Multimedia Appendix 3 showed the close connection between the platforms.

It is possible that users might refer to several platforms to find useful information and suggestions for vaping. We examined several other platforms, including Facebook, Twitter, the Vaping Forum, UK Vapers, E-cigarette Forum, and Aussievapers. The results are shown in Table 2.

Table 2. Platform links.

Link	Reddit (n=27,638), n (%)		JuiceDB (n=14,434), n (%)
	Title	Content	Content
Facebook	32 (0.12)	650 (2.35)	15 (0.10)
Twitter	7 (0.03)	290 (1.05)	0
JuiceDB (Reddit)	14 (0.05)	68 (0.25)	110 (0.76)
The Vaping Forum	4 (0.01)	7 (0.03)	0
UK vapers	13 (0.05)	4 (0.01)	1 (0.01)
E-cigarette forum	0	38 (0.14)	0
Aussievapers	4 (0.01)	13 (0.05)	0

Reddit is a comprehensive platform that links many other forums and social media. However, JuiceDB seemed to be exclusively related to Reddit.

Flavor Discussions

Flavor was one of the most discussed topics among e-cigarette users. Both Reddit and JuiceDB had many posts related to e-liquid flavors. In previous research, we identified eight categories of flavors: fruits, cream, tobacco, menthol, beverages, sweet, seasonings, and nuts [29]. In JuiceDB, there were nine flavor categories: sweet, fruity, rich, creamy, spiced, tobacco, cool, nutty, and coffee. The two category systems were fairly consistent, providing a good schema for future research.

From the Reddit LDA results, the topic contained several keywords related to the taste of flavors, such as strawberry, vanilla, custard, banana, apple, menthol, candy, blueberry, mango, watermelon, cinnamon, peach, caramel, lemon, chocolate, honey, cake, tea, raspberry, orange, cherry, cereal, coconut, pear, grape, cookie, peanut, mint, pineapple, and coffee. This set of flavors covered the majority of flavors found in previous research [29]. Some of them, such as caramel, cereal, and coconut, were newly discovered by the LDA results.

A study about e-cigarette flavors pointed out that new flavors would come out every now and then as the e-cigarette market develops [41]. To discover new flavors manually is expensive in both time and money. Thus, our LDA approach provided a cheap and automatic way for public health departments to complete flavor lists in real-time surveillance and trend analysis.

The findings on JuiceDB were similar. However, because JuiceDB focuses on e-liquid reviews, the topics we found were more focused. Thus, fruit and cream flavors composed a single topic, whereas other flavors made up a separate one. These two topics identified by the LDA method could help us build and complete the flavor list, as well as identify new types and trends.

Experience Sharing

Social media is a way for e-cigarette users to share their vaping experience with one another. People may ask and answer questions about e-cigarettes. Or they simply write down their feelings after trying a particular product. For example, a Reddit user raised a question about sweet e-juice and cavities, which is shown in Multimedia Appendix 4.

Users also shared their methods of using e-cigarettes to help others improve their vaping experience. For example, a common method is called steeping. This is a special method to process the e-liquid, especially for new products. Vapers usually believe that steeping helps to disperse chemicals and flavors throughout the juice. Steeping is simple. Just shake and store in a cool, dark place to get a well-steeped e-liquid. This is an example from JuiceDB:

> *Steeped this juice for 4 days, the color darkened just a bit, the flavor really came out as well.*

In comparison with traditional tobacco products, e-cigarettes use e-liquid to deliver nicotine and other chemicals. Thus, the method of vaping is totally different from smoking. As far as we know, e-liquid steeping is still not well studied among the literature.

Throat hit and vapor production are two other major features of using e-cigarettes. Both JuiceDB and Reddit have thousands of posts related to them. Throat hit is the feeling of smoke hitting the back of the throat [42]. Some people like it, but some do not. Typically, there are two types of e-cigarette users. The first type is smokers who have switched or are going to switch from traditional tobacco products to e-cigarettes. They are seeking a strong throat hit and thick vapor production to acquire feelings and experiences similar to smoking, as in the following example:

> *This juice is basically Boba's Bounty with Banana added in. A nice tobacco/graham cracker flavor bursting with banana but not too overwhelming, it's just right. Great vapor production and throat hit.*

The other type of users have never smoked traditional tobacco products, directly adopting vaping. Thus, they are less likely to like a strong throat hit. Their sharing and recommendations are more mild in taste. For example:

> *Very little throat hit in my mix (50pg/50vg 6mg) but very good vapor production.*

However, both types of users are more prone to like thick vapor production. We believe that the vapor helps users' gain a visually pleasing experience. A huge amount of vapor could produce a salient social image that is perceived and evaluated by e-cigarette users, similar to traditional cigarettes [43]. The image is studied and associated with certain attributes, such as attractiveness, sophistication, and social success, which could be a possible incentive to smoke [44]. Thus, it could also

motivate e-cigarette vaping behavior. Our finding suggests that most e-cigarette users enjoy the social image of vaping.

In summary, both Reddit and JuiceDB provide users a platform to share vaping experiences. JuiceDB content is in the form of reviews and focuses more on e-liquids. Reddit, however, offers more approaches for user interactions, such as questions and answers.

Regulation Debates

Reddit and Twitter had topics about regulations and policy debates, but JuiceDB did not. The keywords from the LDA-identified topics included “kids,” “addiction,” “house,” “quitting,” “safe,” “cancer,” “chemicals,” “government,” “drug,” “control,” “regulation,” and “harmful.” People were discussing the effect of using e-cigarettes, especially the effects on children, and the risk of diseases from chemicals. These discussions went further and led to debates on regulations and bans.

Some Reddit users expressed concerns, whereas others appealed for not banning e-cigarettes. Examples are shown in Multimedia Appendix 5.

In general, we used the keywords “policy,” “policies,” “ban,” “bans,” “regulate,” “regulates,” “regulated,” and “regulation” to search the Reddit database, finding 872 posts. We were interested in generating a basic understanding of people’s attitudes toward e-cigarette regulations. Thus, by reading through the contents, 224 posts were considered to contain personal attitudes, which are summarized in Table 3. There were 21 proponents (9.4%), 136 opponents (60.7%), and 67 neutrals (29.9%) on e-cigarette bans. The proponents raised examples from law, research findings, and moral requirements, such as negative externality to children, to support the bans. Another interesting idea to support e-cigarette regulation was legislation benefit, indicating proper regulations could bring a better environment to the e-cigarette industry and improve the quality of e-cigarette products. However, the opponents also argued from the same fields with different evidence. The most common argument came from personal experience. Vapers argued that e-cigarettes were safer than traditional tobacco products and could save hundreds and thousands of lives. From the perspective of laws, some people said, “there is no apparent direct regulatory authority in the United States to use flavors in e-cigarettes.” Politics was another approach to battle e-cigarette regulations. Some vapers believed regulations were motivated by political pressure. Furthermore, opponents appealed for actions to down bills designed to ban e-cigarettes. Cities and states mentioned in call-for-action posts included Chicago, Berkeley, Connecticut, and Utah. The existence of so many call-to-action posts leads to the observation that Reddit serves as an important platform for vapers to organize campaigns. For instance, instructions for a mail campaign against bans are presented in Multimedia Appendix 6.

Table 3. Regulation debates posts on Reddit (n=224).

Post themes	n (%)
Proponents (9.4%)	
Law	1 (0.4%)
Research	5 (2.2%)
Moral requirement	9 (4.0%)
Legislation benefit	5 (2.2%)
Tax	1 (0.4%)
Opponents (60.7%)	
Personal freedom	5 (2.2%)
Safer product	52 (23.2%)
Law	4 (1.8%)
Politics	8 (3.6%)
Employee efficiency	1 (0.4%)
Research	8 (3.6%)
Call to action	51 (22.8%)
How to oppose	7 (3.1%)
Neutrals (29.9%)	
Possible regulation	11 (4.9%)
Current regulation status	23 (10.3%)
Regulation effect	15 (6.7%)
Company rule	17 (7.6%)
Comparison	1 (0.4%)

Correspondingly, some vapers looked for suggestions to oppose e-cigarette bans, not only federal or state regulations, but also company and university rules.

Some posts were neutral, including forecasting possible future regulations, introducing the current regulation status, analyzing regulation effects, and discussing company-specific rules. Some posts compared e-cigarettes and other addictive products, such as junk food, to discuss regulations on e-cigarette bans.

Twitter, on the other hand, focused more on information transmission. Tweets are restricted to less than 140 words, so they contain much less information than a complete Reddit post. Thus, the contents on Twitter were more straightforward and less descriptive. Twitter users tended to use other websites as references to support their point rather than describe it in detail. For instance:

> *RT @DeLaConcha: RT @tobacconistu: Judge rules FDA cannot ban E-Cigarettes [URL].*

Twitter is also famous for its social networking function. Users connect to one another by following relationships. By retweeting posts from other users, information is quickly transmitted all over the world. Thus, the contents are more timely than Reddit posts. For example, an e-cigarette ban proposal in Coconino County could be tracked on Google as early as April 8, 2014. In our dataset, there was a tweet directing to this page right after it was published.

Finally, as we have mentioned, Twitter is a well-known platform for social media campaigns. By using certain hashtags, users become involved and influence specific topics. Ideas spread quickly through such campaigns. The hashtags #euecigban, #noecigban, and #freevape were broadly used on Twitter.

There were 3118 tweets containing the hashtag #euecigban, 916 posts containing the hashtag #noecigban, and 299 posts containing the hashtag #freevape. We analyzed the same number of posts for each hashtag group. For each hashtag, we randomly picked out 299 posts (the total number of posts that #freevape had), analyzed the content, and classified them into themes, as shown in Table 4. All the themes were against e-cigarette regulations, except for two:

1. No harm: tweets with this theme argued that e-cigarettes should not be banned because their use has little or no negative impact on human health, especially for 0 mg nicotine e-liquid.

2. Smoking cessation and saving lives: this theme stated that e-cigarettes should not be banned because e-cigarettes could act as a substitute for traditional tobacco and, therefore, e-cigarettes could help users quit smoking and save lives.

3. Pharma interests/tax income: some tweets argued that e-cigarette bans were proposed because of the interests of traditional tobacco/pharma companies or taxation from the sales of traditional tobacco.

4. Biased research: some people thought the evidence from research that supports e-cigarette bans was biased.

5. Personal freedom and rights: some people believed banning e-cigarettes was a violation of personal freedom and rights.

6. Simple opposition: some tweets just opposed e-cigarette regulations without providing any evidence.

7. Call to action: tweets in this theme were appealing for some action to oppose the ongoing bills. Usually, it was an imperative sentence with keywords “support,” “sign,” and “action.”

8. Only tag: these tweets contained a hashtag but not any other text content. Usually these tweets had URLs or pictures, which were not analyzed by this research.

9. Neutral descriptions: text content in the tweets were just descriptions without personal attitudes.

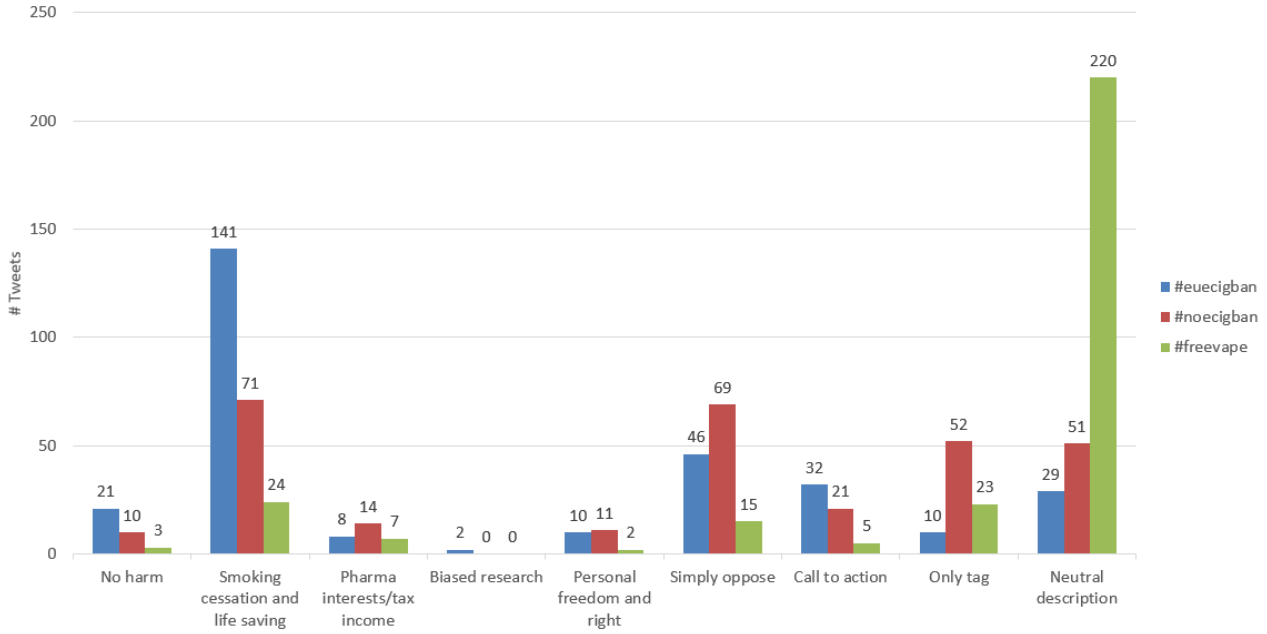
Figure 2 shows the comparison of themes among these three hashtags. We observed that the #euecigban campaign was more reasonable because it had a great proportion of tweets containing evidence to support their statement. However, #noecigban focused more on direct opposition with some URLs and pictures. The campaign by #freevape seemed to be more descriptive and illustrated the current status of e-cigarettes with a neutral perspective.

In summary, Reddit, which is essentially a forum, has more user discussions and interactions than Twitter. But Twitter is good at information transmission and social media campaigns.

Table 4. Twitter hashtag analysis.

Hashtag and category	n (%)
#euecigban (n=299)	
No harm	21 (7.0)
Smoking cessation and life saving	141 (47.2)
Pharma interests/tax income	8 (2.7)
Biased research	2 (0.7)
Personal freedom and right	10 (3.3)
Simply opposition	46 (15.4)
Call to action	32 (10.7)
Only tag	10 (3.3)
Neutral description	29 (9.7)
#noecigban (n=299)	
No harm	10 (3.3)
Smoking cessation and life saving	71 (23.7)
Pharma interests/tax income	14 (4.7)
Biased research	0 (0.0)
Personal freedom and right	11 (3.7)
Simply opposition	69 (23.1)
Call to action	21 (7.0)
Only tag	52 (17.4)
Neutral description	51 (17.1)
#freevape (n=299)	
No harm	3 (1.0)
Smoking cessation and life saving	24 (8.0)
Pharma interests/tax income	7 (2.3)
Biased research	0 (0)
Personal freedom and right	2 (0.7)
Simply opposition	15 (5.0)
Call to action	5 (1.7)
Only tag	23 (7.7)
Neutral description	220 (73.6)

Figure 2. Tweet theme comparison.



Differences Across Platforms

The comprehensive analysis in the previous part presented the results summarized from all the data available. However, another interesting question came from the differences across platforms; specifically, whether the posts from different platforms had different topic distributions. As shown previously, the dataset collected from Twitter was more related to regulation debates, whereas the datasets from Reddit and JuiceDB were more comprehensive because of the keywords selected in the data collection processes. Thus, in this study, we only compared the topic distributions between Reddit and JuiceDB.

As stated in the data analysis section, the LDA algorithm identified five topics from a collection of Reddit or JuiceDB posts. In order to compare across the platforms, we manually classified those topics into three groups: promotion, flavor, and experience. Each of the posts was categorized into one of the groups. For Reddit, the number of topics in promotion, flavor, and experience were 2152, 21,752, and 3734, respectively; for JuiceDB, the number of topics in promotion, flavor, and experience were 4203, 5196, and 5034, respectively.

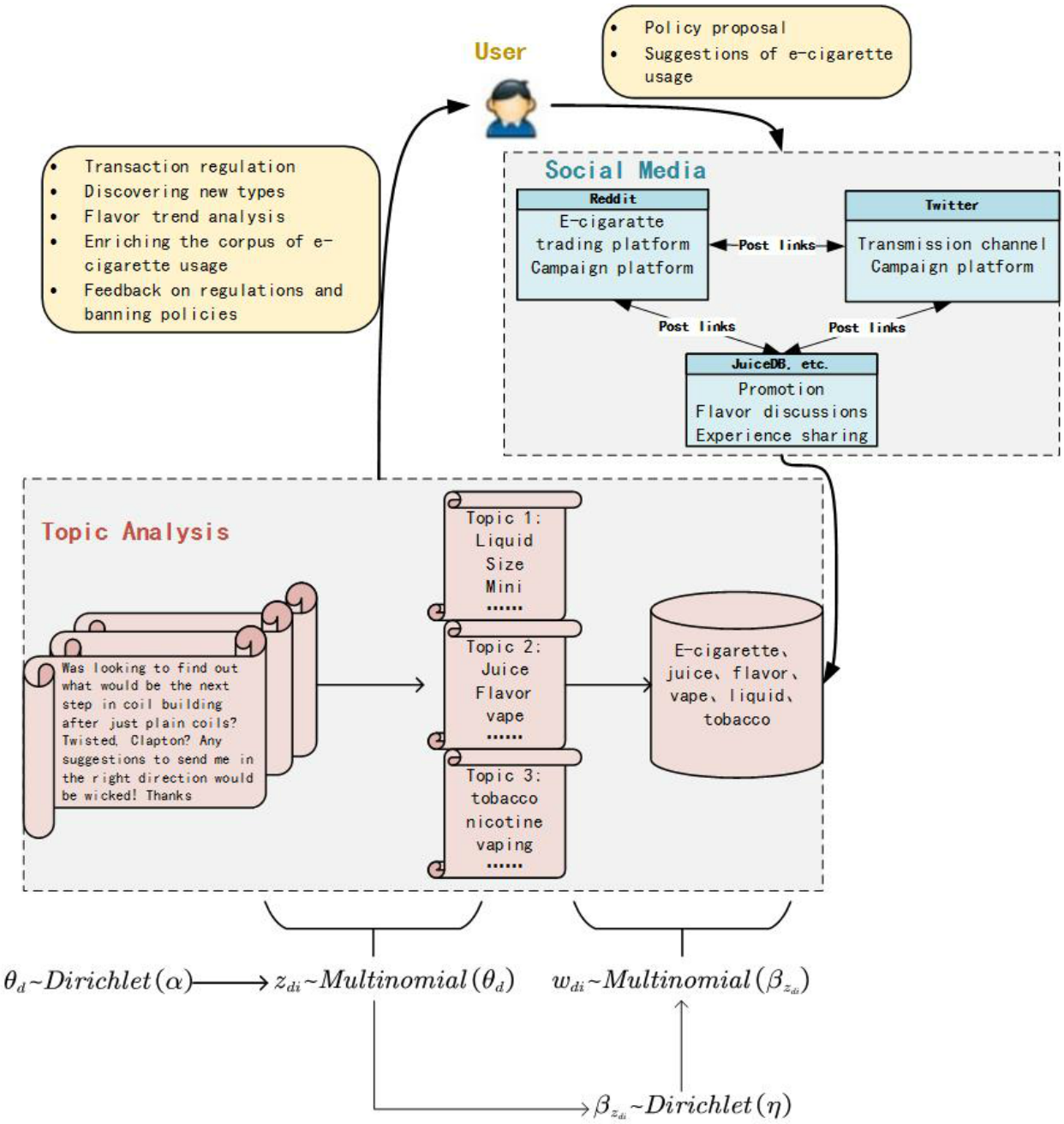
We ran a chi-square test to compare the differences in topic distribution between Reddit and JuiceDB. The results showed that the topic distribution was significantly different (P<.001), which indicated the user discussions focused on different perspectives across the platforms.

Discussion

A Unified Feedback Model

We provide a general framework to analyze user-generated content from social media. After the raw materials are collected, we believe it will be much better if the topic-modeling method is used to generate some insights for further analysis. For instance, we found several topics by applying LDA methods to datasets collected from different social media. These topics are classified into four types: promotions, flavor discussions, experience sharing, and regulation debates. Compared to the results from surveys and experiments, data from social media are collected in the field and have a large data size, which provides a potential approach to generate valuable insights. Moreover, collecting data online uses less time and money than recruiting participants to complete questionnaires. Based on the previous analysis, we propose a unified model for e-cigarette policy proposals, as shown in Figure 3. In this framework, the researchers and policy makers can obtain feedback to policy proposals, which can be used as evidence to support public health policy development. Governments also have official accounts on Twitter and Facebook because they are considered as the most influential social media. Thus, policy proposals could be published by the official account on these two websites. Thanks to the high speed of information transmission, all the major social media will soon be notified. Users in different platforms will provide valuable feedback to the policy. After data collection, the topic-modeling method provides a possible approach to measure the feedback because it presents the implicit structure of the data. The topic and many other metrics can be used together to conduct public health surveillance. Although using keywords can provide a continuous record for trend analysis, the change of topics and corresponding keywords can help us identify which keywords should be listened to. As mentioned previously, topic modeling is helpful in broadening policy makers' horizons, enriching research corpus, and detecting emerging trend.

Figure 3. A unified e-cigarette social media feedback collection and analysis model.



Consider two simple examples. Assume that government departments, such as the FDA, want to collect some data about symptoms and adverse events from using different flavored e-liquids [1]. With our model, major platforms such as Twitter, Facebook, and Reddit could be considered. The topic of flavor discussions could be identified automatically using LDA methods. Posts belonging to this topic should be further examined. Furthermore, JuiceDB, serving as a second-tier platform, could provide additional information to analyze the effect of flavors. Another example is collecting public comments and thoughts for future regulations. The FDA has held three public workshops to obtain information on e-cigarettes and public health. However, our model provides another approach to collect additional information from the field. Reddit and Twitter are important platforms for regulation feedback even though they emphasize different aspects. Information transmission on Twitter is faster whereas discussions on Reddit are more detailed. Both of them provide unique angles to understand public comments. In addition, some other second-tier platforms could be useful for exploring deeper and further thoughts.

Contributions

In summary, the rapid growth of e-cigarette user communities indicates the importance of research in this field. Social media has proven to play an indispensable role in promotions and communications. Previous research has utilized social media as the data source to study e-cigarettes. Most of them focused on only one specific platform [19-31]. Therefore, there is still a lack of comprehensive examination across multiple social media platforms. Chu and colleagues [32] used data from both Facebook and Twitter to study the marketing strategies of

e-cigarette brands. This paper is inspired by the previous research, but contributes to the field by analyzing topics across the platforms using automatic topic-modeling tools. The LDA method is introduced to researchers and policy makers who are interested in data mining and machine learning. Reddit is recognized as a comprehensive forum for e-cigarette discussions, whereas JuiceDB only focuses on e-liquid reviews. Twitter has less information within each post, but is good at data transmission and campaign detection. Furthermore, the types of topics are summarized into four groups: promotions, flavor discussions, experience sharing, and regulation debates. Statistics are summarized to generate insights into the current state of e-cigarette communities. Specifically, we found (1) 11% of the Reddit posts were user trading posts, which showed evidence of the existence of a large secondhand e-cigarette trading market, raising new concerns in regulations and surveillance; (2) flavor discussions from JuiceDB and Reddit followed consistent category systems, which provided a good framework for automatically discovering new products and emerging trends; (3) experience sharing included e-cigarette vaping methods, features, and outcomes, which served as evidence of the patterns of e-cigarette use; and (4) regulation debates from Reddit could be used to collect feedback, whereas Twitter was a popular platform for a social media campaign. The topic distributions within Reddit and JuiceDB were significantly different (P<.001), which indicated the user discussions focused on different perspectives across the platforms. The unified feedback model we presented to collect valuable proposal feedback from social media will save policy makers' time and money.

Limitations

We collected data from Reddit, JuiceDB, and Twitter, which was feasible for our current research. However, several other platforms, such as Facebook and E-cigarette Forum, could be considered to expand the current dataset for further analysis. We only collected regulation-related data from Twitter, but other e-cigarette-related tweets could be of interest. A more general keyword set should be created for data collection across the platforms. Moreover, the keywords "vape," "vapor," and "vaping" should be included in the next step of data collection. However, we still believe the research findings from the current dataset provide valid and valuable insights.

Another limitation of this paper was the lack of demographic information. Because Reddit, JuiceDB, and Twitter do not provide reliable personal characteristics, such as age and gender, we cannot divide our dataset into several subgroups to analyze the different patterns among different age or gender groups.

Finally, this study only used LDA to identify topics among posts. There are many other data mining tools that could be applied to further explore the dataset. For instance, sentiment analysis could be conducted on the regulation-related posts. Positive, neutral, or negative sentiments are an important indicator for understanding public comments.

Future Research

We envision three possible approaches for further study. First, the LDA model could be modified and extended for further analysis. In this paper, we applied the standard LDA techniques as the topic-modeling algorithm, and the results were feasible enough to conduct some analysis. However, given the special context of e-cigarettes, we believe that some modifications to the standard LDA model could produce better and more precise results. For instance, topic-in-set knowledge could be added to achieve supervised learning [45]. Another study modified LDA to find groups in graphs, which could be helpful in finding e-cigarette promoters in social media networks [46]. Social media analysis is famous for its big data. LDA could be applied in a distributed way to process the big data as well [47]. In summary, there are many modifications to the standard LDA model, which could be further explored by us and other researchers.

Second, major types of topics are identified, each of which is interesting and makes practical sense. Some findings and discussions could be further explored. For example, individual trading is an emerging phenomenon in the e-cigarette market, which could produce potential risks to e-cigarette regulations. Vendors' promotions are also worth studying to find patterns. Automatic emerging e-liquid detection and symptoms collection are important as well. Studying feedback on proposed policies would generate insights for policy makers to make better decisions.

Finally, the characteristics of social media platforms should be further analyzed. For example, the problem of bots, fake accounts, and spam on Twitter is worth exploring, from both a research perspective and an application perspective. It will be challenging and meaningful if we can develop an automatic filter for more accurate analysis on Twitter. The algorithm itself and the patterns of spammers are worth studying. The connections between platforms are interesting as well. If we could identify the same account across platforms, the information flow could be easily understood, providing a valuable signal for public health surveillance.

Conclusion

Using topic modeling techniques LDA, we identified topics among posts generated by e-cigarette users. This automatic method could be used to analyze the state of the art in the e-cigarette field. New brands, flavors, and trends could be found using our method, which is of great importance to the fast-developing e-cigarette market. We compared the results from Reddit, JuiceDB, and Twitter and discussed the similarities and differences of the platforms. We hope the characteristics analyzed by this paper can be further used by other researchers and policy makers.

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Conflicts of Interest

Scott J Leischow has served as a paid consultant to or conducted research for Pfizer, GSK, Cypress BioScience, and McNeil Consumer. McNeil Consumer is collaborating with GSK on a current study on nicotine replacement, which is being conducted by Scott J Leischow, and GSK markets bupropion.

Multimedia Appendix 1

Graphical representation of the LDA model.

[PNG File, 15KB - jmir_v19i1e24_app1.png]

Multimedia Appendix 2

LDA model.

[PDF File (Adobe PDF File), 28KB - jmir_v19i1e24_app2.pdf]

Multimedia Appendix 3

Close connections between Reddit and JuiceDB.

[PDF File (Adobe PDF File), 16KB - jmir_v19i1e24_app3.pdf]

Multimedia Appendix 4

Sweet e-juice and cavity.

[PDF File (Adobe PDF File), 15KB - jmir_v19i1e24_app4.pdf]

Multimedia Appendix 5

Regulation debates from Reddit.

[PDF File (Adobe PDF File), 16KB - jmir_v19i1e24_app5.pdf]

Multimedia Appendix 6

An instruction to against e-cigarette ban by mails.

[PDF File (Adobe PDF File), 17KB - jmir_v19i1e24_app6.pdf]

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Abbreviations

API: application program interface
E-cigarette: electronic cigarette
FDA: Food and Drug Administration
LDA: latent Dirichlet allocation
NLP: natural language processing
PG: propylene glycol
RDA: rebuildable dripping atomizer
RT: retweet
VG: vegetable glycerin
WTB: want to buy

WTS: want to sell
WTT: want to trade

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Original Paper

It's About Me: Patients' Experiences of Patient Participation in the Web Behavior Change Program for Activity in Combination With Multimodal Pain Rehabilitation

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Abstract

Background: Patients' participation in their health care is recognized as a key component in high-quality health care. Persons with persistent pain are recommended treatments with a cognitive approach from a biopsychosocial explanation of pain, in which a patient's active participation in their rehabilitation is in focus. Web-based interventions for pain management have the potential to increase patient participation by enabling persons to play a more active role in rehabilitation. However, little is known about patients' experiences of patient participation in Web-based interventions in clinical practice.

Objective: The objective of our study was to explore patients' experiences of patient participation in a Web Behavior Change Program for Activity (Web-BCPA) in combination with multimodal rehabilitation (MMR) among patients with persistent pain in primary health care.

Methods: Qualitative interviews were conducted with 15 women and 4 men, with a mean age of 45 years. Data were analyzed with qualitative content analysis.

Results: One theme, "It's about me," and 4 categories, "Take part in a flexible framework of own priority," "Acquire knowledge and insights," "Ways toward change," and "Personal and environmental conditions influencing participation," were developed. Patient participation was depicted as being confirmed in an individualized and structured rehabilitation framework of one's own choice. Being confirmed was fundamental to patient participation in the interaction with the Web-BCPA and with the health care professionals in MMR. To acquire knowledge and insights about pain and their life situation, through self-reflection in the solitary work in the Web-BCPA and through feedback from the health care professionals in MMR, was experienced as patient participation by the participants. Patient participation was described as structured ways to reach their goals of behavior change, which included analyzing resources and restrictions, problem solving, and evaluation. The individual's emotional and cognitive resources and restrictions, as well as health care professionals and significant others' attitudes and behavior influenced patient participation in the rehabilitation. To some extent there were experiences of restrained patient participation through the great content of the Web-BCPA.

Conclusions: Patient participation was satisfactory in the Web-BCPA in combination with MMR. The combined treatment was experienced to increase patient participation in the rehabilitation. Being confirmed through self-identification and finding the content of the Web-BCPA trustworthy was emphasized. Patient participation was experienced as a learning process leading to new knowledge and insights. Higher user control regarding the timing of the Web-BCPA and therapist guidance of the content may further increase patient participation in the combined treatment.

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KEYWORDS

interview; pain; patient participation; qualitative research; Web-based intervention

Introduction

Patient participation is a complex and multifactorial concept, and despite a large body of literature in the field, there is no consensus about a unifying definition that describes the concept [1-4]. To take part in or to be involved in one's health care are fundamental definitions of patient participation [1,2,4,5]. The concept of patient participation may be applied to different areas of patient health care, such as the attending of treatments, decision making, and self-care [1,3,4]. In addition, there may be different implications of patient participation depending on the perspective in focus (patient, the health care organization, society) [1-3]. In the clinical health care meeting, patient participation can be described by the model of Patient-Centered Medicine (PCM) that includes understanding the patient as a whole person, acknowledging the patient's expertise, shared decision making, and developing an ongoing therapeutic patient–health care professional relationship [6,7]. Health care professionals' surrender of power and control to the patient has been considered an important aspect of patient participation [1]. Eldh et al [2] found that health care professionals had a narrower description of patient participation than the patients. Patient participation can influence treatment adherence and results, as well as health outcomes [8-10].

Patients with persistent pain have reported negative patient participation characterized by mistrust and dismissal from the health care professionals regarding their pain [11-14]. In contrast, patients with persistent pain in multimodal rehabilitation (MMR) have described positive patient participation built on mutual trust and respect in encounters with their health care professionals [15,16]. MMR is a recommended treatment for patients with persistent musculoskeletal pain [17-19]. It is based on a cognitive approach and a biopsychosocial explanation of persistent pain, and includes physical and psychosocial treatment components [17,19-21]. Activity in daily life and work is one main goal of MMR. The individual's active participation in treatment sessions, as well as in setting goals, rehabilitation planning, and decision making is emphasized [16,21,22]. However, patients may have experiences of restrained patient participation in decision making due to the knowledge gap between the patient and the health care professionals, as well as the staff's professional authority [1,6,7,15,23].

The entry of eHealth has had an impact on patient participation by increased access to health information, the extended delivery of health care, and a shift of power to the patient [24,25]. Web-based interventions have the potential to increase patient participation by enabling patients to play a more active role in their health care [25-28]. However, Web-based interventions suffer from nonusage attrition and low adherence [29-31]. It has been suggested that characteristics of the user, such as motivation, symptom panorama, and education level influence Web-adherence. In addition, Web-adherence is also related to the characteristics of the Web-based intervention, such as the flexibility of the program and how it is connected to specific personal needs of the user [30,31]. Altogether, there is a need of further research to find out how patients experience their participation in Web-based interventions [27,29].

In the county of Norrbotten, northern Sweden, the Web behavior change program for activity (Web-BCPA) was developed to propose an eHealth solution for a biopsychosocial treatment of persistent musculoskeletal pain. The Web-BCPA is a modified version of an existing Livanda Web-based program "To manage pain," which had been developed in accordance with cognitive behavior therapy principles and focused on the individual's active participation [32]. In cooperation with the founders of Livanda, "To manage pain" was revised with the aim to fit patients in an early stage of persistent pain. Altogether, the Web-BCPA aims to increase participants' physical and cognitive activity in the rehabilitation and encourage activity in everyday life and work, including physical activity and promoting self-care [33]. There are a few studies that have reported on patient participation in Web-based interventions [30,34], and to our knowledge this is the first study of patient participation combining a therapist guided treatment with a self-guided Web-based intervention. Increased knowledge about what the Web-BCPA could add to patient participation in MMR may further illuminate the concept of patient participation in pain rehabilitation. Thus, the aim of this study was to explore patients' experiences of patient participation in the Web-BCPA in combination with MMR in primary health care.

Methods

Study Design

A qualitative interview study was performed to obtain the variety of patients' experiences of patient participation in the Web Behavior Change Program for Activity (Web-BCPA) in combination with MMR and to generate further knowledge of the topic [35,36]. The study was approved by the Regional Ethical Review Board of Umeå University, Sweden (Umu dnr 2011-383-31M).

Informants and Selection

Informants eligible for the interview study were persons that participated in the randomized controlled trial (RCT) with the aim to investigate effects of the Web-BCPA for persistent pain in primary health care (NCT01475591), in the county of Norrbotten, Northern Sweden. They had been included to the RCT with the following inclusion criteria: (1) aged between 18 and 63 years; (2) persistent musculoskeletal pain with a duration of at least three months in the back, neck, shoulder, and/or generalized pain; (3) Örebro musculoskeletal pain screening questionnaire (ÖMPSQ) score ≥90, screening for psychosocial factors that indicates an estimated risk for long-lasting pain and future disability [37]; (4) work ability of at least 25 percent; (5) familiar with written and spoken Swedish; and (6) access to

computer and Internet. Exclusion criteria were reduced cognitive ability or need of other health care. Additional inclusion criteria to this interview study were that the informants had spent at least 15 minutes per module in 5 of 8 modules in the Web-BCPA.

The study was performed from April 2012 to October 2014. Informants were consecutively included to the study in time for their 4-month follow-up of the RCT. Thirty-four persons were identified and informed about the interview study, and 22 persons gave their oral consent to be contacted through telephone calls by the interviewer for more details about the study. Three persons declined participation and finally 19 informants gave their written consent to participate. These included 15 women and 4 men, with mean age of 45 years. The majority (18 out of 19) lived with a spouse or partner, and about 50% (9/19) of the informants had children in the household. The informants' educational level varied from elementary to university education. Furthermore, 63% (12/19) of the informants had permanent employment and 68% (13/19) were working at least 25% of a full time job or searching for work. The informants had musculoskeletal pain in the back, neck, shoulder, and/or generalized pain for in average 7.5 years. They rated mean pain intensity 67/100 on the visual analogue scale and had a mean ÖMPSQ score of 130 (Table 1).

Table 1. Informants' characteristics.

Characteristics	Mean (range) or n (%)
Age in years, mean (range)	45 (27-60)
Woman, n (%)	15 (79)
Married or cohabit, n (%)	18 (95)
Children in the household, n (%)	9 (47)
Education level[a] , n (%)	
Elementary	2 (11)
Secondary	12 (63)
University	5 (26)
Working condition, n (%)	
Permanent or self-employed	12 (63)
Temporary employment	3 (16)
Unemployed	3 (16)
Social benefits	1 (5)
Working[b], n (%)	13 (68)
Pain duration in months, mean (range)	90 (5-156)
Pain intensity last 7 days[c], mean (range)	67 (45-90)
ÖMPSQ[d], mean (range)	130 (90-158)

[a]Elementary equals the first 9 years of education, secondary the following 3 years of education, and university represents all further education.

[b]Working at least 25% of a full time job or searching for work at time for baseline.

[c]The visual analogue scale. Score between 0 (no pain) to 100 (worst imaginable pain).

[d]The Örebro musculoskeletal pain screening questionnaire. Maximum score 210. A score ≥90 indicate a moderate estimated risk for long-lasting pain and future disability, and ≥105 indicates a higher estimated risk.

Study Context

The informants received the Web-BCPA in combination with MMR.

The Web-BCPA was a self-guided Web-based intervention for pain management based on cognitive behavior therapy principles. The Web-BCPA consisted of 8 modules: (1) pain, (2) activity, (3) behavior, (4) stress and thoughts, (5) sleep and negative thoughts, (6) communication and self-esteem, (7) solutions, and (8) maintenance and progress. The modules contained information, assignments, and exercises, assimilated via educational texts, videos, and writing task. Assignments were interactive with the user. The Web-BCPA was delivered to the informant 1 module per week during the first 8 weeks of rehabilitation. The informants had access to the Web-BCPA 24/7 for 4 months. Administrative support in the Web-BCPA was provided, but there was no therapist guidance of the content. The Web-BCPA in detail has been described in a previous publication [33].

The informants spent 445 minutes (mean) in the Web-BCPA, with a range of 88 to 841 minutes. In total, 68% (13/19) of the informants had opened all 8 modules.

In the MMR, the patient and the team of health care professionals had drawn up an individualized rehabilitation plan. The rehabilitation plan included identification of the patient's resources and restrictions, formulation of goals,

planning of treatments, and dates for follow-up. The treatments were individual and/or in group sessions, and included for example physical activity, activity planning, symptomatic treatment, counseling, as well as home exercises. Further details about the MMR have previously been presented [33].

Each informant had between 7 and 36 (mean 18) treatment sessions. The informants had treatments by an occupational therapist (18 persons out of 19), physician (19 out of 19), physiotherapist (18 out of 19), and psychosocial counselor (15 out of 19). Nine informants had completed the MMR, and 10 continued their rehabilitation at time for the interview.

Data Collection

Data was collected from qualitative interviews using a semistructured interview guide with open-ended questions. The interview began with an open question: "Please, tell me what patient participation is like for you?" The informants were then asked to describe their experiences of patient participation in the rehabilitation, the Web-BCPA combined with MMR. Each informant was interviewed once by the first author, within 1 month after the 4 months follow-up of the RCT. Eleven informants were interviewed at various health care centers in the county of Norrbotten, 7 persons at a conference-room at the county council building, and 1 person at home. The interviews were digitally recorded using an mp3 recorder, and ranged 31 to 56 (median value 48) minutes.

Data Analysis

Data was analyzed using qualitative content analysis inspired by Graneheim and Lundman [38]. Content analysis is a systematic way to analyze the content in a text and qualitative content analysis includes latent interpretation of texts, which has been proven useful in many fields of research, for example health care sciences [38,39]. The researcher's knowledge of the context of the study is important in the selection of informants, data collection, and data analysis [38].

First, the verbatim transcribed interviews were read several times to get an overall sense of the content. Then meaning units (words or sentences that are related to each other through their content and context) that answered to the aim of the study were marked. To shorten the text, the meaning units were condensed and labeled with a code. The codes were kept close to the text to keep the manifest expression of the text. The analysis was then copied into the freeware computer program Open Code [40].

Next step was to compare and compile the codes according to similarities and differences to create preliminary categories on a further abstraction level. The preliminary categories were compared against all data to construct definite categories, which were internally homogeneous and externally heterogeneous [38,41] A theme, which expressed the latent content, a thread of underlying meaning through the categories, developed during the analysis [38]. All authors participated in all steps of the analysis.

Results

Overview of Theme and Categories

The analysis of the informants' experiences of patient participation in the Web-BCPA in combination with MMR resulted in 1 theme "It's about me", and 4 categories: "Take part in a flexible framework of own priority," "Acquire knowledge and insights," "Ways toward change," and "Personal and environmental conditions influencing participation" (Textbox 1). The theme and categories are described in the following section, together with quotes from the informants.

Textbox 1. Results of the qualitative content analysis of informants' experiences of patient participation in the Web Behavior Change Program for Activity (Web-BCPA) in combination with multimodal rehabilitation (MMR), presented with theme and categories.

Theme:

- It's about me

Category:

- Take part in a flexible framework of own priority
- Acquire knowledge and insights
- Ways toward change
- Personal and environmental conditions influencing participation

It's About Me

The theme "It's about me" depicted patient participation as being confirmed in an available, flexible, and individualized framework of own choice. Informants' experiences of being confirmed ran through all 4 categories and were expressed as patient participation in the interaction with the Web-BCPA and with the health care professionals in MMR. Being confirmed as a patient and as a person in one's own team with many treatment options was experienced as a tailored rehabilitation. Though, the freedom of choice in the Web-BCPA entailed perceptions of restrained patient participation for some informants. A single situation of mistrust and disrespect with a health care professional in the MMR restrained patient participation but did not affect the overall perceptions of patient participation in the rehabilitation.

> *...it was obvious that it (the rehabilitation) was about me, it wasn't about just anyone...it was about my problems, my strengths and how I felt...they (the health care professionals) started from a blank page, I was not fitted into an average template of how it*

> *ought to be...it (the rehabilitation) started with my point of view...* [Interview 4, woman]

To acquire knowledge and insights were thought of as patient participation, and included self-reflection, self-identification, and feedback. Informants experienced that being able to identify themselves with the content in the rehabilitation and finding it trustworthy were important to patient participation and being confirmed. Patient participation was described as their own process toward behavior change. Informants' emotional and cognitive resources and restrictions, as well as health care professionals' attitudes and behavior were important to patient participation.

Take Part in a Flexible Framework of Own Priority

Within the category "Take part in a flexible framework of own priority," patient participation was understood as taking part in a structured and flexible rehabilitation concept with opportunities to influence and a variety of treatments to choose according to one's own needs and priorities.

> *...previously I had read about CBT (Cognitive Behavioral Therapy), but I had never thought of it as a help for my condition... I want to compare this rehabilitation with a smorgasbord from which is it easy to taste...* [Interview 14, woman]

Informants had experiences of patient participation in the solitary work in the Web-BCPA that included logging in, reading the texts, working with the assignments, and performing the exercises. Patient participation was emphasized by having access to the Web-BCPA on computer or tablet at all hours and locations. The opportunities to work in the Web-BCPA at home were experienced to provide continuity in the rehabilitation.

> *...thanks to the program (the Web-BCPA) I was able to perform the basic body awareness exercises of my own choice...and to repeat those that I felt most effective as many times that I preferred...the flexibility made it mine (the rehabilitation)...* [Interview 4, woman]

Although, some informants perceived restrained patient participation by the fact that they were not able to choose the starting time of the Web-BCPA course themselves (due to study protocol), as well as not being able to select a faster advancement in the program by themselves. Higher patient participation through participatory design of the content in Web-based interventions was suggested. Some informants experienced difficulties to choose area of interest in the Web-BCPA and that it became a burden to complete. In contrast, informants reported that they were supported by the health care professionals, including the rehabilitation coordinator, to make those choices in the MMR.

Patient participation was experienced as being part of one's team with access to face-to-face meetings with health care professionals and available examinations and treatments through flexibility in treatment hours and timing. To simultaneously meet all health care professionals and significant others in dialogue and co-operation at team-conference meetings was emphasized. Also, the reasoning process between the health care professionals, and health care professionals reading and documenting in the patient records were perceived as patient participation.

> *...they (the health care professionals) were sensitive to understand me as a person...all of them...I felt very much involved when I met all health care professionals at the same time than when I met each at separate occasions...our decisions about the rehabilitation were mutual...* [Interview 10, woman]

Restrained patient participation was reported by the informants when a health care professional included in the patient's rehabilitation but with clinical practice outside of the health care center did not attend the team-conference meeting. For example a physiotherapist of the private health care sector. Some informants experienced restrained patient participation when health care professionals decided to withdraw treatment with reference to that a patient's symptoms were not severe enough.

Some informants thought of the rehabilitation concept similar to have a work or be in school, since participating entailed own efforts, to have something to contribute with and feeling satisfied. To some informants taking part in the Web-BCPA and the MMR was an integrated rehabilitation. Others described the Web-BCPA and the MMR as 2 parallel rehabilitations, which could entail different agenda.

Acquire Knowledge and Insights

In the category "Acquire knowledge and insights," patient participation was experienced as an interactive learning process toward knowledge and insights. Informants reported that gained knowledge and insights from working in the Web-BCPA strengthened their self-confidence and increased patient participation in the dialogue with health care professionals.

> *...my own thinking about my situation was confirmed by the content in the web-program (Web-BCPA)...this made me feel safe to share those thoughts (with the health care professionals) to acquire new knowledge that I can use in meetings with people that are involved in my rehabilitation...I was equipped with putting words on my thinking...* [Interview 14, woman]
>
> *...do you mean that it was easier to ask questions (to the health care professionals)?* [Interview 14, interviewer]
>
> *...yes...to be involved in my rehabilitation is much about me...to be confirmed by the content in the Web-program made me more powerful in meeting them (the health care professionals)...* [Interview 14, woman]

Patient participation was experienced by the informants as being able to identify themselves through the information and explanations about pain and symptoms, treatments, and advices given by the Web-BCPA content and the health care professionals. Self-identification was experienced to help informants to choose or exclude activities in the Web-BCPA. The informants found that there was a comparable message in the Web-BCPA and the MMR, and that "it was like made for them," which increased trustworthiness and deepened knowledge and insights. Self-reflection and rehearsal was emphasized in the solitary work at a self-chosen work pace in the Web-BCPA,

and experienced by the informants to favor learning and patient participation. Informants perceived that self-reflection was present to some extent in the contacts with health care professionals.

> *...working by myself in the Web-program made me reflect more and gave me insights, which I certainly passed on (to the team-members)...at the team-conference meetings there were more reasoning than reflection...* [Interview 1, woman]

Some informants described that new knowledge from the Web-BCPA developed into applied knowledge through feedback from a health care professional in the MMR. A continuous exchange of feed-back with health care professionals was emphasized in patient participation and in learning.

Ways Toward Change

"Ways toward change" represented the informants' experiences of patient participation in the Web-BCPA and MMR as ways to change one's behavior. The informants' experienced patient participation when they analyzed their situation taken into account their resources and restrictions, set goals for behavior change, and planned treatments and activities. Also, patient participation was stated when treatments, self-care, and planning were followed-up and evaluated. Awareness of improvements and goal attainment was perceived to favor patient participation and to motivate them to further actions for change. The informants stated that a written goal to strive for in the rehabilitation assured the change progress and patient participation. To adjust a goal or treatment planning in relation to progress or setback was described as patient participation.

> *...I feel it is important to set goals and to follow-up those goals...and to understand why a goal is reached and why another is not...this made me aware of that I needed other tools (in the rehabilitation)...* [Interview 14, woman]

Informants described that they guided themselves in their ways toward change in the Web-BCPA and that problem solving was emphasized. Some informants experienced restrained patient participation through difficulties to come up with a problem area. Patient participation was reported when informants monitored results shown by the interactive graphs in the Web-BCPA.

> *...days when I had a lot of pain I used to remain sedentary, and as soon as I had a better day I was eager to do all kinds of activities that day...before I started the assignment activity planning (in the Web-BCPA) I was not aware of how my behavior related to the days with pain, but by monitoring this over time I started to plan my daily activities in a more balanced way...* [Interview 11, woman]

In the MMR, informants experienced that drawing up a rehabilitation plan in mutual agreement with health care professionals was ways to behavior change. Some informants emphasized patient participation as having their own choice to play an active role in rehabilitation planning by contributing a lot in decision-making with own preferences and own suggestions. Others experienced patient participation as having a choice to play a more passive role by responding to and considering the health care professionals' opinions. A development to play a more active role in rehabilitation planning with time was reported. There were reports that patient participation and the change process benefited from choosing the same problem area in the Web-BCPA and in the MMR. Some informants experienced that the change process proceeded through new behavior and motivation even though they had completed their rehabilitation.

Personal and Environmental Conditions Influencing Participation

Informants talked about various conditions related to the rehabilitation framework that influenced patient participation in the rehabilitation. They described emotions and cognitions that affected patient participation. Having motivation, interest, commitment, and self-confidence were perceived to favor patient participation. In addition, some informants stated that their work experience, such as having a solution-focused work, or to enjoy working at the computer, facilitated patient participation in the rehabilitation.

> *...I feel that one has to be motivated to participate in the course (the Web-BCPA) since it requires that I set aside time to log in to the program several times a day...it takes time to read all the texts and to do the assignments...* [Interview 13, woman]

Pain, fatigue, and other psychological symptoms were perceived to limit patient participation. Some informants experienced that having such symptoms restrained participation more in the Web-BCPA than in the MMR. On the other hand, informants described that the Web-BCPA provided opportunities to rehabilitation during periods with severe symptoms without having to be present at the health care center. In addition, perceiving lack of knowledge in medical issues and treatments was experienced to restrain patient participation.

Previous experiences of a positive therapeutic relationship with a health care professional in the team were perceived to facilitate patient participation in the MMR. Awareness of a health care professional's stressful work situation and limited health care resources were stated by the informants to restrain patient participation. Support, trust and respect from a family member, employer, the Swedish Social Insurance Agency (SSIA) or the Employment Service were experienced to facilitate patient participation in the rehabilitation. Some informants experienced that demands on return to work of the SSIA entailed stress and fatigue and restrained patient participation and caused setbacks in the rehabilitation.

> *...I planned to complete the program (the Web-BCPA)...I am not sure how much I had left...probably the last module...but I was denied sick-leave compensation by the Social Insurance Agency and had to put in a lot of energy to explain my situation and meet with the psychosocial counselor...I did not have the strength to do anything else...I have used so much energy to fight for my cause...* [Interview 8, man]

Discussion

Principal Findings

Patient participation in the Web-BCPA in combination with MMR was explored in this study. All informants had experiences of satisfying patient participation. The comprehensive theme "It's about me" revealed patient participation as an individualized and empowered interaction with the Web-BCPA and with health care professionals within the MMR, a rehabilitation the informants perceived as their own. Our findings showed that informants' perceptions of being confirmed were fundamental to patient participation. The importance of being confirmed in the patient–health care interaction has previous been reported [14,15,42,43]. However, findings that informants experienced being confirmed through the solitary work in the Web-BCPA implicate new knowledge to patient participation. They described that they were confirmed when they could identify their illness experience and life situation, as well as their own thoughts and cognitions about their pain condition, in the texts and the assignments of the Web-BCPA. There were many implications to being confirmed and the informants perceived this fundamental to other experiences of patient participation in the rehabilitation, such as the gain of knowledge and insights, and behavior changes. In addition, perceptions of being confirmed entailed the informants' experiences of a trustworthy and comparable message in the Web-BCPA and in the MMR.

The informants described that gained knowledge and insights from the Web-BCPA increased their self-confidence and empowered them in the dialogue with health care professionals. Previous research has showed that patients wish to play a more active role in decision making in their MMR but the lack of knowledge in medical issues and treatment options restrained them [15]. To narrow the knowledge gap between the patient and the health care professional has been reported as an important factor to increase patient participation and to improve the cooperation [1,2]. Our findings indicate that the Web-BCPA can be a useful tool in narrowing the knowledge gap.

Acquiring knowledge and insights was both experienced as patient participation and described as means to increase patient participation. The informants perceived that the solitary work in the Web-BCPA had an important role to acquire knowledge and insights by providing opportunities for self-reflection and rehearsal. Such internal cognitive processes are known to reinforce and modify learning [44,45]. In contrast, the informants reported less self-reflection in the MMR. On the other hand, informants emphasized the feedback in meetings with health care professionals in MMR, which was experienced to facilitate applied knowledge. Feedback from health care professionals has been shown to support an individual's behavior change [45-47]. Some informants made a clear statement that patient participation in the MMR was the effective treatment in the rehabilitation for behavior change. Other informants gave examples of successful problem solving in the Web-BCPA that led to behavior change. This is in line with participants' experiences of behavior change as increased engagement in physical and social activity after taking part in a Web-based intervention with mindfulness-based cognitive therapy aimed to reduce depressive symptoms [48].

An overall interpretation of our data that we find interesting to discuss and which may inspire to further research regarding patient participation, was a distinction between "taking part" and "participating" in the rehabilitation. Some informants described patient participation as having attended meetings with health care professionals and having had treatments, more on an operational level of adherence, without further reflections on the emotional or cognitive processes that may be involved in patient participation. In contrast, other informants' talked a lot about their emotional and cognitive experiences in relation to patient participation, such as feelings, reflections, and appraisal. These various perceptions of patient participation could be important not only to patients' experiences of patient participation, but also to treatment adherence and outcomes. Some informants that reported on having reached a goal or having been successful in behavior change, talked about this in relation to emotional and cognitive processes, such as awareness and insights. In line with Herlitz et al [47], emotional feedback from health care professionals to enhance a patient's emotional and cognitive relation to their rehabilitation, may be important to ensure adherence and positive outcomes. It may not be sufficient to only attend the treatments.

The informants' experiences of patient participation in the Web-BCPA in combination with the MMR had much in common with PCM [7,49,50], which is considered to be a key element of high-quality health care [51,52]. Informants perceived the combined treatment as a personalized and customized rehabilitation. Lyden et al [53] found similar consistency with the PCM model among participants in a Web-based intervention designed to promote weight loss through healthy eating and physical activity. The participants reported the Web-based intervention as individualized with opportunities to make their own decisions [53]. Furthermore, our findings may add to the PCM model that an individual's learning process and the acquiring of knowledge and insights might need to be included in the model. It may not be sufficient to acknowledge a patient's present expertise of their illness experience and their life situation. By increasing knowledge and insights about pain and cognitive skill processes, patient participation in the rehabilitation can improve.

Strengths and Limitations

We included women and men of various ages and from different health care centers in the county of Norrbotten, to collect a variety of experiences which may have increased credibility. The informants' experiences of patient participation in the Web-BCPA in combination with the MMR were based on the interaction with the Web-BCPA, as well as team-conference meetings and individual meetings with nurses, occupational therapists, physicians, physiotherapists, psychologists, psychosocial counselors, and rehabilitation coordinators. One limitation with the selection of participants was that patients that had spent less time in the Web-BCPA were excluded from this study, which may have positively influenced the results. However, the objective of this study was to explore patients' experiences of patient participation in the Web-BCPA, and

therefore we decided that to have such experiences, the participant needed to have had the chance to assimilate some of the content of the Web-BCPA. We set a lower limit of time spent in the Web-BCPA to 75 minutes, and that the informants should have opened 5 modules out of 8.

To increase the credibility of the findings, all authors participated in the data analysis, which was performed with care. All researchers had a professional background in physiotherapy and 1 was also a psychologist, which may have influenced the analysis. Meaning units and codes were kept close to the text, which may have reduced the risk of misleading interpretations. During analysis, all authors reflected on and discussed codes, categories, and theme until consensus was obtained. Our results are 1 possible description of patient participation in the Web-BCPA in combination with the MMR. The 4 categories are not totally exclusive as the theme ran through all categories, and it is not always obvious when an experience belongs to 1 category or another since human experiences are intertwined [38].

Data was collected by performing interviews consecutively over the whole RCT time period of 2 years. This may imply both an advantage and a disadvantage. The advantage is that experiences of patient participation were captured as the project developed at the health care centers. The disadvantage is the risk of inconsistency when data collection extends over time, and the interviewer may acquire new insights with time [38]. To increase dependability, an interview guide was used which gave all informants the same opportunities to contribute with their experiences. The interviews were rich and contained detailed descriptions of experiences of positive and negative patient participation.

We consider that part of our results may be transferable to patients with persistent pain in comparable multimodal rehabilitation in primary health care, as well as to other team rehabilitation using a cognitive approach. There is a limited transferability of our results to patients' interaction with similar self-guided Web-based interventions since the treatment was given in combination with MMR.

Conclusions

Patient participation in the Web-BCPA in combination with MMR was experienced as personal confirmation "It is about me," where it was possible to take part in a rehabilitation framework of one's own priority and have the opportunity to influence. Being confirmed was emphasized in the interaction with the Web-BCPA and with health care professionals in the MMR. Patient participation was to acquire knowledge and insights and to find ways to behavior change. In the Web-BCPA, the solitary work and self-reflection were stated as patient participation. Dialogue and feed-back from health care professionals were emphasized in the MMR. The combined treatment was experienced to increase patient participation in the rehabilitation. Although, not being able to fully control the administration of the Web-BCPA, as well as having difficulties to choose from its content, were experienced to restrain patient participation.

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Conflicts of Interest

None declared.

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Abbreviations

MMR: multimodal rehabilitation
ÖMPSQ: Örebro musculoskeletal pain screening questionnaire
PCM: Patient-Centered Medicine
RCT: randomized controlled trial
Web-BCPA: Web Behavior Change Program for Activity

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Review

Internet Health Information Seeking and the Patient-Physician Relationship: A Systematic Review

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Abstract

Background: With online health information becoming increasingly popular among patients, concerns have been raised about the impact of patients' Internet health information-seeking behavior on their relationship with physicians. Therefore, it is pertinent to understand the influence of online health information on the patient-physician relationship.

Objective: Our objective was to systematically review existing research on patients' Internet health information seeking and its influence on the patient-physician relationship.

Methods: We systematically searched PubMed and key medical informatics, information systems, and communication science journals covering the period of 2000 to 2015. Empirical articles that were in English were included. We analyzed the content covering themes in 2 broad categories: factors affecting patients' discussion of online findings during consultations and implications for the patient-physician relationship.

Results: We identified 18 articles that met the inclusion criteria and the quality requirement for the review. The articles revealed barriers, facilitators, and demographic factors that influence patients' disclosure of online health information during consultations and the different mechanisms patients use to reveal these findings. Our review also showed the mechanisms in which online information could influence patients' relationship with their physicians.

Conclusions: Results of this review contribute to the understanding of the patient-physician relationship of Internet-informed patients. Our main findings show that Internet health information seeking can improve the patient-physician relationship depending on whether the patient discusses the information with the physician and on their prior relationship. As patients have better access to health information through the Internet and expect to be more engaged in health decision making, traditional models of the patient-provider relationship and communication strategies must be revisited to adapt to this changing demographic.

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KEYWORDS

Internet; information seeking; physician-patient relations; health information

Introduction

As the Internet becomes a ubiquitous part of individuals' information lives, most people have access to and are becoming comfortable with using the Internet for their information needs [1]. In health care, the rapid proliferation of health information on the Internet has resulted in more patients turning to the Internet as their first source of health information [2-4] and

acquiring knowledge on their health conditions before seeking a professional diagnosis. Patients are feeling more empowered [5,6] and are more inclined toward being involved in their health and health decision making [7]. This may thus change the way in which patients interact with and participate in consultations with their physicians and how they feel about their relationship with their physicians.

Notwithstanding the potential benefits of Internet health information seeking, some concerns have been raised about the plausible negative effects of Internet health information seeking on patients. First, as online health information content can range from being peer reviewed or professionally reviewed to personal blogs, opinions, or anecdotes of other patients, information quality can vary, and patients may not possess the necessary skills to evaluate medical information and relate it to their own health circumstances [8-10]. As a consequence, online information can lead to patients' being misinformed, lead to distress, and increase the tendency toward self-diagnosis or self-treatment [9]. Internet-informed patients may have more questions and may request additional treatments or medications during consultations [11]. Hence, online information can add a new interpretive role to physicians' responsibilities during consultations [12,13]. Second, when patients' online findings do not align with physicians' diagnosis or treatments, concerns have been raised as to how a patient's appointment satisfaction and trust in the physician would be affected [2,8,14] and how conflicts or even arguments could occur between the physician and patient [12]. This may then result in dissatisfied patients who may seek a second opinion, change the physician, change their treatment plan [15], or self-medicate using recommendations found on the Internet [16].

As patients' Internet health information seeking becomes more pervasive, the expectations and needs of Internet-informed patients in their interactions with their physicians are expected to change. Thus, it is pertinent to have a comprehensive understanding of the influence of online health information on the patient-physician relationship. To the best of our knowledge, no review has synthesized and analyzed how patients' Internet health information seeking affects the patient-physician relationship. The closest reviews we have found are by McMullan [17] and Wald et al [18]. McMullan [17] examined physicians' reactions to online information and identified 3 possibilities: (1) physicians could feel threatened by the information and respond defensively by asserting their "expert opinion," (2) physicians and patients could collaborate in obtaining and analyzing the information, and (3) physicians could guide patients to reliable health information websites. Wald et al [18] reviewed the past literature to identify the advantages and disadvantages of Internet-acquired information, and the challenges to providing guidelines to health care providers for effective interaction with Internet-informed patients.

The focus of this review was to systematically review and synthesize the existing research on Internet health information-seeking behavior and its impact on the patient-physician relationship to give implications for future research and practice. Specifically, our review sought to understand how and in what ways the Internet information search behavior of patients prior to consultations would affect doctor-patient encounters and patients' relationships with their doctors. Our research question was "How and in what ways does patients' Internet health information-seeking behavior influence the patient-physician relationship?"

Methods

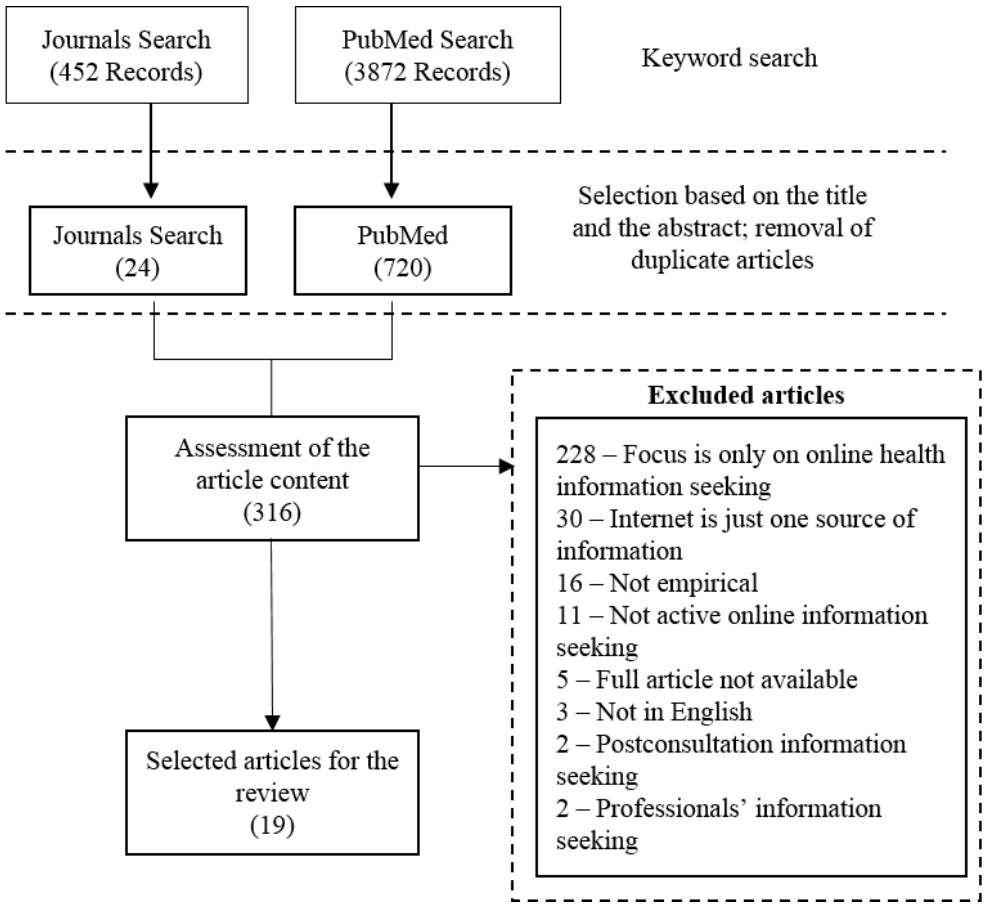
Search Procedure

We systematically searched PubMed to identify articles and citations from January 1, 2000 to October 1, 2015. We also searched articles from key medical informatics journals and information systems journals (*Journal of the American Medical Informatics Association*, *International Journal of Medical Informatics*, *Journal of Medical Internet Research*, *Journal of Health Communication*, *Information Systems Research*, *Management Information Systems Quarterly*, and *Journal of the Association for Information Science and Technology*) to include additional relevant studies.

The search strategy included all possible combinations of keywords under 3 broad themes: (1) online OR Internet OR Web, (2) wellness information OR health information, (3) search* OR seek*. Further, we used the Medical Subject Headings (MeSH) "patient-physician relations" and "Internet" to perform a separate search in PubMed. PubMed searches yielded 3872 records, while journal searches yielded 452 records. We removed duplicate articles and screened the remaining articles in 2 stages. The first stage involved screening titles and abstracts to identify and exclude irrelevant articles. The remaining articles were then subjected to a second stage of screening of their main content. Figure 1 depicts the flow of the article selection procedure.

We included articles that were in English and were empirical studies focused on the Internet health information-seeking behavior of health care consumers and aspects of the patient-physician relationship. We excluded nonempirical articles, which included review articles, content assessment studies of websites, and research commentaries.

Figure 1. Search procedure for empirical studies on Internet-informed patients' relationship with their physicians.



Analysis Procedure

We conducted this systematic review to analyze published empirical studies on Internet-informed patients' relationship with their physicians. The 19 articles selected were first assessed for research quality, and 2 researchers independently performed the quality assessment. We assessed intercoder consistency at the end. As the selected articles were mainly empirical cross-sectional studies, we used quality assessment tools that were able to assess the methodological quality, findings, and contribution of the research articles. We evaluated qualitative studies using the Critical Appraisal Skills Programme quality assessment tool [19], which consists of 10 questions that assess the quality of the research methodology and the contribution of the qualitative studies. We assessed quantitative studies using a customized coding scheme that consists of 14 questions adapted from 3 well-established quality assessment tools used for quantitative studies (US National Heart, Lung, and Blood Institute quality assessment tool for observational, cohort, and cross-sectional studies [20], and quality assessment criteria proposed by Young and Solomon [21] and Davids and Roman [22]). Multimedia Appendices 1 and 2 present the 2 quality assessment tools used in this review. We assessed the intercoder consistency to determine the inclusion of articles for the review. All articles met the quality rating except for 1 article (the rating was <0.7 after the agreement of both researchers), which we thus removed from the final analysis.

The remaining 18 articles were then manually coded by 2 researchers based on preidentified themes: (1) patients' discussion of online information during consultation, and (2) implications for the patient-physician relationship. During the coding process, both researchers independently identified subthemes and then added them to the existing themes upon agreement. Any disagreements were discussed and resolved before the final subthemes were confirmed. The first category included themes related to characteristics of doctor-patient consultations that led patients to reveal their online findings during visits with their doctor, such as strategies for using and revealing online information, facilitators of and barriers to discussion of online findings during consultations, and demographic factors affecting the discussion of online information. The second category, implications for the patient-physician relationship, focused on the influence of the patients' Internet research on their relationship with the doctor, and include subthemes such as patients' perception of a positive or negative impact on the patient-physician relationship, patients' sense of control, confidence, and empowerment during the consultation, patients' perceived consultation effectiveness, and patient satisfaction.

Results

Characteristics of Included Articles

Our initial PubMed and journal search returned over 4000 titles and citations. By applying the inclusion and exclusion criteria, we identified 744 records for further screening based on the title and abstract. Of these, we retained 316 articles for content screening, and then selected 19 peer reviewed journal articles

that met the review criteria. Of the rejected articles, 228 focused on patients' Internet health information seeking but did not address patient-physician relationship aspects. In 30 articles, the Internet was not the primary source of information. Of the remaining articles, 16 were not empirical studies, 11 were not about active information seeking, 5 were not available in full-text version, 3 were not in English, 2 focused only on postconsultation information seeking, and 2 focused on professional information seeking. Finally, we excluded 1 article among the 19 during the quality assessment procedure, leaving only 18 articles for the review. Of these 18 articles, 7 used surveys to gather data, 6 used interviews, 3 used semistructured interviews, and 2 used a mixed-methods approach. All articles were published within the period of 2003 to 2015 (see Table 1 and Table 2 for the complete list of articles and summaries) [3,4,7,12,15,23-35].

Of the 18 articles, 6 focused primarily on the implications for the patient-physician relationship, 2 studied the discussion of online information with physicians, and the rest studied both themes.

Table 1. Summary of articles on Internet-informed patients' relationship with their physicians.

Study	Method	Country	Participant characteristics	Number of participants
Stevenson, 2007 [3]	Focus group interviews	UK	Adult patients with diabetes mellitus, ischemic heart disease or hepatitis C	34 patients (12 female, 22 male)
Kivits, 2006 [4]	Email interviews	UK	Users of UK websites devoted to healthy eating, fitness, and general health	31 (28 female, 3 male)
Broom, 2005 [7]	Interviews	Australia	Prostate cancer patients	33 male
Sommerhalder, 2009 [12]	Semistructured interviews	Switzerland	Patients and physicians from primary care and medical specialist practices	32 patients (12 female, 20 male) and 20 physicians (4 female, 16 male)
Murray, 2003 [15]	Telephone survey	US	Residents aged ≥18 years	3209 (1757 female, 1452 male)
Sillence, 2007 [23]	Observation and interviews	UK	Women faced with decisions concerning the menopause and hormone replacement therapy	15 female
Chung, 2013 [24]	Survey	US	Participants in the Health Information National Trends Survey (HINTS) 2007	5078 (3141 female, 1934 male)
Silver, 2015 [25]	Semistructured interviews	Canada	Community dwelling, ≥50 year, fluent in English, resident in Toronto, regular user of online health information	56 (30 female, 16 male)
Hart, 2004 [26]	Interviews	UK	Patients who had contacted health services in relation to hormone replacement therapy or menopause and Viagra or erectile dysfunction	47 (32 female, 15 male)
Schrank, 2010 [27]	Semistructured interviews	Vienna	Patients with schizophrenia or schizoaffective disorder	26 (12 female, 14 male)
Hay, 2008 [28]	Interviews and surveys	US	Rheumatology patients	120 (92 female, 28 male)
Newnham, 2006 [29]	Survey	Australia	Oncology patients just diagnosed with cancer	109 (44 female, 49 male)
Chiu, 2011 [30]	Focus group interviews	Taiwan	Cancer patients	46 (28 female, 18 male)
Russ, 2011 [31]	Survey	Israel	Patients at 10 primary care clinics	138 (82 female, 53 male)
Ybarra, 2008 [32]	Telephone survey	US	Participants in the national survey Surveying the Digital Future, Year 4	2010 (1214 female, 796 male)
AlGhamdi, 2012 [33]	Survey	Saudi Arabia	Patients at an outpatient clinic	801 (398 female, 400 male, 3 missing data)
Bianco, 2013 [34]	Survey	Italy	Adults aged ≥18 years	1039 (704 female, 335 male)
Xie, 2009 [35]	Interviews	US	Older adults, aged ≥60 years	20 (11 female, 9 male)

Table 2. Summary of findings of the articles.

Study	Themes	
	Discussion of online information with physicians	Implications for the patient-physician relationship
Stevenson, 2007 [3]	*Barriers to discussion of online information*: Patients experienced resistance from doctors over bringing information, even about their day-to-day health management, into the consultation. *Facilitators of discussion of online information*: Some patients reported that doctors positively encouraged them to search for information on the Internet. They also felt that Internet information should be checked with physicians.	*Quality of the patient-physician relationship*: Patients saw the Internet as an additional resource to support doctors' advice and enhance the relationship with their doctor.
Kivits, 2006 [4]	*Strategies for using and revealing online information*: During consultations, patients preferred to be silent, asking questions and discussing information based on their Internet search, but not revealing that they used the Internet.	*Patients' sense of control, confidence, and empowerment*: By discussing information they accessed on the Internet or setting questions in advance, patients mentioned being able to better understand and participate in consultation sessions with their doctors. Patients were also better informed, as they used the knowledge gained from Internet searches to check and complete the information received from doctors. Although most patients felt that physicians would feel challenged if the patients discussed information they found on the Internet, those who discussed the information said they had received positive attention.
Broom, 2005 [7]	*Barriers to discussion of online information*: Patients might feel being disapproved of by the physician if they shared their Internet search. Some physicians discouraged patients asking questions from their Internet research, giving them the impression that they were disapproved of or being treated as problematic patients.	*Patients' sense of control, confidence, and empowerment*: Internet search provided clarity in terms of treatments options and, as a result, diminished patients' reliance on their specialists. Further, Internet search behavior led patients to experience a heightened sense of control and therefore enter into a comprehensive negotiation with their specialist. However, patients' sense of empowerment depended on how receptive providers and specialists were to their desire to take part in the decision-making process.
Sommerhalder, 2009 [12]	*Strategies for using and revealing online information*: Patients used several different strategies to introduce information found on the Internet to their physicians: ask additional questions; suggest specific diagnoses, diagnostics, or treatments, without directly revealing where they found the information; bring printouts of Internet search results into consultations; silently verify doctor's advice against their online findings; actively avoid talking about the online information findings. *Barriers to discussion of online information*: Patients did not discuss their online findings due to lack of time during consultations, or reluctance to interfere with the consultation process.	*Patients' perceived consultation effectiveness*: Patients viewed the consultation as important to their understanding of online health information. Physicians recognized the change in their role. Patients were more knowledgeable, which made initiating an interaction on health-related issues easier and enabled discussion on a more elaborate level; discussing with physician gave patients greater clarity, orientation, and certainty. *Quality of the patient-physician relationship*: Bringing up online information during consultations also resulted in conflicts with patients, and some patients ignored their physicians' expertise.
Murray, 2003 [15]	*Demographic factors*: Those who brought information to the consultation tended to have a higher self-rated ability to critically appraise health information on the Internet and their health status.	*Patients' sense of control, confidence, and empowerment*: Most felt more in control and more confident during the consultation as a result of bringing information to their physician. *Quality of the patient-physician relationship*: The effect of taking information to the physician on the patient-physician relationship was likely to be positive as long as the physician had adequate communication skills and did not appear challenged by the patient bringing in information. Patients' who felt their physicians were challenged tended to be uninsured patients, and those who described themselves as excellent or very good at critically appraising information on the Internet.

Study	Themes	
	Discussion of online information with physicians	Implications for the patient-physician relationship
Sillence, 2007 [23]	Not available.	*Patients' perceived consultation effectiveness*: Patients felt that using the Internet improved their communication with physicians *Patients' sense of control, confidence, and empowerment*: Patients felt better equipped to go to the physician and more empowered. The online information and advice influenced patients' decision making without threatening their desire to communicate with physicians, but they still saw the physician as the primary source of information and advice.
Chung, 2013 [24]	*Demographic factors*: Men were more likely than women to have a conversation regarding online information with physicians. Patients who had trouble understanding or trusting online health information were no more likely to ask questions or seek guidance during consultations. Reactions of physicians to online information were perceived as negative by patients who experienced poor health and those who had more concerns about the quality of their searched information.	Not available.
Silver, 2015 [25]	*Barriers to discussion of online information*: Patients had not discussed or revealed their online health information findings due to fear of embarrassment; feeling it would be insulting to the physician; using online information to negate the need to see a physician; not remembering to bring it up. *Facilitators to discussion of online information*: Patients discussed online findings during doctor visits when a family member was present; the doctor initiated inquiries about patient-acquired information; they had encountered an advertisement suggesting talking with a doctor.	Not available.
Hart, 2004 [26]	*Strategies patients used to exchange online information*: Patients who looked up health information on the Internet prior to their consultation usually had not directly revealed to the practitioner that they had done so. *Barriers to discussion of online information*: Some practitioners sought to assert their authority by dismissing the discussion of patients' findings acquired from the Internet.	*Quality of the patient-physician relationship*: Patients' trust in their physician as the main information source remained at a very high level, despite their Internet health information searches.
Schrank, 2010 [27]	*Barriers to discussion of online information*: Patients feared their doctors could feel criticized if they revealed online findings or had an unchangeable preconceived view.	*Quality of the patient-physician relationship*: Online information showed the potential to significantly change the relationship with the attending doctors, with the most important aspect being a shift of the subjectively perceived hierarchy. The quality of existing patient-physician relationships played a major role in how patients assessed doctors when discussing online findings, where reactions were mostly judged as positive in a good relationship.
Hay, 2008 [28]	*Barriers to discussion of online information*: Patients did not discuss their Internet information seeking mostly because they feared being perceived as challenging or confronting their physician.	*Patient satisfaction*: Physician and patient appointment satisfaction was significantly higher when the Internet information was discussed.

Study	Themes	
	Discussion of online information with physicians	Implications for the patient-physician relationship
Newnham, 2006 [29]	Not available.	*Quality of the patient-physician relationship*: Most patients did not believe that information searching adversely affected the doctor-patient relationship. 40% felt that the doctor-patient relationship was unaffected by information searching, 24% felt it improved the relationship, while only 8% felt it had adversely affected the relationship. 42% of patients who searched for information trusted their doctor as much as nonsearchers did.
Chiu, 2011 [30]	*Barriers to discussion of online information*: Patients worried that it might offend the doctors, they respected doctors' authority, and were not used to asking doctors questions. *Demographic factors*: In a culture where the patient-physician hierarchy is prominent, patients were hesitant to ask questions, as it might displease the doctor.	*Patient perceived consultation efficiency*: Participants who searched the Internet before seeing their doctors could understand their doctors and the jargon they used better, thus leading to better doctor-patient communication.
Russ, 2011 [31]	*Demographic factors*: Those who presented information to their doctors tended to be older (average 43 years) than nonsharers (36 years, not significant), and information sharers tended to have more children under the age of 18 years.	*Patient satisfaction*: Patients who searched the Internet for information tended to feel that they received satisfactory information about their health during their consultation more than those who did not, and that they received more attention than the nonsharers.
Ybarra, 2008 [32]	Not available.	*Patients' sense of control, confidence, and empowerment*: Most respondents felt more comfortable with information from the health provider as a result of their Internet searches.
AlGhamdi, 2012 [33]	Not available.	*Quality of the patient-physician relationship*: Of 801 study participants, 45% had searched for online health information before coming to the clinic; 72.5% of those discussed the information with their doctors, and 71.7% of those who did so believed that this positively affected their relationship with their doctor.
Bianco, 2013 [34]	Not available.	*Quality of the patient-physician relationship*: Only 25% of those who searched the Internet for health-related information discussed the information they found with their general physician. Most believed it had no effect on the patient-physician relationship, 13.4% believed the Internet information search had a positive effect, and only 8.1% believed it had a negative effect.
Xie, 2009 [35]	Not available.	*Patients' sense of control, confidence, and empowerment*: A total of 4 online health information needs of patients were highlighted, of which 2 focused on the interaction with the physician: (1) advanced knowledge found on the Internet, on a specific health condition or treatment, helped patients to feel that they were better prepared to interact with doctors in the sense that they could better understand what doctors said; (2) the basic information about a health condition found on the Internet provided a general understanding of their health issue, so that it would help patients to know what to expect and to be prepared to better cope with a stressful situation.

Discussion of Online Information With Physicians

Of the 18 articles reviewed, 12 examined patients' discussion of information they found on the Internet with their physicians. These studies examined this category along 4 themes: (1) strategies patients use to reveal their Internet information searches, (2) facilitators of and (3) barriers to the discussion of online findings, and (4) demographic factors affecting discussion of online findings. Table 3 summarizes the themes and subthemes related to patients' discussion of online information with physicians covered by each study. are summarized in Table 3.

Table 3. Themes and subthemes on patients' discussion of online information with physicians.

Themes	Subthemes	Study reference												
		[3]	[4]	[7]	[12]	[15]	[24]	[25]	[26]	[27]	[28]	[29]	[30]	[31]
Facilitators to discussion of online findings during consultations														
	Having a family member present at physician visits							✔						
	Physician-initiated inquiries and encouraging patients to discuss	✔						✔				✔		
	Encountering a treatment-related advertisement that suggested talking with a physician							✔						
Barriers to discussion of online findings during consultations														
	Preestablished view of the patient-physician relationship							✔		✔	✔		✔	
	Physician resistance	✔		✔					✔					
	Perceived embarrassment							✔						
Demographic characteristics														
	Culture												✔	
	Sex						✔							
	Health literacy						✔							
	eHealth literacy					✔								
	Health status					✔								
	Age													✔
	Number of children <18													✔
Strategies for using or revealing online findings during consultations														
	Ask additional questions				✔									
	Make suggestions based on their online findings				✔									
	Directly disclose online findings				✔									
	Silently verify without asking any questions		✔		✔				✔					
	Bring printouts of online information				✔									

Strategies for Using and Revealing Online Information

A total of 3 articles examined strategies patients used to reveal their online findings during their doctor visits. These studies found 5 different strategies to be used by patients who brought online information to their consultations. These strategies were asking additional questions [4,12], making suggestions based on their online findings [12], directly disclosing online findings [12], verifying silently without asking any questions [4,12], and bringing printouts of online information [12]. Asking additional questions would allow patients to clarify contradictory points between their own view and the information from the physician. Making suggestions on different diagnostics and treatments would be helpful to patients in verifying their personal interpretations of online health information. Patients who preferred concealing their Internet search discussed online information without directly revealing that they had found the information on the Internet [4,12,26]. However, some patients preferred more accurate verification of their online findings by showing printouts of their Internet research to prompt discussions during consultations [12]. In fact, patients who directly disclosed online findings preferred critical appraisals from physician and appreciated their physician's evaluations. Patients who silently verified their Internet search results did so to avoid interrupting the diagnosis process [12].

Facilitators of and Barriers to Discussion of Online Findings During Consultations

Silver [25] highlighted 3 facilitating factors that encouraged patients to discuss online health information with their physicians: (1) having a family member present at doctor visits, (2) doctor-initiated inquiries, and (3) encountering a treatment-related advertisement that suggested talking with a doctor. Having a family member present would help patients remember what to ask and made the context more comfortable to share online findings. Online advertisements or recommendations about certain medications and treatment options that contained information believed relevant to their

own health condition prompted some patients to initiate a conversation with their physicians [25]. Further, some patients reported incidences of doctors' positively encouraging patients to search the Internet for information [3]. These factors spurred patients to communicate their Internet research findings during consultations. In a study by Newnham et al [29], more than half of the patients who searched for online information prior to consultations had discussed information obtained in their search with their physician and had found their physician to be willing to discuss this information.

A total of 8 studies examined barriers to patients' willingness to discuss their online findings with their physicians during consultations. The most common reason found was that patients were usually skeptical of how physicians would react to the knowledge they acquired through the Internet: patients were afraid doctors would perceive them as challenging doctors' opinion if they directly revealed their online findings to their doctors [28]. Patients were mindful in ensuring that doctors played the central role during consultations [27]. They feared that revealing their knowledge gained from Internet searches would be an insult to professional health care providers [25] who could feel criticized or have an unchangeable preconceived view [27]. For example, Chiu [30] showed that patients cautiously made an effort not to offend doctors with their online findings. Patients expressed concerns over how physicians may perceive them as being "challenging" and "confrontational" if they discussed their health condition from a more informed point of view during consultations [28].

The second most common barrier for patients was the resistance or discouragement from physicians encountered when patients tried to discuss their Internet information research during consultations. Patients felt physicians' resistance toward them when they tried to discuss with their physicians the health information they had found on the Internet on their conditions or even about day-to-day health management [3,7]. Patients also felt that some physicians reacted in a way that implicitly or explicitly discredited the patients' ability to become informed via the Internet, presenting serious barriers to shared decision making during consultations, with the physicians asserting their authority by dismissing patient-acquired knowledge [7,26]. Patients felt that physicians were employing strategies to avoid online information-related dialogues or that they briefly answered patients' queries with short answers to reclaim the traditional consultation model of one-way information provision. As a result, patients carefully observed their physicians before deciding whether to reveal their Internet research [25,30], and patients would only bring up their Internet health searches if they felt the situation was right.

A third major barrier was the fear of embarrassment [25]. Patients who identified this to be a barrier felt they did not possess the required skill set to evaluate online medical information. They had a lower level of confidence in the trustworthiness and the credibility of online information. They manifested a sense of being unsure of how to explain the information they found and how to relate it to their own condition, and hence did not want to mention it to their physicians.

Finally, other than the main barriers, some patients did not discuss their findings during consultations because they did not think the information was important enough and they searched the Internet just to be informed [15]. Other reasons for not revealing their online findings were a reluctance to interfere with physicians' diagnostic process [12] and lack of time during doctor visits [12].

Demographic Factors Affecting Discussion of Online Information

The impact of patients' demographic characteristics on their decision to discuss online health information with health care providers was studied in 4 studies. These studies examined demographic characteristics such as culture [30], sex [24], age, having children [31], health status [15], health literacy [24], and eHealth literacy [15]. Chiu [30] addressed the cultural influence on patient-physician encounters and patients' Internet research. In a culture where the hierarchy of the patient-physician relationship is deemed to be like that of a son to a father, physicians have absolute authority to decide on the treatment, and patients must absolutely trust their doctors [36]. For such patients, even though online information empowered them with the knowledge to have a better discussion with doctors, they tended to do so cautiously, with an effort not to offend doctors and to assume greater responsibility in trying to understand their doctors' advice with their knowledge gained from online health information.

The impact of sex was studied in a study by Chung [24], which showed that men were more likely than women to have a conversation regarding online health information with their physicians. Russ et al [31] showed that the average age of those who shared online information with doctors tended to be higher and they tended to have more children under the age of 18 years. Murray et al [15] found that people in poor health were more likely to talk to their physicians about online health information than were those in good health. Further, Chung [24] also showed that patients with low health literacy or who had trouble trusting online health information were not more likely to ask questions or to seek guidance during consultations. In contrast, Murray et al [15] showed that self-rated ability to critically appraise online health information was positively related to patients' decision to discuss online information during consultations. Patients who rated themselves as excellent or very good at assessing the reliability of information on the Internet were more likely to take information to their physicians than were those who were not confident in assessing the reliability of Internet information [15].

Implications for the Patient-Physician Relationship

A total of 15 articles studied the implications of patients' online health information seeking for the patient-physician relationship. Of these, 8 studies focused on the patients' perceptions of positive and negative implications for the patient-physician relationship, while 10 studies examined the indirect effects on the patient-physician relationship (ie, patients' sense of control, confidence, and empowerment, perceived consultation efficacy, and patient satisfaction). Table 4 summarizes the themes and subthemes related to implications for the patient-physician relationship covered by each study.

Table 4. Themes and subthemes on implications of patient-physician consultation for the patient-physician relationship.

Themes	Subthemes	Study reference														
		[3]	[4]	[7]	[12]	[15]	[23]	[24]	[27]	[28]	[30]	[31]	[32]	[33]	[34]	[35]
Patients' perception of impact on patient-physician relationship																
	Opportunity to discuss online findings	✔				✔						✔		✔	✔	
	Physician's receptiveness to online information			✔	✔	✔										
	Prior relationship with patient								✔							
	Physician's communication skills					✔										
	Patient demographics					✔		✔								
Patients' sense of control, confidence, and empowerment																
	More in control and confident during consultation		✔			✔							✔			
	Heightened sense of empowerment			✔			✔									✔
Patients' perceived consultation effectiveness																
	Better understanding of the illness condition		✔													
	Feeling better equipped during consultations to understand doctor						✔				✔					✔
	Greater participation in consultations		✔													
	More comfortable with doctor's advice												✔			
	Provision of greater clarity, orientation, and certainty				✔											
Patient satisfaction																
	Satisfaction with the doctor's advice											✔				
	Satisfaction with the appointment									✔						

Patients' Perception of Positive or Negative Impact on the Patient-Physician Relationship

Of the 18 studies, 8 examined the factors directly affecting the patient-physician relationship. In the studies we reviewed, a greater proportion of participants were found to believe that Internet health information seeking did not adversely affect their relationship with physicians [3,29,33,34]. In the study by Newnham et al [29], 40% of patients felt the patient-physician relationship was unaffected by information searching, 24% felt it improved the relationship, and only 8% felt it adversely affected the relationship. However, the articles we reviewed showed that the effect of online information on the patient-physician relationship depended on several factors.

First, 5 studies showed the effect of patients' discussion of their online findings with physicians. AlGhamdi and Moussa [33] reported that 45% had searched the Internet for health information before coming to the clinic; 72.5% of those discussed the information with their doctors, and 71.7% of those who did so believed that this positively affected their relationship. Patients who perceived their information search to have improved their relationship with physicians saw the Internet as an additional resource that supported doctors' advice and enhanced the relationship with doctors [3]. They valued their relationship with their doctors and expected doctors to be more welcoming toward their Internet health research [15]. The positive influence of online information was stronger when patients had an opportunity to discuss their online findings [31,33,34].

On the other hand, bringing up online information during consultations also resulted in conflicts between patients and physicians. Conflicts stemming from different interpretation of online health information led to intensive discussions with physicians and patients [12]. Further, when patients valued the information they found on the Internet above their physicians', this information led patients to ignore physicians' expertise [12].

Second, Murray et al [15] found that how physicians reacted to patients when they shared their online findings during consultations could determine the positive or negative effect on the relationship's quality. When patients perceived physicians to be threatened by their bringing online information, 49% of the patients were seriously dissatisfied with the consultation and 4% believed their relationship was worsened [15]. Bringing information was found to have a positive effect when the physician did not appear challenged by the online information [7,12,15].

Third, 1 study we reviewed showed the effect of physicians' communication skills when patients discussed their online findings. Patients felt that the relationship was strengthened when physicians displayed adequate communication skills in discussing patients' queries [15].

Fourth, Schrank et al [27] showed the influence of the quality of the existing relationship with physicians when patients assessed their physicians' reaction during the discussion of online information. Patients judged their physicians' reactions as mostly positive when they had a good prior relationship, even when the doctors' replies were evasive or openly critical of the patients' Internet search [27].

Fifth, 2 studies examined the influence of patients' demographic characteristics on their assessment of physicians' reaction to online information [15,24]. Murray et al [15] showed that most patients felt their physicians reacted positively to online health information, but those who felt their physicians were challenged tended to be uninsured patients, who described themselves as excellent or very good at critically appraising information on the Internet. Further, Chung [24] showed that physicians' reactions to online information was perceived as negative by patients who experienced poor health, and they also had more concerns about the quality of the health information they sought on the Internet.

Patients' Sense of Control, Confidence, and Empowerment During Consultation

A total of 5 articles reviewed examined the effect of Internet health information search on patients' empowerment, perceived confidence, and control during a consultation. Murray et al [15] showed that patients felt more in control and confident during the consultation as a result of bringing information to their physicians. Patients also felt more confident in their physicians' diagnosis once they had discussed their online findings [4,15,32]. Further, Internet search behavior led patients to experience a sense of control and therefore enter into a comprehensive negotiation with their specialist [7].

Of the studies we reviewed, 3 found that online health information can empower patients [23,35] to play a more active role in their disease management. A study of prostate cancer patients showed how the Internet affected their decision-making ability. Online information empowered them "to do something" rather than "just being told what to do" by their specialist [7]. Internet search provided clarity in terms of treatment options and, as a result, diminished patients' reliance on their specialists.

Although Internet information search was shown to shift the subjectively perceived hierarchy between the doctor and the patient [27], patients still valued traditional doctor-patient consultations as important to their understanding of online health information [27]. The patients' sense of empowerment was dependent on how receptive providers and specialists were to the patients' desire to take part in the decision-making process [7]. Doctors' resistance toward discussing online findings was found to result in higher levels of anxiety, confusion, and frustration.

Patients' Perceived Consultation Effectiveness

In the studies we reviewed, most patients felt that Internet health information seeking prior to consultations had improved their communication with doctors and the effectiveness of their consultations. First, participants who searched for online health information prior to their consultations felt better equipped to communicate with their physicians during the consultations [23,35]. They believed the patient-physician communication had improved because they could understand their doctors and the jargon they used better [30]. Kivits [4] also found that, by discussing information they had accessed on the Internet or setting questions in advance, patients were able to better understand and participate in consultation sessions with their doctors.

Second, patients who searched the Internet for information prior to the consultation felt more confident and comfortable with the doctor's advice. Ybarra and Suman [32] showed that a majority of patients had felt more comfortable with information from health care providers because of their Internet searches. Patients felt more informed as they used the knowledge gained from Internet searches to check and complete the information received from doctors. Further, discussions with physicians were found to give patients greater clarity, orientation, and certainty [12]. On the other hand, when physicians exerted resistance to patients' online information sharing during consultations, it created a barrier to receiving effective care from the physician [7].

Patient Satisfaction

Only 2 studies examined the influence of patient satisfaction on the patient-physician relationship. Russ et al [31] found that online information seekers felt they had received satisfactory information about their health from their physician when compared with nonseekers. The appointment satisfaction of physicians and patients was found to be significantly higher when online health information was discussed [28], even if the information was not explicitly stated to be from the Internet. Patients who shared online information felt that they received more attention from their physician, compared with nonsharers [31].

Discussion

Principal Findings

Based on our review of the 18 empirical studies that examined patients' Internet health information seeking and the implications for the patient-physician relationship, we found that a greater proportion of patients did not feel that their Internet health information-seeking activities had an adverse impact on the patient-physician relationship [3,29,33,34]. The recent proliferation of health information on the Internet has resulted in a shift in the traditional information balance [37,38], where patients are increasingly equipped with health information related to their conditions, eroding the prior exclusivity of health information among health professionals. However, our findings show that patients' positive attitude toward physicians did not change unless physicians imposed restrictions on their online information sharing during consultations (eg, [3,7,26]). Patients went on the Internet mostly to be actively involved in the decision making related to their health. Patients still valued consultations with physicians [27], and their trust in physicians remained very high [26,27]. Patients used the information found on the Internet to help them prepare for their visit, ask better questions, and understand what the physicians told them. These were shown to empower patients to play a more active role in their disease management and to be more effective in

understanding and communicating with their physicians [32]. Internet-informed patients were also more confident in and comfortable with their physicians' advice [15].

In the studies we reviewed, some looked at how Internet health information seeking affected the patient-physician relationship, while others focused on how patients' use of the online health information affected the patient-physician relationship. Although we identified 5 different types of strategies in the literature (including silently verifying information, bringing printouts, explicitly verifying information by asking questions, and asking extra questions without directly revealing their Internet search), most studies focused simply on whether patients discussed the online health information during physician consultations and the associated outcomes. Among these studies, evidence showed that patients experienced a better patient-physician relationship when they had the opportunity to discuss their online health information with their physicians, and their physicians were receptive to discussing the online information. However, if patients experienced resistance from their physicians to their discussion of online information, patients were found to become frustrated and anxious [7] and would withhold their discussion [3,7]. Conflicts arising from physicians and patients having different interpretations of the online information and when patients valued this information more also had adverse implications for the patient-physician relationship [12]. In general, we found more evidence of positive than of negative implications of discussing online health information.

As patients become better informed and like to be more actively involved in decision making about their health, traditional models of the patient-physician relationship need to be adapted to patients' changing needs by incorporating their perspective into a relationship-centered medical paradigm [39]. In contrast to the physician-centric paternalistic models of care, a deliberative or participatory model has been recommended for encounters with Internet-informed patients [40], where physicians delineate the patients' clinical situation and provide help in explaining and deciding on the available options [41]. Under this model of care, the physician acts as a teacher or a friend by engaging patients in a dialogue through the decision-making process [39].

Allowing or encouraging patients to discuss their Internet information searches with physicians is increasingly important, given that acquiring information on the Internet has the potential to misguide patients with inaccurate information and make them excessively anxious [8]. Therefore, the information patients wish to use in decision making ought to be verified to ensure that it is based on facts [40]. Additionally, not disclosing their Internet information searches could erode patients' trust in their physicians if the diagnosis or the recommendations are different from their Internet research findings [2]. Our findings showed that enabling patients to communicate their Internet research was one of the key mechanisms to ensure that patients' opinion was valued and to enhance physicians' relationships with their Internet-informed patients. When physicians embrace openness to online information [7,12,15,24] and encourage patients to discuss the online information they have, patients' perception of physician resistance and fear of embarrassment could be reduced and patients are more likely to discuss online information with their physicians.

Research Gaps

In interpreting our findings, we should take note of the various research gaps in the existing studies. First, these empirical studies were primarily based on cross-sectional surveys, focus groups, or interview data, or a combination of these. Most of the results are descriptive, making it difficult to ascertain the causal effect of Internet health information seeking on the patient-physician relationship. In order to quantify the causal relationship between influencing factors and the quality of the patient-physician relationship, future research could involve more quantitative approaches, such as field experiments or surveys carried out in multiple waves. Second, the studies we reviewed focused mainly on understanding the patients' perspectives, and hence our conclusions are limited to their perspectives, which might differ from those of physicians. Future research should explore physicians' perspectives on patients' Internet health information-seeking behavior and how physicians' communication strategies during consultations could affect the patient-physician relationship.

Limitations

We should also interpret our findings in the light of these limitations. First, the search criterion we used for retrieving the studies was initially broad to cover all the aspects that have been studied in relation to patients' active Internet health information seeking. As there is no consistent terminology for the patient-physician relationship and its related dimensions, our main search query did not include MeSH terms. This may have resulted in missing out potentially relevant articles. However, we mitigated this limitation by performing a second round of search with a basic MeSH query. Second, we considered only articles that were in English. Therefore, we excluded several non-English articles from our review.

Conclusion

Results of this review contribute to the understanding of the influence of health information sought by patients on the Internet on the patient-physician relationship. In contrast to the belief that patients' Internet research can erode the patient-physician relationship [2], our findings show that patients' Internet health information seeking has the potential to improve the relationship [3,27,29,33,34]. Patients typically see the Internet as an additional resource that can help them to better understand doctors' recommendations and advice [3]. Thus, it has the potential to change the structure of the traditional patient-physician relationship [27,38] from one where patients perceive health care providers as the sole custodians of medical information [42]. Further research needs to be carried out to understand the needs and wants of Internet-informed patients, how physicians can adapt to this shift, and how traditional patient-physician relationship models must be adapted to meet the changing health paradigm.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Critical Appraisal Skills Programme (CASP) quality assessment for qualitative studies.

[PDF File (Adobe PDF File), 141KB - jmir_v19i1e9_app1.pdf]

Multimedia Appendix 2

Quality assessment tool for quantitative studies.

[PDF File (Adobe PDF File), 145KB - jmir_v19i1e9_app2.pdf]

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Abbreviations

MeSH: Medical Subject Headings

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Review

Cancer Survivors' Experience With Telehealth: A Systematic Review and Thematic Synthesis

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Abstract

Background: Net survival rates of cancer are increasing worldwide, placing a strain on health service provision. There is a drive to transfer the care of cancer survivors—individuals living with and beyond cancer—to the community and encourage them to play an active role in their own care. Telehealth, the use of technology in remote exchange of data and communication between patients and health care professionals (HCPs), is an important contributor to this evolving model of care. Telehealth interventions are "complex," and understanding patient experiences of them is important in evaluating their impact. However, a wider view of patient experience is lacking as qualitative studies detailing cancer survivor engagement with telehealth are yet to be synthesized.

Objective: To systematically identify, appraise, and synthesize qualitative research evidence on the experiences of adult cancer survivors participating in telehealth interventions, to characterize the patient experience of telehealth interventions for this group.

Methods: Medline (PubMed), PsychINFO, Cumulative Index for Nursing and Allied Health Professionals (CINAHL), Embase, and Cochrane Central Register of Controlled Trials were searched on August 14, 2015, and March 8, 2016, for English-language papers published between 2006 and 2016. Inclusion criteria were as follows: adult cancer survivors aged 18 years and over, cancer diagnosis, experience of participating in a telehealth intervention (defined as remote communication or remote monitoring with an HCP delivered by telephone, Internet, or hand-held or mobile technology), and reporting qualitative data including verbatim quotes. An adapted Critical Appraisal Skill Programme (CASP) checklist for qualitative research was used to assess paper quality. The results section of each included article was coded line by line, and all papers underwent inductive analysis, involving comparison, reexamination, and grouping of codes to develop descriptive themes. Analytical themes were developed through an iterative process of reflection on, and interpretation of, the descriptive themes within and across studies.

Results: Across the 22 included papers, 3 analytical themes emerged, each with 3 descriptive subthemes: (1) influence of telehealth on the disrupted lives of cancer survivors (convenience, independence, and burden); (2) personalized care across physical distance (time, space, and the human factor); and (3) remote reassurance—a safety net of health care professional connection (active connection, passive connection, and slipping through the net). Telehealth interventions represent a convenient approach, which can potentially minimize treatment burden and disruption to cancer survivors' lives. Telehealth interventions can facilitate an experience of personalized care and reassurance for those living with and beyond cancer; however, it is important to consider individual factors when tailoring interventions to ensure engagement promotes benefit rather than burden.

Conclusions: Telehealth interventions can provide cancer survivors with independence and reassurance. Future telehealth interventions need to be developed iteratively in collaboration with a broad range of cancer survivors to maximize engagement and benefit.

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KEYWORDS

neoplasms; telemedicine; systematic review; survival; patient satisfaction; patient preference

Introduction

The term "cancer survivor" is used to encompass all individuals living with cancer "from the time of diagnosis and for the balance of life" [1]. Rates of cancer survival are considered a key metric for cancer control [2]. There are 2.5 million cancer survivors in the United Kingdom and this is predicted to increase to 4 million by 2030, in line with the increase in both cancer incidence and net survival rates identified for many cancer types worldwide between 1995 and 2009 [3]. Lifetime risk of cancer now varies between 33% in Australia before 75 years [4] to over 50% in the United Kingdom for those born after 1960 [5]. Variation in European cancer survival rates is associated with levels of health services funding and organization [6,7], with such relationships also being observed in other countries worldwide [8]. This exponential rise in cancer survivors is met by finite resources, thereby placing considerable strain on cancer service provision. Consequently, alternative approaches to service delivery and provision of supportive care are needed and are driving technological innovation in health care [9].

The effort to develop and implement technological innovations to support cancer survivorship is a global one, reflecting the drive to transfer the care of cancer survivors from hospital to community settings [10] and encourage them (and their families or caregivers) to play an active role in managing their care [11]. This evolving model of cancer care has led researchers to investigate use of telehealth in health care delivery. Telehealth refers to the use of technology to provide remote personalized health care to patients [12,13] which allows exchange of data and communication between patients and health care professionals (HCPs) [14]. Examples of initiatives in active development include the UK-based eRAPID remote symptom reporting system [15], a Web-based exercise program in the Netherlands [16] and rural chemotherapy administration under guidance from centrally-based oncologists in Australia [17].

However, little is known about cancer survivors' engagement with, and acceptance of, cancer telehealth interventions, and their lived experience of being remotely monitored—often the focus is on intervention outcomes. Of recent reviews, 3 sought to synthesize trial findings from studies reporting outcomes from interventions tested with cancer survivors in a supportive capacity [18,19] and in the delivery of follow-up [20]. They appraised benefits in terms of quality of life and management of symptoms (including pain, depression, anxiety, fatigue, and sexual dysfunction) using patient-reported outcome measures, but found the benefit of telehealth to vary between studies. One review of supportive telehealth interventions [18] was inconclusive regarding their efficacy in reducing depression (only 4 of 9 studies focusing on depression reported significant effects) but did suggest benefits in terms of reducing pain (of the 3 studies on pain control, 2 reported significant effects). Another review of supportive telehealth interventions [19] found that 9 of 20 studies indicated a significant improvement in at least one psychosocial outcome measure. However, only one of these found that this improvement was sustained at the end of the follow-up period [21]. The review appraising research addressing remote follow-up [20] concluded that this form of telehealth neither significantly decreased psychological distress, nor enhanced quality of life of cancer survivors. Only 2 studies reviewed reported significant improvements in quality of life or fatigue levels. This suggests that the current evidence on telehealth effectiveness is relatively mixed and that the type of telehealth intervention employed may impact final outcomes.

Telehealth interventions are "complex," comprising many components, and can be time consuming and expensive to develop and test. Medical Research Council guidance on developing and evaluating complex interventions highlights the importance of qualitative research for developing the theoretical understanding of complex interventions' impact and processes of action [22]. The systematic reviews discussed above synthesized solely results from studies reporting patient-reported outcomes. However, they did not incorporate elements pertaining to patients' needs for, or experiences of, or engagement with telehealth. Yet, these are important considerations for successful uptake of telehealth interventions. Systematic reviews conducted to date have primarily enabled consideration of whether telehealth offers benefit to cancer survivors [18-20], but a qualitative synthesis of the cancer survivor's experience of telehealth will enable consideration of how and why cancer survivors experience any benefit, or not.

The aim of this review therefore was to systematically identify, appraise, and synthesize qualitative research evidence on the experience of adult cancer survivors who have engaged with telehealth intervention(s) and provide a fine-grained understanding of users' perspectives. The intent was to enhance characterization of the impact of telehealth interventions upon the experience of cancer survivorship and identify potential steps to improve engagement of cancer survivors with telehealth.

Methods

The reporting of this qualitative synthesis follows the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines [23].

Search Strategy

A comprehensive search strategy was developed to identify all the studies relevant to our research question. The search strategy was developed for Medline (PubMed), then adapted and applied to PsychINFO, Cumulative Index for Nursing and Allied Health Professionals (CINAHL), Embase, and the Cochrane Central Register of Controlled Trials. These databases were chosen to encompass nursing, medicine, social sciences, and psychology. To retrieve other relevant publications, the reference lists of selected publications were hand searched and articles considered against the eligibility criteria. Nonresearch publications and "gray" literature were excluded. The search was conducted on August 14, 2015, and updated on March 8, 2016. Search results were uploaded and stored using Endnote version 7.4 (Clarivate Analytics). Duplications of studies were removed.

Search terms were split into 3 categories: cancer survivors (population), eHealth (intervention), and survivor experience (outcome). Each category included medical subject headings (MeSH) and keywords using trunctation (*) within title or abstract fields (see Multimedia Appendix 1 for full Medline search strategy). The search terms were informed by previous systematic reviews of eHealth [24,25] and database thesauri. Broad search terms were used for eHealth, rather than the more restrictive term "telehealth," to ensure that all relevant interventions were captured. Boolean terms "OR" and "AND" were used to combine searches within and between categories respectively. The search was restricted to papers published in English between 2006 and 2016 to encompass recent papers of the last decade for relevancy. Database searches are less successful at identifying qualitative studies, and abstracts of studies reporting qualitative data are variable in content, not always indicating the research method [26]. Consequently, the initial search was not limited by research design; papers which incorporated qualitative data were identified at the stage of assessing full text articles for eligibility.

Inclusion and Exclusion Criteria

Textboxes 1 and 2 present the papers eligible for inclusion in and exclusion from the study.

Textbox 1. Inclusion criteria for the study.

- Original articles in English published in the period of January 1, 2006, to March 8, 2016
- Papers reporting on adults (over 18 years) who had received a diagnosis of cancer, regardless of gender, tumor type, or comorbidities
- Papers reporting on participants who had experienced a telehealth intervention, which enabled remote communication or remote monitoring with health care professionals (HCPs) (the main component of the intervention was delivered by telephone, using the Internet, or using hand-held or mobile technology)
- Papers reporting qualitative data—including verbatim quotes—on cancer survivors' experience of using a telehealth intervention

Textbox 2. Exclusion criteria for the study.

- Broader experience of eHealth—did not provide remote communication or monitoring with health care professionals (HCPs) (eg, chat rooms, social media, remote peer support)
- Data collected during development of an intervention based on the user's expectations rather than experience
- Experience of carers only
- Experience of users with conditions other than cancer
- Gray literature or reviews
- Qualitative data that did not include verbatim quotes

Screening and Data Extraction

A 2-stage screening process was conducted. In stage one, 3 reviewers (first author and 2 members of the research team) screened all identified titles and abstracts that were potentially eligible for inclusion irrespective of research methodology. Full papers were then obtained and potentially eligible studies were assessed for inclusion independently by at least two of the 5 members of the review team (AC, AM, WK, FM, RM); at this stage papers that did not incorporate qualitative data were excluded. Uncertainties around paper inclusion were resolved by the final member of the review team (last author) if necessary.

All members of the research team independently extracted data for each paper using a data extraction form devised by the team; data from each paper were extracted twice by 2 separate members. All text from the papers labelled as "results" or "findings" was extracted electronically and entered into Nvivo 10, a qualitative data analysis computer software package (QSR International). Data extraction forms were compared across reviewers for each paper to ensure accuracy and comprehensiveness of data extraction.

Quality Assessment

The review team adapted the Critical Appraisal Skill Programme (CASP) checklist for qualitative research [27] to include assessment of information power, a concept proposed by Malterud et al [28] as an alternative to saturation in qualitative research. Information power refers to how researchers can achieve adequate sample size in qualitative studies by having a clearly defined aim, a specific sample, a theoretical approach, high quality dialogue, and clear analytic strategy. The adapted tool was piloted on a subsample of studies (n=12) by 6 members of the review team (AC, AM, FM, ER, RM, WG). Following minor amendments, the tool was used independently by 2 members of the review team to assess the remaining studies. All studies fulfilling the eligibility criteria were assessed with the adapted checklist comprising: research design, sampling strategy, analysis, presentation and interpretation of findings, reflexivity, ethical considerations, relevance, and transferability. The decision was made to include all studies in the analysis, however, less emphasis was given to studies assessed by the checklist as relatively lacking in rigor.

Thematic Synthesis

The findings of primary research studies were synthesized using methods proposed by Thomas and Harden [29]. These methods

aim to achieve a high level of analysis and integration via 3 stages of synthesis: (1) Line-by-line coding of the results section of each paper, (2) development of descriptive themes which remain close to the themes from the primary research, and (3) development of analytical themes, which go beyond the primary research findings and generate a higher level of conceptual understanding.

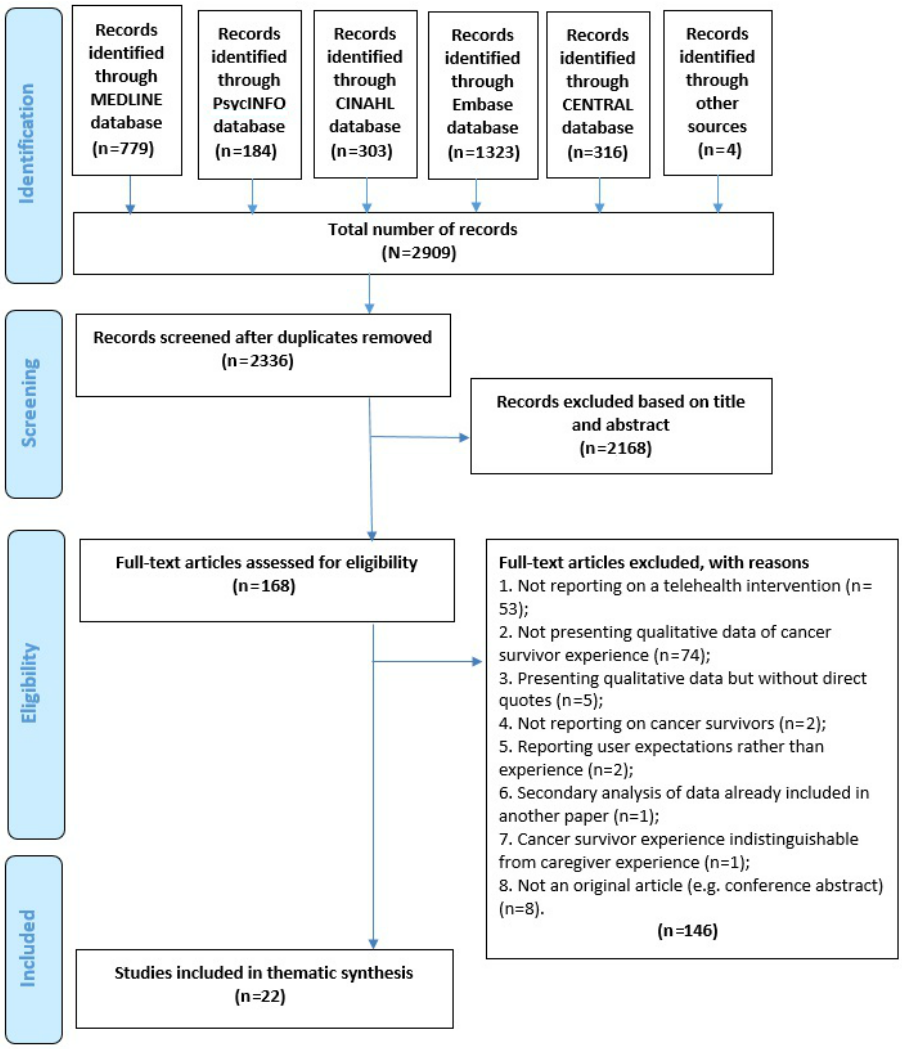
Of the review team, 2 members (AC and GL) coded the results section of each included article line by line and developed descriptive themes through inductive analysis, involving comparison, reexamination, and grouping of codes. Descriptive themes were shared with and considered by all authors to ensure they were consistent and apposite. Descriptive themes were grouped and analytical themes were developed through an iterative process of reflection on, and interpretation of the descriptive themes within and across studies.

Results

The search yielded 2909 records. Based on titles and abstracts, 168 records were selected for full text screening, resulting in a selection of 22 publications that met all eligibility criteria (Multimedia Appendix 2). Some of these studies were nested within larger trials of telehealth interventions. Multimedia Appendix 2 describes just the qualitative component extracted from each study.

All the included studies were deemed to be of sufficient quality to contribute equally to the thematic synthesis. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart is presented in Figure 1.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) study selection flowchart.



Characteristics of Included Studies

The 22 included studies used semistructured or in-depth interviews, or open-ended questions within surveys undertaken, with a total 445 patients (sample sizes listed in Multimedia Appendix 2). Of the total studies, 4 included only female survivors, [30-33], 1 study included only men [34], while the remaining 17 included both male and female participants [35-51]. Only 4 studies reported on the ethnicity of their participants [33,38,47,48]. Survivor cancer diagnoses included breast, lung, colorectal, ovarian, head and neck, prostate, hematological disease, and lymphoma. Study participants included adults who were newly diagnosed with cancer, those on active treatment, as well as those receiving follow-up care. The media used within telehealth interventions were heterogeneous: 11 studies appraised telephone-based

interventions, [30-32,34,35,42,43,47,49-51], 5 studies related to primarily Web-based interventions, [33,36,39,40,48], 1 study evaluated email communication [37], and 5 looked at interventions using handheld monitoring devices [38,41,44-46]. The purpose of the interventions was diverse and included: 15 which supported patients through treatment; 6 which monitored symptoms [36,38,41,44-46]; and 9 which provided psychological support, information, advice or self-management strategies [33-35,39,40,42,43,47,49]. For 2 studies, telehealth acted as a form of communication between patients and HCPs at various stages of their journey [37,48] and 5 interventions replaced clinic visits for follow-up patients [30-32,50,51]. The majority of studies were carried out in the United Kingdom (Scotland and England; n=10). Others were conducted in the United States (n=3), Sweden (n=2), Canada (n=2), Australia (n=2), China (n=1) Hong Kong (n=1), and Singapore (n=1).

Regarding the aims of the 22 studies, 9 explored the views of patients and health care professionals as to the use of telehealth [30,41,44-48,50,51], 9 the experience of only patients [31,32,34-36,38,40,42,43], and 4 the experience of both patients and family members [33,37,39,49]. For 11 studies, the primary aim was to test the acceptability and feasibility of telehealth interventions [33-35,38,41-45,47,48]: 8 focused primarily on the experience of intervention use [30-32,40,46,49-51], and 3 aimed to explore the potential benefits of telehealth [36,37,39]. Of the 22 studies, 8 were qualitative studies nested within larger trials of telehealth interventions [30,34,38,40,46,47,49,51]. The intervention was nurse-led in 16 studies [30-32,34,36-41,43,45,47,49-51], with the remainder involving other health care professionals such as doctors or psychologists.

Thematic Synthesis Findings

Three analytical themes encompassing patients' experience of telehealth interventions emerged, with 3 descriptive themes underpinning each of these:

Theme 1: Influence of Telehealth on the Disrupted Lives of Cancer Survivors

This theme articulates how the remote nature of telehealth limited the disruption to peoples' lives. Cancer survivors across many of the studies felt that their lives had been disrupted by the disease. Telehealth interventions enable the management of care remotely—away from the hospital environment—thereby minimizing this disruption. This analytical theme encompasses 3 descriptive themes: convenience, independence, and burden.

Convenience: "At My Convenience"

Results suggest there is benefit of telehealth in terms of convenience for cancer survivors, which allowed them to either return to normal activities or limit the interruption to daily routines. Ten studies reflected on this convenience in different ways. In telehealth interventions where telephone contact was used to replace face-to-face care, patients did not have to travel into the hospital, thereby saving time and money, and reducing the stress and burden of travel [30-32,50]. This level of convenience was highlighted as especially important for those with caring and work responsibilities [30,31,50]. Web-based or email-based interventions were viewed as flexible as they could be easily logged into at any time, meaning survivors could make contact or complete activities when it suited them and fitted into their lives [33,36,37,39,40,46]. Telehealth interventions were easily integrated into daily routines.

Independence: "I Learned What I Could Do"

Studies reviewed suggested that telehealth can alter the way in which survivors relate to HCPs. Remote consultations and monitoring mean survivors have a sense of physical independence, which puts an emphasis on self-care. Eight studies reported that participants felt telehealth had educated them about ways they could improve or manage their symptoms, or raised their awareness of potential issues to look out for with regards to their disease [36,38,41,43-45,51]. Survivors were given confidence to independently assess when they could manage their own care and when they should call for help [38,49]. In some cases, survivors reflected on their own data or summary information produced from the intervention, which motivated self-care efforts [45-47].

Burden: "Just One More Thing to Do"

If a telehealth intervention is difficult to engage with or time consuming, then it becomes a disruption in itself. Of the Web-based interventions, 2 were seen as an extra burden for survivors [36,48], while another study found that the online weekly supportive intervention was perceived by survivors as too time consuming [33]. In these studies, the possible convenience and independence that telehealth could provide was negated by these difficulties. "Burden" appears in contrast to "convenience." These data suggest that survivors' telehealth experiences are varied and complex; telehealth interventions may have "tipping points," where they become burdensome instead of providing convenience.

Theme 2: Personalized Care Delivered From a Distance

This theme illustrates how telehealth can enable close and personalized relationships between cancer survivors and service providers even though the technology is remote and functions through physical distance. This perception of personalized care is underpinned by 3 descriptive themes: perception of personal space, which is created by survivors engaging with health care in their chosen environment, expanded sense of time that the remote environment engenders, and the effect remote connection has on the sense of human contact.

Space: "A Space I Was Missing"

In telehealth interventions, cancer survivors experience a different form of contact with their providers, engaging with their care physically from their place of choice. Of the included studies, 4 reported that remote communication gave them a sense of space to focus on their concerns and needs as they were in a familiar and relaxing environment [30,39,40,50]; while in another study where telephone follow-up replaced face-to face care, participants reported a sense that they were moving on and away from the hospital setting and its associations with disease [30]. The invisibility and perceived anonymity that telehealth provided reduced survivors' sense of vulnerability, and in some cases enabled patients to raise concerns remotely that they would not have wanted to discuss face-to-face [40,47].

Time: "Time Was Never an Issue"

A prevalent theme reported across a number of studies (n=5) was that by being away from the clinical environment, survivors felt they had time to express their concerns and did not feel as rushed as they would have in a hospital setting [30-32,40,50]. Of the included papers, 3 focused on how communication with HCPs was enhanced due to these perceptions of increased available time [32,34,40]. In the 3 studies reporting on telehealth interventions using written communication, the medium seemed to defy the limits of time as the communication could be written or inputted at any point, and the response could be retained for future reference [37,39,40].

The Human Factor: "It Feels Impersonal"

Of the included studies, 9 reported that for some cancer survivors, telehealth was perceived as impersonal and lacking physical human contact [30,33,37,39,42,45,46,48,50], and 4 reported that survivors had not met in person the HCP they were connecting with via telehealth [30,39,42,50]. In some cases, a preference to know the HCP was related to the need for disclosure of personal and sensitive information [30,39].

The computer was highlighted as a particularly impersonal medium [33]; one study using a Web-based system reported that survivors were unsure whether their responses had been read by providers [48], and 3 other studies discussed how structured interventions were not tailored enough to survivors' individual symptoms and concerns [45,46,48]. However, for other survivors, a structured format created a sense of security that all issues would be adequately considered [30,48,50].

Theme 3: Remote Reassurance—A Safety Net of HCP Connection

A common theme across the studies was that survivors felt they had immediate access to professional advice and that this acted as a safety net in that possible issues with their treatment, symptoms, or recovery would not be missed [30-32,35-37,40,41,43-46,49,51]. This was supported by 2 descriptive themes: where survivors could make an active connection with HCPs and where survivors felt passively monitored by providers. A third descriptive theme detailed instances when telehealth negatively affected the connection with HCPs.

Active Connection: "I Can Always Get in Touch"

Eight studies reported that telehealth interventions helped to reassure survivors by providing access to support and care through an active connection to HCPs [30-32,35,40,41,49]. Even if that opportunity was not used, cancer survivors felt a sense of safety knowing that they could make contact at any time [40]. In the case of telephone follow-up, patients valued the ease of being able to access a nurse between appointments, with rapid referral to the cancer service if needed [30,32]. This connection helped survivors feel safe; HCPs could offer reassurance at times of need or act swiftly to minimize any problems or concerns. For others, telehealth provided a sense of being cared for through the connection; somebody was at the end of the line to provide support [35,41].

Passive Connection: "Somebody to Keep an Eye on Them"

Eight studies identified how survivors felt monitored or watched over by health professionals in telehealth interventions [32,36,41,43-46,51], 5 studies reported on symptom management telehealth interventions where survivors entered data and HCPs responded when issues or problems arose [36,41,44-46], whereas 3 studies reported on interventions where survivors received phone calls from HCPs [32,43,51]. Contrary to the previous theme, the survivors in these interventions were not required to actively initiate contact with an HCP and instead were passively monitored. This perception of a "watchful eye" contributed to a sense of reassurance and ultimately to a sense that survivors were safe [45,46,51]. Patients felt that they were in the hands of a professional—an expert—who would be able to detect if survivors needed further tests, changes in medication or further intervention, and would set this in motion [32,40,43,44,51].

It is noteworthy that the reassurance provided by telehealth interventions was enhanced by the sense that telehealth provided consistency and continuity of contact. A trusting relationship, which extended "beyond the hospital boundaries" [40], was facilitated by this continuous contact [30,31,40,49]. While this aspect of cancer care may not be unique to telehealth, the data from these studies suggests that participants associate telehealth with continuity and consistency and contrast this with some impersonal clinical encounters [32].

Slipping Through the Net: "Missed the Connection"

The reassurance provided by the frequency and constancy of contact with HCPs in telehealth interventions was jeopardized in some studies [30,33,35,37,39,40,46,49,50]. In some cases, this arose when survivors allocated to telehealth were unable to engage with it due to particular personal circumstances, for example, survivors with hearing issues in a telephone-based intervention [35], or computer-based studies where survivors had poor computer literacy [37]. In 2 studies it was reported that technical issues in the telehealth intervention prevented connection being made [33,46]. In these examples, there was the sense that survivors' concerns and issues might have slipped through the net.

Tables 1-3 list the studies reporting each of the above descriptive themes by their respective analytic themes. Table 4 provides a selection of quotes from participants to illustrate each theme.

Table 1. Themes identified in each study: influence of telehealth on the disrupted lives of cancer survivors.

Paper	Convenience "It didn't really encroach"	Independence "I learned what I could do"	Burden "Just one more thing to do"
Beaver, Williamson, and Chalmers, 2010 [30]	✓[a]		
Chambers et al, 2015 [35]			
Chan et al, 2013 [36]	✓	✓	✓
Cornwall, Moore, and Plant, 2008 [37]	✓	✓	
Cox et al, 2008 [31]	✓		
Cox and Faithfull, 2015 [32]	✓		
Fergus et al, 2014 [33]	✓		✓
Hogberg et al, 2013 [39] Head et al, 2011 [38]	✓		
Hogberg et al, 2015 [40]	✓		
Kearney et al, 2006 [41]		✓	
Kilbourn et al, 2013 [42]			
Lai et al, 2015 [43]		✓	
Livingston et al, 2006 [34]			
Maguire et al, 2015 [44]		✓	
McCann et al, 2009 [46] McCall et al, 2008 [45]	✓	✓	
Ream et al, 2015 [47]		✓	
Snyder et al, 2013 [48]			✓
Stacey et al, 2016 [49]		✓	
Williamson, Chalmers, and Beaver, 2015 [50]	✓		
Zheng et al, 2013 [51]		✓	

[a]✓ indicates the theme was present within the paper.

Table 2. Themes identified in each study: personalized care delivered from a distance.

Paper	Space "A familiar and relaxing environment"	Time "Time was never an issue"	The human factor "It feels impersonal"
Beaver, Williamson, and Chalmers, 2010 [30]	✓[a]	✓	✓
Chambers et al, 2015 [35]			
Chan et al, 2013 [36]			
Cornwall, Moore, and Plant, 2008 [37]		✓	✓
Cox et al, 2008 [31]		✓	
Cox and Faithfull, 2015 [32]		✓	
Fergus et al, 2014 [33]			✓
Head et al, 2011 [38]			
Hogberg et al, 2013 [39]	✓	✓	✓
Hogberg et al, 2015 [40]	✓	✓	
Kearney et al, 2006 [41]			
Kilbourn et al, 2013 [42]			✓
Lai et al, 2015 [43]			
Livingston et al, 2006 [34]		✓	
Maguire et al, 2015 [44]			
McCall et al, 2008 [45]			✓
McCann et al, 2009 [46]			✓
Ream et al, 2015 [47]	✓		
Snyder et al, 2013 [48]			✓
Stacey et al, 2016 [49]			
Williamson, Chalmers, and Beaver, 2015 [50]	✓	✓	✓
Zheng et al, 2013 [51]			

[a]✓: indicates the theme was present within the paper.

Table 3. Themes identified in each study: remote reassurance-a safety net of health care professionals (HCPs) Connection.

Paper	Active connection "I can always get in touch"	Passive connection "Somebody to keep an eye on them"	Slipping through the net "Missed the connection"
Beaver, Williamson and Chalmers, 2010 [30]	✓[a]		✓
Chambers et al, 2015 [35]	✓		✓
Cornwall, Moore, and Plant, 2008 [37]	✓		✓
Chan et al, 2013 [36]			
Cox et al, 2008 [31]	✓		
Cox and Faithfull, 2015 [32]	✓	✓	
Fergus et al, 2014 [33]			✓
Head et al, 2011 [38]			
Hogberg et al, 2013 [39]			✓
Hogberg et al, 2015 [40]	✓	✓	✓
Kearney et al, 2006 [41]	✓	✓	
Kilbourn et al, 2013 [42]			
Lai et al, 2015 [43]		✓	
Livingston et al, 2006 [34]			
Maguire et al, 2015 [44]		✓	
McCall et al, 2008 [45]		✓	
McCann et al, 2009 [46]		✓	✓
Ream et al, 2015 [47]			
Snyder et al, 2013 [48]			
Stacey et al, 2016 [49]	✓		✓
Williamson, Chalmers, and Beaver, 2015 [50]			✓
Zheng et al, 2013 [51]		✓	

[a]✓ indicates the theme was present within the paper.

Table 4. Quotations from participants from primary studies to illustrate each theme.

Analytic themes	Descriptive themes	Quotations from participants in primary study
Influence of telehealth on the disrupted lives of cancer survivors	Convenience: "It didn't really encroach"	"Because I'm still working, I'm self-employed and I travel all over the country... and it's difficult sometimes to be at a hospital at a certain time. So that was good." [30]
		"It was very easy, it was very simple to do and eh, it didn't really encroach on lifestyle or anything like that at all, just had to remember to do it (laughs), set the 'pinger' on the cooker." [46]
		"I haven't got a car so I'd have to take two buses you see to go to the hospital. When I get to the hospital I have about an hour and a half wait in the waiting room. And I go see the doctor, 2 min and I'm out again." [50]
	Independence: "I learned what I could do"	"It is educational in the sense that I have an overall view about the side effect of chemotherapy." [36]
		"I learned what I could do to make myself feel better" [38]
		"I'm one of those people that likes statistics and numbers and things...and you could see on Tuesday I must have been quite bad...the graph's right up and then it's back down to normal today..." [45]
	Burden: "Just one more thing to do"	"We have very limited free time available and found it difficult to finish the lessons within a week." [33]
		"It really was just one more thing to do. I didn't feel that good a lot of the time so I really didn't feel like doing one more thing. But I did it because I had to." [48]
Personalized care delivered from a distance	Space: "A familiar and relaxing environment"	"It is much more relaxed to know that you don't have the alien thing of the hospital. You can have it in your home (telephone follow-up). You have it at work. You can have it on your mobile if you want sat in the car." [30]
	Time: "Time was never an issue"	"I felt that time was never an issue, that whatever I wanted to talk about, it was relevant. The time was given and it was discussed and that was good." [32]
		"It has also been very nice with a written response. You can read it several times." [40]
		"Quite happy. I did feel that I perhaps gleaned more information, I didn't feel rushed or anything. And I'm sure that I sort of gleaned more information from my colorectal nurse than I would have perhaps done in a clinic situation." [50]
	Human factor: "It feels impersonal"	"If I should share my innermost thoughts, I'd probably like to have some kind of relation with the person I'm writing to. Otherwise, I need to know exactly what I'm asking for." [39]
		"But there was things I thought – noo, that's how I feel and that's what I've got but they're no asking that, so I could'nae put it doon, do you know what I mean." [46]

Analytic themes	Descriptive themes	Quotations from participants in primary study
remote reassurance-a safety net of health care professionals (HCPs) Connection	Active connection: "I can always get in touch"	"The sessions helped me because there was somebody on the end of the line when you're having a down day. And I mean if you're having a down day you can ring them. You know it's not like you're alone in the world." [35]
		"I used to make myself little cards that I carry round with me, one in my handbag, one at home here and one in my filing cabinet at work, so if I ever felt I needed to ring her up I've got ... ready access." [32]
		"It's really good to just have the opportunity lying there, I do not have to use it, but just knowing that there is a possibility is a security. That I can ask has been an incredible relief." [40]
	Passive connection: "Somebody to keep an eye on them"	"It was quite positive. It was quite reassuring; you did feel that you were being monitored. You didn't think if you put in those symptoms that you would slip through the...you know that if you had really worrying symptoms you would have slipped through the system. Somebody would have picked it up." [46]
		"Well as far as I am concerned yes, because it was very helpful because I had this bad cough and 1 or 2 alerts came up and the nursing staff at the other end were immediately onto it the fact that we were in contact with the hospital very much quicker than we would be if we'd waited and maybe even phoned." [44]
		"I found it helpful and interesting. It made me feel that my existence had some purpose...I think it is something which ought to be continued. It does make people feel they are being looked after...and somebody is keeping an eye on them." [45]
		"I felt safe and reassured because the hospital staff followed up with me like a kite in their hand, so that I would not fly away." [51]
	Slipping through the net: "Missed the connection"	"I have trouble on the phone, I have dreadful trouble with the mobile. Just mainly because of the complications with the hearing." [35]
		"I got an answer that...made me...made me realize I had not put it (the issue) in the right way, and then I realized that I cannot sort this out, via this communication...with such long intervals." [40]
		"I did miss the camaraderie that you get from other patients. And, of course, what tends to happen when you go on hospital visits is that you tend to be there at the same time as the other people who had their ops (operations) with you." [50]

Summary of Synthesis

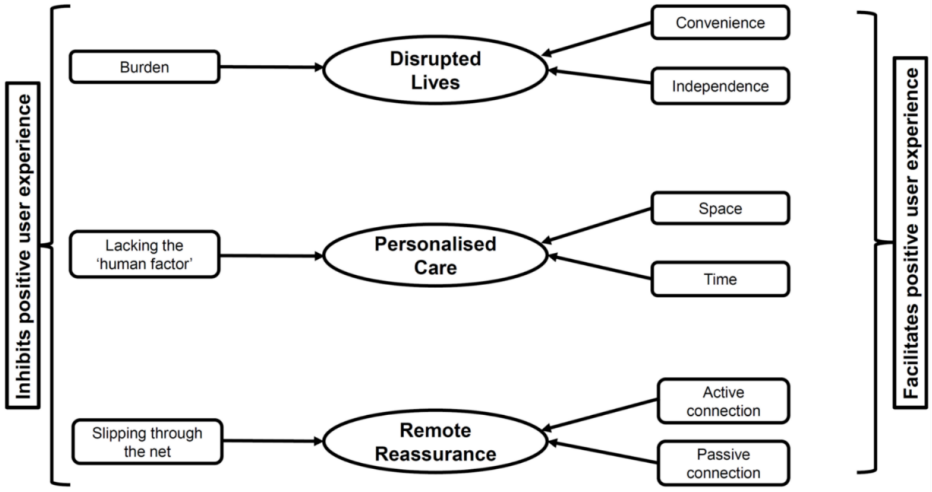
The analytical constructs that have emerged through this qualitative synthesis demonstrate the complex experience of telehealth use in cancer survivorship. Telehealth can be experienced positively in terms of supporting a less disrupted life through providing convenience and independence to live life as a survivor rather than a patient. However, in order to embrace a more independent role, a trusted relationship with an HCP is crucial. This highlights an interplay for cancer survivors between appreciating the opportunity for home-based care and the reliance upon instant access to clinical support. Such interplay also exists between the convenience of such care and the increased responsibility, and potential burden, placed upon the survivor.

Discussion

Overview

This paper is the first to metasynthesize the reported experiences of cancer survivors who have participated in telehealth interventions. From the analysis, 3 key analytic themes and 9 descriptive subthemes emerged, showing that telehealth interventions in the area of cancer care represent a convenient approach, which can reduce treatment burden and disruption to cancer survivors' lives. Our findings suggest that while telehealth interventions can facilitate an experience of personalized care for those living with and beyond cancer, interventions need to take personal factors into account so as to maximize benefit and minimize burden. The relationship between these themes is presented in a model (Figure 2) which summarizes our findings on cancer survivor experience of telehealth. Each of the analytical themes is presented in the center, and their descriptive themes on either side represent the factors inhibiting (left) or facilitating (right) the positive user experience of telehealth. These themes will be discussed below in the context of current literature.

Figure 2. A model of cancer survivor engagement with telehealth—factors inhibiting and facilitating positive user experience.



Principal Findings

The first analytic theme pertains to the concept of the cancer survivors' disrupted life. Biographical disruption is a well-known consequence of chronic illness [52], and consistently in the literature cancer patients emphasize their desire to return to, and lead a life as "normal" as possible [53-59]. Yet there are a number of obstacles in the cancer survivor's journey that can limit the ability to achieve this, particularly treatment burden [60]—an emerging concept within the chronic conditions literature including cancer [61]. Key sources of increased treatment burden for patients with chronic conditions include fragmented or poorly organized care lacking in continuity [62-65], poor communication with or between HCPs, barriers to accessing services, or insufficient time with health care professionals [63-65]. Our qualitative synthesis suggests that many of the above issues can in principle be addressed to some extent by telehealth provision, as demonstrated by the themes pertaining to time, convenience, and connection to HCPs. With treatment burden minimized and integrated into daily routines, biographical disruption from cancer survivorship becomes easier to address.

However, some cancer survivors experience telehealth as time-consuming [33] or as an additional burden [36,48], as reflected by one of the key issues facing telehealth provision: balancing benefit against burden. This issue has been highlighted in similar qualitative syntheses on telehealth interventions among patients with chronic conditions, for example, chronic obstructive pulmonary disease (COPD) [66]. To be successful, a telehealth intervention must balance any burden posed by technology and remote monitoring against the benefits of convenience and independence, as depicted in Figure 2. However, only 3 studies included in this review identified perceived burden resulting from the use of telehealth, and these consisted of trialing remote symptom reporting [36], patient-reported outcome completion [48], or Web-based coping or adjustment therapy [33], all requiring daily or weekly engagement with the intervention. This would suggest that while the majority of telehealth interventions included within our review were acceptable to cancer survivors in terms of the perceived balance of burden versus benefit, the required frequency of reporting or engaging with telehealth interventions is an important factor to consider in intervention design. Involvement of service users in the early stages of telehealth intervention design may be one way of ensuring this balance is maintained.

The second analytical theme represents the concept of personalized care from a distance. Enabling care within the home can offer benefits such as a familiar and relaxing environment within which to interact with an HCP, and the sense that the focus of care can shift toward the patient's preferences and needs [67]. This is supported by this synthesis, as the feeling of having more time to communicate concerns was reported within 5 of the studies reviewed [30-32,40,50]. These results align with a recent metasynthesis identifying longer appointment times as being more accessible outside of the hospital care setting [68]. However, these advantages of telehealth are also accompanied by a certain feeling of remoteness, with survivors in some studies considering telehealth interventions (particularly computer or Web-based) to be impersonal or lacking in human contact, with patients feeling unsure whether anyone was "out there" listening to their submitted responses [48]. The issues of space, time, and impersonality are subsequently connected to personalized care in Figure 2.

This synthesis shows cancer survivors can experience telehealth interventions as lacking the "personal touch," even when they are augmenting [33,37,39,42,45,46,48] rather than replacing [30,50] routine care. Nonetheless, some studies reviewed demonstrated that survivors were able to develop trusting relationships with HCPs via the telehealth medium [30,31,40,49], and other studies of telehealth interventions have demonstrated the capacity for such relationships to develop [69-71]. In addition, cancer survivors found they could more easily raise concerns with their HCP remotely, concerns that they would otherwise feel uncomfortable to discuss in person [40,47]. It can therefore be argued that personalized care, as enabled by telehealth interventions, can potentially provide reassurance and control to patients—that they can have the time and space to focus on articulating their health concerns.

This heterogeneity in the study findings pertaining to personalized care could be down to a number of factors, such as the method of delivering the intervention. For example, 4 of the 10 studies where patients reported a sense of impersonality in telehealth did not provide the opportunity to cancer survivors to meet their telehealth professional face-to-face prior to intervention delivery [30,39,42,50], despite face-to-face meeting being considered beneficial to promoting user engagement [72]. Another potential factor to consider is the population targeted within the included studies. In many of the studies where survivors were able to develop a trusting relationship with their HCP, the cancer survivors were relatively young, in their 20s and 30s (Multimedia Appendix 2). It could thus be argued that individuals who regularly use Web- or computer-based communication mediums may feel more comfortable with telehealth remote contact, and subsequently may find it easier to develop a relationship with their HCP. However, some concerns about ability to use technology in a telehealth context can be unfounded [73], and a case-by-case approach may be necessary to ensure that patients who struggle with technology can be provided some telehealth training so that they do not miss out. Overall, further exploration is required of the steps that need to be taken to encourage cancer survivors to develop a trusting relationship with telehealth care providers.

Further to the second analytic theme of "personalized care," some survivors felt that telehealth interventions using structured symptom or patient-reported outcome questionnaires or providing self-care information were not sufficiently tailored to their circumstances [45,46,48], contributing to the sense that the intervention was impersonal. The advantage of a structured approach, for example, standard questionnaire items, is that it allows patients to know what symptoms they need to report. In the literature there are instances whereby chemotherapy symptoms were under-reported due to differences in self-care approach [74], or knowledge gaps in whether a symptom is due to cancer or the treatment received for the cancer [75,76]. However, some other studies included in our synthesis found that the structured format for logging responses was reassuring for survivors [30,48,50]. As findings are equivocal in this area, measures used in telehealth interventions may need to undergo a more iterative development process in order to increase personalization. This synthesis did not focus on the design process of telehealth interventions, but involvement of patients during this process, as discussed previously, could facilitate personalization. Ventura et al [77], in their evaluation of characteristics of eHealth supportive interventions (mainly in cancer), found that only 5 of 16 studies assessed had based intervention development on the needs assessment of the target population, indicating that consideration of individual needs at the early stages of telehealth development is still limited.

The final analytical theme identified was that of a "safety net" that cancer survivors felt was provided by either an active or passive connection to HCPs. Instances of active connection enabled the survivor to initiate the contact to receive support or advice, while passive connections such as responses to symptom or patient-reported outcome questionnaires, or routine telephone follow-up, were initiated by the HCP. This lead to survivors feeling reassured that they were being monitored, that medical assistance would be swift where it was deemed necessary, and that they could actively raise concerns. However, such connections may induce over-reliance on HCPs, potentially affecting cancer survivors' autonomy and control. The risk for such dependency has been highlighted in recent reviews on telehealth in COPD [66] and chronic heart failure [78]. To date, there are no studies indicating the occurrence of any adverse events resulting from use of telehealth interventions in cancer care, therefore the dangers of this kind of dependency are unknown and represent an area for further evaluation. Given some instances highlighted in this review where survivors felt they may have "slipped through the net" due to technical problems [33,46] or not knowing whether their responses had been seen [48], ensuring consistency of monitoring during telehealth interventions is important, and steps can be taken to improve videoconferencing call quality and connection quality [79].

This synthesis indicates that telehealth interventions can provide cancer survivors with the necessary support they need to feel safe to manage their condition within their chosen environment. The findings can also be considered in terms of the person-based approach put forward by Yardley et al [80] for facilitating acceptance of eHealth interventions: promoting autonomy, competence (minimal disruption and achievement of self-regulation), and a positive experience of relatedness. Our findings suggest that the use of telehealth interventions with cancer survivors can facilitate autonomy and reduce disruption, and positive HCP relationships can be facilitated by remote monitoring. Thus, telehealth has the potential to address these needs. However, further research should address the personalization of telehealth, how to facilitate trusting survivor-HCP relationships, and how to mitigate the risks of dependency.

Limitations

Only studies conducted since 2006 were included in this synthesis to capture the exponential increase in telehealth interventions over the past 10 years [83]. Therefore, the findings from our qualitative synthesis may not reflect cancer survivor experience of earlier telehealth interventions. Secondly, the ethnicity of participants was rarely reported—although studies contained a mix of cancer types, broad age ranges, and included all stages of disease from newly-diagnosed to the palliative care stages; people from black and minority ethnic groups may not have been adequately represented. Other demographic data such as languages spoken, health literacy level, presence or absence of cognitive impairment, and education level were also not reported in many studies, thus limiting our understanding of the experience of cancer survivors from underrepresented cultural and socio-economic groups. Similarly, due to the clinical heterogeneity of the samples included, it is not possible to draw conclusions regarding specific cancer types, disease stages, or age ranges that could benefit in particular from telehealth interventions.

The studies reviewed covered different disease stages, demonstrating that telehealth can support patients at any point in their cancer journey. It is noteworthy that overall the patients did not comment on the timing of the intervention, nor on its

duration. Many of the survivors engaging in telehealth only do so for a relatively short period of time, with just 2 studies [30,32] engaging survivors with the telehealth intervention for 2 years or more. As a result, there was little data overall on the long-term experience of engagement with telehealth interventions for this group.

Arguably, other important factors might impact on cancer survivors' experience of telehealth such as treatment stage, or the health care professional groups who are points of contact for the intervention. The conclusions drawn by this metasynthesis are limited by the research conducted to date which did not enable these factors to be addressed. Future research on telehealth interventions should explore the experience of cancer survivors at different stages of survivorship, and the impact of the HCPs monitoring these interventions on the experience of cancer survivors.

For 6 studies [31,33,36,37,41,49], qualitative data was collected only using open-ended survey questions, limiting the conclusions that could be drawn from survivor responses when compared with other studies which provided richer data. This synthesis only considered the experiences of adult cancer survivors who had participated in telehealth. Future reviews could also consider the experiences of HCPs, carers, or children and young adults, and the involvement of all these groups in the intervention design process. Research reporting the experiences of individuals who choose not to engage with telehealth or withdraw from interventions could also be explored to enhance understanding of the barriers to engagement in telehealth.

Conclusions

This thematic synthesis supports the value of telehealth as a convenient and reassuring approach to delivering cancer care, which can minimize treatment burden and subsequent disruption to cancer survivors' lives. As to how this synthesis could inform the development of future telehealth interventions, we would suggest that telehealth developers should balance the use of standardized patient outcomes measures with the introduction of more specifically tailored measures to minimize any sense of impersonal care. Furthermore, telehealth interventions need to be developed to balance benefit of remote monitoring and communication against burden, and consider survivor needs—perhaps through their involvement in the early stages of intervention design. The themes identified in the study are echoed in the existing literature on telehealth both in cancer and other long-term conditions. The model developed as part of this review therefore has the potential to not only facilitate understanding of the patient experience of telehealth in other conditions, but to guide the design of telehealth interventions in these areas to avoid factors that inhibit positive user experience, thereby improving telehealth engagement.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy for Medline.

[PDF File (Adobe PDF File), 27KB - jmir_v19i1e11_app1.pdf]

Multimedia Appendix 2

Summary of characteristics of qualitative components of publications included in the review.

[PDF File (Adobe PDF File), 49KB - jmir_v19i1e11_app2.pdf]

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Abbreviations

ANS: age not specified
ASyMS: advanced symptom management system
CNS: cancer not specified
CINAHL: Cumulative Index for Nursing and Allied Health Professionals
DNS: duration not specified
ENTREQ: Enhancing Transparency in Reporting the Synthesis of Qualitative Research
FNS: frequency not specified
GNS: gender not specified
HCP: health care professional
ND: newly diagnosed

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Original Paper

Toward Patient-Centered Telerehabilitation Design: Understanding Chronic Pain Patients' Preferences for Web-Based Exercise Telerehabilitation Using a Discrete Choice Experiment

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Abstract

Background: Patient-centered design that addresses patients' preferences and needs is considered an important aim for improving health care systems. At present, within the field of pain rehabilitation, patients' preferences regarding telerehabilitation remain scarcely explored and little is known about the optimal combination between human and electronic contact from the patients' perspective. In addition, limited evidence is available about the best way to explore patients' preferences. Therefore, the assessment of patients' preferences regarding telemedicine is an important step toward the design of effective patient-centered care.

Objective: To identify which telerehabilitation treatment options patients with chronic pain are most likely to accept as alternatives to conventional rehabilitation and assess which treatment attributes are most important to them.

Methods: A discrete choice experiment with 15 choice tasks, combining 6 telerehabilitation treatment characteristics, was designed. Each choice task consisted of 2 hypothetical treatment scenarios and 1 opt-out scenario. Relative attribute importance was estimated using a bivariate probit regression analysis. One hundred and thirty surveys were received, of which 104 were usable questionnaires; thus, resulting in a total of 1547 observations.

Results: Physician communication mode, the use of feedback and monitoring technology (FMT), and exercise location were key drivers of patients' treatment preferences (P<.001). Patients were willing to accept less frequent physician consultation offered mainly through video communication, provided that they were offered FMT and some face-to-face consultation and could exercise outside their home environment at flexible exercise hours. Home-based telerehabilitation scenarios with minimal physician supervision were the least preferred. A reduction in health care premiums would make these telerehabilitation scenarios as attractive as conventional clinic-based rehabilitation.

Conclusions: "Intermediate" telerehabilitation treatments offering FMT, some face-to-face consulting, and a gym-based exercise location should be pursued as promising alternatives to conventional chronic pain rehabilitation. Further research is necessary to explore whether strategies other than health care premium reductions could also increase the value of home telerehabilitation treatment.

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KEYWORDS

patient preference; patient acceptance of health care; telerehabilitation; choice behavior; decision making; decision support techniques; patient compliance; chronic disease; exercise therapy; chronic pain

Introduction

Chronic Pain and Treatment

Chronic pain is considered a major public health problem. Breivik et al [1] explored the prevalence of chronic pain in 15 European countries and Israel and found that 19% (N=8.815) of their study sample suffered from chronic pain varying from moderate to severe intensity. Due to an aging society, it is expected that the prevalence of chronic pain may rise even higher, as chronic pain prevalence is greater in older adults [2,3]. Chronic pain often interferes with family and home responsibilities, recreational activities [1], and sleep [4], and it is linked with an increased risk of depression [5]. In addition to the physical and emotional burden chronic pain brings, it accounts for considerable direct health care costs, including costs related to tests, medication, and treatment, as well as indirect costs such as lost income and reduced work productivity [6]. In European countries, pain is estimated to cost economies between 3% and 10% of gross domestic products [4], resulting in an estimate of at least €140 billion [7].

Physical training has been proven to decrease pain and improve function [8-10] and therefore plays an important role in current (multidisciplinary) pain rehabilitation programs. The majority of these programs are clinic-based and supervised [11]. Although conventional rehabilitation programs are effective, poor adherence and high relapse have been shown to compromise the effectiveness of these programs [11-14] and as such lead to increased costs [15].

Patient-Centered Design

An important factor in facilitating treatment adherence is the design of patient-centered treatment programs [16-18]. The Institute of Medicine defines patient-centered care as "providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions" [19]. The concept of patient-centered care has received increased attention in recent years and is considered an important aim for health care system improvement [19,20].

Clinical guidelines for the management of chronic pain follow up on this patient-centered approach and recommend that patient preferences should be considered and that treatment programs should be individualized [21]. The underlying assumption is that by designing programs that address patients' preferences and beliefs, treatment adherence will improve [22]. In addition, there is evidence that patient preferences affect treatment outcome. A systematic review found an increase in the effectiveness of the treatment among participants in musculoskeletal medicine trials, who were randomized to their preferred treatment compared with those who were indifferent to the treatment allocation [23]. In addition, patients' preferences should be respected on the basis of moral grounds alone regardless of their relationship to the health outcomes [24].

The assessment of chronic pain patients' preferences is, therefore, a necessary first step toward the design of patient-centered pain rehabilitation programs that help better meet patients' needs. The gap between what patients prefer and what is offered can be identified, and treatment may be optimized [22].

One method to estimate patients' preferences is the use of a discrete choice experiment (DCE). A DCE is a preference elicitation methodology that is being increasingly used in health care research [25,26]. Respondents are offered a series of choices between 2 or more treatment alternatives, described by a combination of treatment attributes, and choose their preferred treatment. Analysis of these choices allows for the estimation of the relative importance of treatment attributes. A DCE can assist in prioritizing health care resource allocation, as it provides a better understanding of the factors that are most important to patients and can be used to inform patient-centered telerehabilitation design. In addition, the use of DCEs is especially valuable in the context of innovative treatments, for example, chronic pain telerehabilitation treatment, as it allows for the estimation of patients' preferences for multiple treatment scenarios that do not yet exist.

Telerehabilitation

In recent years, the use of telerehabilitation, providing remote delivery of rehabilitative services through Internet and communication technology, has been steadily increasing [27]. Systematic reviews have demonstrated that telerehabilitation has small but significant effects on pain experience and reduction in functional disability [28-30]. A review by Kairy et al [27] concluded that telerehabilitation can lead to clinical outcomes that are similar to those of traditional rehabilitation programs. Telerehabilitation is considered a promising alternative strategy next to conventional clinic-based rehabilitation programs, as it can facilitate access and adherence to health interventions [31]. Since pain rehabilitation involves changes in often long-lasting personal behavior and lifestyle, it is important that patients are able to use the acquired skills outside of the rehabilitation clinic. However, as most rehabilitation programs are supervised and provided in clinics, they may not be conducive to fostering maintenance or compliance in patients' natural environments [11]. Telerehabilitation, offering care in the patients' environment, can be a better fit with the patient's lifestyle, and by doing so, translation of the acquired skills into the patients' environment will become easier [16,32]. Furthermore, telerehabilitation has the potential to foster patient self-management [33]. For example, performance can be monitored and feedback can be provided on progress without the real-time involvement of a therapist, which perhaps will empower patients to take an active role in their own rehabilitation [34]. Self-management is especially encouraged in patients with a long-term condition such as chronic pain and has been shown to improve patient outcomes [35]. International clinical practice guidelines endorse the promotion of self-management behavior, including physical

activity, for chronic pain patients as an important component of care [21,36]. In a systematic review, Liddle et al [37] found that educating chronic pain patients about appropriate exercise and function activity to promote active self-management is effective.

At present, within the field of pain rehabilitation, patients' preferences of telerehabilitation remain scarcely explored and little is known about the optimal combination between human and electronic contact from the patients' perspective. In addition, limited evidence is available about the best way to explore patients' preferences. To our knowledge, this is the first study in the field of telemedicine that uses a DCE to explore what patients want as well as explore their priorities. As telerehabilitation represents a fundamental change from conventional treatment programs, it is vital to understand patients' preferences, and DCEs may prove to be invaluable, as the market potential of different prospective telerehabilitation services can be simulated.

Therefore, this study aims to identify chronic pain patients' preferences for telerehabilitation services using a DCE. The primary objective is to determine what treatment attributes are most important to chronic pain patients and identify which telerehabilitation scenario chronic pain patients are most likely to accept as an alternative to conventional rehabilitation. Conventional rehabilitation was described as physical activity through supervised group exercise at the clinic. The telerehabilitation scenarios that were explored varied at different levels, allowing exploration of the potential benefit of telerehabilitation. Jansen-Kosterink [38] states that the potential value of telemedicine services depends on the technology used, the clinical purpose it serves, and how the telemedicine service is implemented in daily clinic practice (service configuration). To that end, the scenarios explored different types of technology used for different clinical purposes (eg, monitoring or coaching) and also explored different methods of service configuration (eg, clinic-based care or home-based treatment). The scenarios represented a continuum of health care services ranging from clinic- based rehabilitation to home-based telerehabilitation with a focus on patient self-management. Furthermore, a willingness to accept (WTA) was estimated to explore whether patients were willing to trade health care premium reduction for more resource-efficient telerehabilitation treatments. To our knowledge, this is the first study in the field of telerehabilitation to assess patients' preferences with a DCE.

Methods

Study Design

Implemented as part of a larger survey that explored patients' attitudes toward telerehabilitation, patients' preferences for hypothetical telemedicine treatments were elicited using a self-administered discrete choice survey. The discrete choice experiment followed the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) checklist [39] on patient-preference methods. The following steps were taken: (1) identification of the key treatment attributes and assignment of levels to the attributes; (2) design of the experiment and determination of hypothetical treatment scenarios using various combinations of attributes and levels; (3) choosing an elicitation format and obtaining choice data in patients; and (4) analysis of the choice data. These steps are described in the following section.

Identification of Key Attributes of Telemedicine Treatment and Assignment of Levels

Qualitative interviews with 10 chronic pain patients (6 females, mean age 41.0 years, with pain complaints lasting longer than 6 months) and an expert focus group with 6 professionals (4 rehabilitation therapists, 1 nurse practitioner, and 1 rehabilitation doctor) were used to select the following attributes (Table 1) for inclusion in the survey: (1) treatment mode and location, (2) physician contact mode, (3) physician contact frequency, (4) feedback and monitoring technology, (5) program flexibility, and (6) health care premium reduction. The health care premium reduction attribute was used to estimate a "willingness to accept" value. This value represented a reduction in health care premiums and was used to explore whether patients were willing to trade more expensive conventional rehabilitation services for premium reductions.

Using the 6 attributes, a pilot questionnaire was developed and tested on 15 patients (11 females, mean age 42.5 years, with pain complaints lasting longer than 6 months) attending treatment in the rehabilitation clinic. In the pilot, data were collected on the time taken to complete the questionnaire and the patients' understanding of the questionnaire. Only minor adaptations were made after the pilot tests, in particular regarding the wording of the attributes.

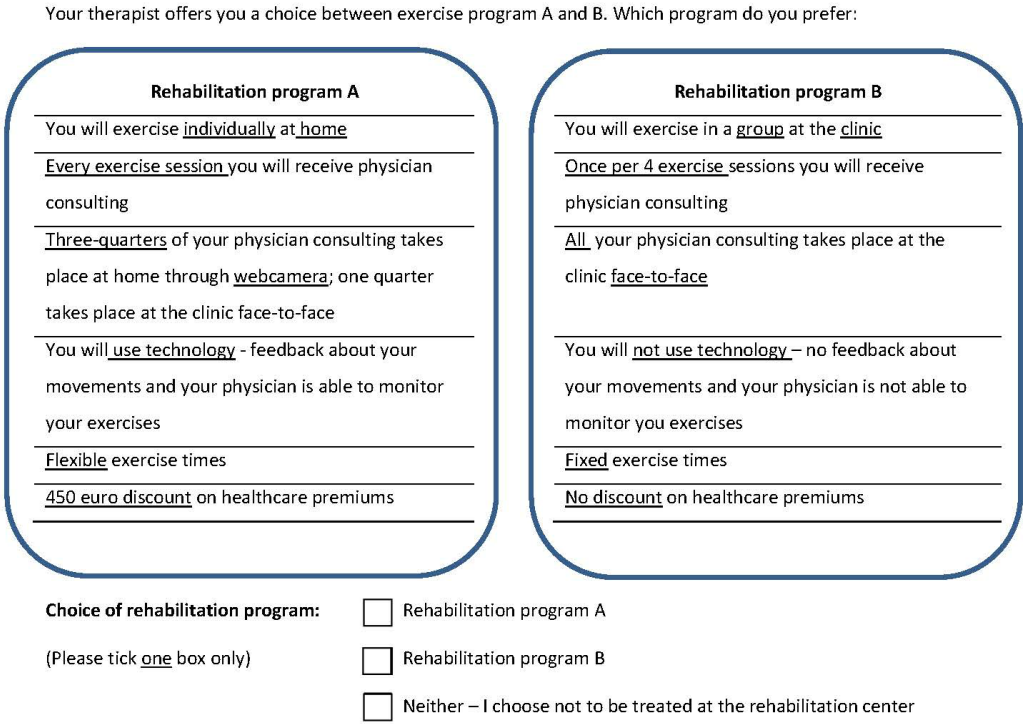
Table 1. Treatment attributes and levels used to construct the rehabilitation scenarios.

Attribute	Levels
Treatment mode and location	You exercise in a group at the gym
	You exercise individually at the gym
	You exercise individually at home
	You exercise in a virtual group at home
Physician contact mode	All physician contact takes place at the clinic face-to-face
	One quarter of your physician contact through Web camera
	Three-quarters of your physician contact through Web camera
	All your physician contact takes place through Web camera
Physician contact frequency	Every exercise session you will have physician consulting
	Once per 2 exercise sessions you will have physician consulting
	Once per 3 exercise sessions you will have physician consulting
	Once per 4 exercise sessions you will have physician consulting
Feedback and monitoring technology	Use of technology—feedback and monitoring of your exercises
	No technology—feedback and monitoring of your exercises
Program flexibility	Fixed exercise times
	Flexible exercise times
Health care premium reduction	No discount
	€50 discount
	€150 discount
	€450 discount

Survey Format and Scenario Development

Patients were offered 15 choice sets consisting of 2 telemedicine treatment scenarios and 1 opt-out scenario. They were asked to choose their preferred scenario. The scenarios comprised short statements based on the treatment attributes described earlier. Figure 1 represents a questionnaire example. The choice questions were designed to mimic the “real” choices, and as such, the opt-out option was included to ensure that the patients were not forced to make a choice between treatments when they might choose neither in practice. The attributes and levels in this study (4 attributes with 4 levels and 2 attributes with 2 levels) resulted in a total of 1024 hypothetical treatment scenarios. For practical reasons, not all of these could be presented to each respondent. Hence, we employed a commonly used D-optimal experimental design algorithm, which reduced the number of choice sets to the smallest number of choice sets required to generate statistically efficient preference estimates for the treatment attributes included. This resulted in a so-called fractional factorial design, using 3 versions of the questionnaire, which explored 45 choice sets in total. The resulting questionnaire design was orthogonal and balanced in terms of the number of times each level of an attribute was seen in a scenario. Subjects were randomly assigned to a questionnaire version. Sawtooth software (Sawtooth Software Inc) was used to design the choice tasks. Prior to choosing between treatment scenarios, all attribute levels were described to the patients.

Figure 1. Questionnaire example.



Survey Administration

Patients in this study were recruited from a waiting list of a rehabilitation center. These patients were waiting to enroll in a group-based supervised exercise program, which was part of the multidisciplinary pain rehabilitation program. In total, 300 questionnaires were administered per mail. Questionnaires were sent to patients' home along with their invitation for a physician-led interview at the clinic. They were asked to return the completed questionnaire during the interview. Subjects were included if they were 18 years or older. Respondents did not receive incentives.

Consistency Tests

In addition to the 15 choice sets, 3 fixed choice sets that were not included in analysis were presented to test patients' response consistency and assess the internal validity of the stated-preference data. Validity was tested in 2 ways. The first was to include a choice set that presented a dominant scenario to assess whether patients chose the treatment scenario with the best treatment attributes. In this choice set, all treatment attributes of both scenarios were kept the same, except for WTA. Second, 2 choice sets were included that presented identical scenarios in reversed-order scenarios ("mirror set"). Patients who were inconsistent on both of these validity checks were excluded from the analysis.

Model Estimation

The choice between the 2 alternative scenarios and the status quo can be seen as 2 choices simultaneously: first, the patient chooses between the status quo and telemedicine treatment, and second, the patient chooses between alternatives A and B. These 2 choices may depend on each other; that is, depending on the levels of the telemedicine treatment, the preference between status quo and telemedicine may change. We only observe the choice between the 2 telemedicine treatments when the status quo is not chosen; consequently, we will have complete observations of the first choice but a selected (censored) sample for the second choice. These types of data can be analyzed with a bivariate probit model with sample selection [40]. Patients' utility for a telemedicine scenario is specified as linear in treatment attributes, and the utility of no treatment is an alternative- specific constant. Categorical test attributes were effects coded, and WTA was treated as a continuous variable. Accordingly, 2 functions were used (Textbox 1).

Textbox 1. Functions.

$$V_{treatment}=\beta_{groupgym}\times D_{groupgym}+\beta_{individualgym}\times D_{individualgym}+\beta_{individualhome}\times D_{individualhome}+\beta_{grouphome}\times D_{grouphome}+\beta_{100\%webcamera}\times D_{100\%webcamera}+\beta_{75\%webcamera}\times D_{75\%webcamera}+\beta_{25\%webcamera}\times D_{25\%webcamera}+\beta_{consultingeverysession}\times D_{consultingeverysession}+\beta_{consultingper2sessions}\times D_{consultingper2sessions}+\beta_{consultingper3sessions}\times D_{consultingper3sessions}+\beta_{FeedbackMonitoringTechnology}\times D_{FeedbackMonitoringTechnology}+\beta_{fixedsessions}\times D_{fixedsessions}+\beta_{nodiscount}\times D_{nodiscount}+\beta_{5\%discount}\times D_{5\%discount}+\beta_{15\%discount}\times D_{15\%discount}+\varepsilon_{treatment}$$

$$V_{no\text{-}treatment}=(\beta_0+\beta_{male}+\beta_{<45\ years}+\beta_{education}+\beta_{workhours}+\beta_{internet})\times D_{no\text{-}treatment}+\varepsilon_{no\text{-}treatment}$$

The $V_{treatment}$ β parameters represent relative importance weights, where larger values suggest more preferred attributes. Patient-specific characteristics are constant for any pair of treatment alternatives and cancel out the utility differences

unless they are interacted with the uptake parameter. Therefore, patient characteristics were interacted with $D_{\text{no-treatment}}$, which represents a dummy indicating that the respondents chose the "non-option." The parameters indicate the effect of patients' characteristics on telemedicine treatment uptake. The error terms $\varepsilon_{\text{treatment}}$ and variable $\varepsilon_{\text{no-treatment}}$ represent the part of the utility that is unobservable, and these error terms may be correlated with correlation ρ. The following patient characteristics were included in the final regression model: gender, age, education, Internet experience, and work hours.

The relative importance of the treatment attributes is represented by the coefficient estimates of the bivariate probit model. With these estimates, uptake of hypothetical telemedicine treatments can be predicted for different levels of incentives and other treatment attributes. For ease of presentation and interpretation, the model results were rescaled from 0 to 10 using a linear transformation of β coefficients from 0 (least desirable level) to 10 (most desirable level). Data were analyzed with heckprob function in Stata 11.2 (Statacorp).

Scenario Comparison of Telerehabilitation Treatment

As well as the individual treatment attributes, patients' preferences for 5 hypothetical telerehabilitation treatments were explored. These scenarios represented a continuum of health care settings ranging from clinic-based rehabilitation to home-based telerehabilitation with a focus on patient self-management and less physician involvement. All 5 scenarios were considered realistic treatment scenarios from a clinical perspective. One scenario represented conventional clinic-based rehabilitation. The conventional treatment consists of a supervised group-based exercise program at the rehabilitation clinic. The exercise program is part of a multidisciplinary pain rehabilitation program. In every session, exercises are supervised face-to-face by a rehabilitation physician. This conventional scenario was used to determine how patients valued the 5 telerehabilitation scenarios relative to conventional care. This was estimated with a willingness to accept value that represented a health care premium reduction in euros.

Results

Overview

We received 130 surveys that resulted in a total of 1950 observations from choice sets, with 13 observations missing. Patients who failed to pass both the validity checks were excluded from the analysis, which resulted in 104 usable questionnaires and a total of 1547 observations. The 104 respondents were spread fairly evenly across the 3 versions, with 42, 31, and 31 patients for versions 1, 2, and 3, respectively.

Respondent Demographics

The majority of the research sample (mean age 43.8 years, SD 14.8) was female (66 out of 104) and had completed a middle-high education (51 out of 104 participants). The majority of the respondents were unemployed (69 out of 104 participants) at the time and had Internet access (97 out of 104 participants). Patients' mean visual analogue scale (VAS) pain score was 6.3 and pain complaints varied in the lower back, hip, knee, joint, and neck areas and lasted longer than 6 months (Table 2).

Relative Importance of the Treatment Attributes

The results of this study indicate that physician contact mode, feedback and monitoring technology, health care premium reduction, physician contact frequency, exercise location, and program flexibility are all significant determinants of patients' treatment preference ($P<.001$). The sign and significance of the regression coefficients (Table 3) show that respondents preferred to have all physician counseling face to face. These face-to-face consultations were preferred over consultations that were offered either entirely or partly via remote video communication. Patients were relatively indifferent as to whether they had 25% or 75% of their consultation via video communication; however, having all consultations with video camera was the least preferred option. Furthermore, patients favored the use of feedback and monitoring technology while exercising and preferred to exercise at a gym location. In addition, they preferred physician contact every session and flexible exercise sessions and favored the highest discount on their health care premium. Conversely, respondents preferred not to undergo treatment that involved video consulting and minimized physician contact, exercising individually in the home environment without feedback and monitoring technology at fixed time frames. The attribute levels are generally well ordered, except for the attribute "consulting frequency." Less frequent supervision (once per 4 exercise sessions) is preferred over more frequent supervision (once per 3 exercise sessions).

Table 2. Respondent characteristics.

Characteristics (N=104)	Mean (SD) or n (%)
Gender, n (%)	
Female	66 (63.4)
Age, years	
mean (SD)	43.8 (14.8)
max, min	79, 20
VAS pain score	
mean (SD)	6.3 (1.7)
max, min	10, 2.1
Education, n (%)	
Low	6 (5.8)
Middle	50 (48.1)
High	48 (46.2)
Employment, n (%)	
Employed	35 (33.7)
Internet, n (%)	
Yes	97 (93.3)

Figure 2 illustrates the relative importance of the attribute levels on a standardized scale, with preference weights scaled between 0 and 1. For the most important attribute (physician contact mode), the most preferred level (100% face-to-face counseling sessions) is assigned a preference weight of 1. All other attribute levels are scaled relative to the most important attribute. Physician contact mode, the presence of feedback and monitoring technology, and exercise location were the most important attributes. The utility of moving from 100% face-to-face contact to 100% video consulting exceeded that for any other change between attribute levels. The smallest utility difference was between 25% video consulting versus 75% video consulting and €50 health care premium reduction and no health care premium reduction.

Figure 2. Relative importance of the attribute levels on a standardized scale.

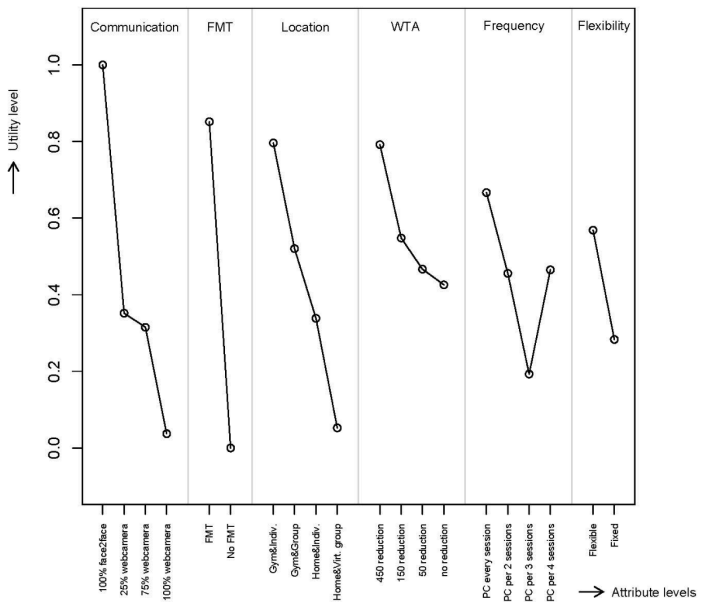


Table 3. Coefficient estimates of the bivariate probit model (N=1547).

Attribute level	Beta coefficient (standard error)	95% CI	*P* value
Treatment mode and location			
Group at gym	.05 (0.05)	–0.04 to 0.14	.29
Virtual group at home	–.20 (0.04)	–0.28 to –0.12	<.001
Individually at gym	.20 (0.04)	0.11 to 0.28	<.001
Individually at home	–.04 (0.05)	–0.14 to 0.05	.35
Consulting frequency			
Every exercise session	.13 (0.04)	0.05 to 0.21	.001
Once per 2 exercise sessions	.02 (0.04)	–0.06 to 0.09	.68
Once per 3 exercise sessions	–.13 (0.04)	–0.20 to –0.05	.002
Once per 4 exercise sessions	–.02 (0.04)	–0.10 to 0.06	.60
Consulting mode			
100% Face-to-face consults	.31 (0.04)	0.22 to 0.39	<.001
25% Video consults	–.04 (0.05)	–0.13 to 0.04	.32
75% Video consults	–.06 (0.04)	–0.13 to 0.02	.17
100% Video consults	–.21 (0.04)	–0.29 to –0.12	<.001
Feedback and monitoring technology			
Yes	.22 (0.02)	0.19 to 0.26	<.001
No	–.22 (0.02)	–0.26 to -0.19	<.001
Flexibility exercise sessions			
Fixed	–.08 (0.02)	–0.12 to -0.03	<.001
Flexible	.08 (0.02)	0.03 to 0.12	<.001
Health care premium reduction	.004 (0.001)	0.00 to 0.01	.001
Decision of treatment (no treatment=0)			
Constant	1.59 (0.15)	1.30 to 1.87	<.001
Gender	–.09 (0.10)	–0.29 to 0.12	.41
Age >45 years	–.20 (0.10)	–0.40 to -0.01	.04
Secondary education	.10 (0.13)	–0.16 to 0.36	.43
Higher education	.13 (0.13)	–0.12 to 0.37	.31
Internet	.21 (0.20)	–0.18 to 0.59	.29
Work hours	–.34 (0.10)	–0.53 to -0.15	.001

Comparison of Treatment Scenarios

Using the results of the bivariate probit model, the choice probabilities of 5 hypothetical telerehabilitation scenarios were explored (Table 4). These could be arrayed on a continuum from clinic-based rehabilitation to home-based telerehabilitation with a focus on patient self-management and less physician involvement, with scenario B as the most conventional scenario, E and F the least conventional, and C and D varying in between. Scenario A represented conventional clinic-based rehabilitation.

Table 4 shows that scenario C is preferred the most out of all treatment scenarios. This treatment scenario is considered an "intermediate" scenario that falls between conventional and telemedicine care. Patients are offered a clinical exercise environment with feedback and monitoring technology; however, face-to-face consulting with a physician is limited. Remarkably, scenario C is also the only scenario that outweighs the utility of conventional care (A). This demonstrates the willingness of patients to accept both a reduction in consulting frequency and face-to-face consulting when remote feedback and monitoring technology is offered.

Patients' preferences for the 5 hypothetical telerehabilitation scenarios revealed that scenario F is the least preferred scenario. This scenario offers therapy at home with minimal physician supervision and requires a high level of patient self-management. Furthermore, the results demonstrated that conventional rehabilitation (A) is preferred over all home-based treatment scenarios varying in levels of monitoring and physician consulting (D-F). The model suggests that a reduction in health care premiums could raise the utility of these less preferred

telerehabilitation treatments, which could increase future acceptance. For example, offering a reduction of 206.30 euros per year would make the least preferred scenario F equally attractive to conventional care. A smaller reduction (€70.70) is necessary to make scenario E equally attractive to conventional care.

Table 4. Utility of the different treatment scenarios (A-F; N=1547).

Treatment attributes	A	B	C	D	E	F
Location	Gym; group	Gym; group	Gym; individual	Home; individual	Home; virtual group	Home; virtual group
Communication	100% face-to-face	25% video	75% video	75% video	75% video	100 % video
Frequency	Every session	Every session	1×4 sessions	Every session	1×4 sessions	1×4 sessions
Feedback and monitoring technology	No	No	Yes	No	Yes	No
Flexibility	Fixed	Fixed	Fixed	Flexible	Flexible	Flexible
Health care premium reduction	None	None	None	None	None	None
Utility (SD) (Heckman)	0.18 (0.08)	–0.17 (0.08)	0.27 (0.08)	–0.42 (0.09)	–0.13 (0.08)	–0.73 (0.08)
WTA[a] necessary to reach utility scenario A (euros)	–	79.3	0	136.6	70.7	206.3

[a]WTA: willingness to accept.

Preferences for No Treatment

No treatment was preferred over treatment A or B in 136 observations, corresponding to 34 individuals who chose the "non-option." Of these, 9 individuals did so on one occasion. One individual always chose the no treatment option. The parameter estimates for the patient characteristics age (P=.04) and work hours (P=.001) interacted with no treatment and were statistically significant. Older patients were more likely to choose the opt-out option than younger patients. Second, patients having a higher number of working hours were less likely to choose the opt-out option.

Discussion

Principal Findings

Although telemedicine is assumed to be improving efficient allocation of resources, its actual success depends on the patients' acceptance and adherence. Therefore, future telemedicine services need to be designed with the patients' perspective in mind. This study explored chronic pain patients' preferences for telerehabilitation treatments using a discrete choice experiment and determined which future telerehabilitation design was preferred the most by chronic pain patients and which treatment attributes were most important to them. In addition, WTA was estimated to explore how patients valued telerehabilitation services relative to conventional rehabilitation and if they would be willing to trade health care premium discounts for more resource-efficient telerehabilitation treatments. Although DCEs are widely used in health care, this is the first study in the field of telerehabilitation estimating preferences for treatments to inform patient-centered treatment design.

Five hypothetical telerehabilitation scenarios were explored, which could be arrayed on a continuum from clinic-based rehabilitation to home-based telerehabilitation with a focus on patient self-management and minimal physician supervision. The most preferred treatment out of all 5 was an "intermediate" scenario that falls between conventional clinic-based rehabilitation and a telerehabilitation program with a focus on self-management and with no frequent face-to-face supervision. Patients preferred treatment outside the home environment, with a combination of video consultation and face-to-face consulting and the use of feedback and monitoring technology. Patients' preference for an "intermediate" scenario demonstrates patients' willingness to "trade" between treatment attributes and underscores the potential of the use of remote feedback and monitoring technology in chronic pain telerehabilitation. Patients were willing to accept less frequent physician consulting offered mainly through video communication, provided that they were offered assistance through remote feedback and monitoring technology and could exercise outside their home environment during flexible exercise hours. A key finding is that this "intermediate" scenario was preferred over conventional rehabilitation, which suggests that this scenario would make a feasible alternative to conventional care.

On the contrary, home-based telerehabilitation scenarios with minimal physician contact, provided entirely through video communication, and without the use of remote feedback and monitoring technology were preferred the least. This is an important finding, as a paradigm is emerging in which people with chronic disease are encouraged to take an active role in self-management and become actors in their own health care [41,42]. Offering remote feedback and monitoring technology as well as some physician face-to-face consulting would make home-based rehabilitation more attractive; however, it would not make these scenarios equally attractive to conventional

rehabilitation. As such, to foster patient acceptance of home-based telerehabilitation with minimal physician supervision, other incentives are necessary to make these treatment scenarios more attractive.

WTA was estimated and demonstrated that chronic pain patients were willing to trade a reduction in health care premiums for less preferred treatment attributes, for example, less face-to-face physician consulting or a home-based treatment scenario. A reduction in health care premiums would make less preferred resource-efficient telerehabilitation scenarios with a focus on patient self-management equally attractive to conventional clinic-based rehabilitation. Ultimately, even a home-based telerehabilitation scenario with minimal physician consulting, the least preferred scenario out of all 5, could become an acceptable alternative to conventional clinic-based care if health care premium reduction is offered. However, these results must be interpreted with caution. Further research is necessary to explore whether, next to health care premium reductions, other strategies such as the use of motivational tools (eg, serious gaming) could increase the value of home-based telerehabilitation treatment.

In addition to the estimation of patients' preferences for the various telerehabilitation scenarios, the importance of the individual treatment attributes was estimated. While all attributes impacted patients' treatment preference, physician contact mode proved a key driver of preference for chronic pain rehabilitation with patients having a strong preference for some physician face-to-face contact. Treatment scenarios with partly remote physician video communication were preferred over scenarios that offered remote video communication only. The psychosocial nature of chronic pain treatment could be underlying this preference. In the treatment of chronic pain especially, the patient-physician communication plays an important role, as pain must be identified as a subjective phenomenon in the discussion [43] and both empathy and emotional support are considered essential [43,44]. Although touch is not necessary to convey empathy and establish a therapeutic bond [45,46] per se, a qualitative study in chronic pain patients established that some patients associated remote physician consultation with a loss of personal attention [47]. This same feeling of loss of personal attention was also found by Mair et al [48]. A physician's inability to perform a hands-on physical examination during a remote consultation is also a cause for concern to some patients [46-49], which could also explain patients' strong preference for physician face-to-face contact. Some patients consider face-to-face supervision an essential means to provide effective feedback and instruction. Furthermore, supervision during exercise may reduce patients' insecurity and fear of exercising [50]. These findings indicate that integration of some face-to-face physician consultation is important to increase patient acceptance, which is consistent with other literature that found that attrition rates may be reduced by even minimal human contact [41]. A recent study of chronic pain patients suggests that Web-based chronic pain management intervention may be the most effective for patients with mild or moderate chronic pain who have better overall psychological and physical health. Individuals with numerous comorbidities, or spinal, neuropathic, or fibromyalgia pain, may require face-to-face contact, as this could be necessary in achieving optimal outcomes in pain management [51].

The importance that chronic pain patients place on feedback during exercise is also reflected in the value that patients place on the use of monitoring and feedback technology, which proved nearly as important as face-to-face physician contact. Strikingly, although none of the research sample had prior experience with the telemedicine technology, a factor that is associated with increased acceptance [52,53], the majority of our research sample preferred to use remote monitoring and feedback technology. Possibly, the use of the latest technology translates into "quality of care," as some patients expect that the use of remote monitoring and feedback could provide even more accurate feedback than a therapist [47]. These results suggest that the lack of experience with the technology does not impede the acceptance of telerehabilitation and that, on the contrary, the use of innovative technology can be used as a way to increase acceptance of home telerehabilitation.

Treatment location proved a third important attribute, with patients having a preference for exercising individually outside the home environment. Patients attached great value to exercise in a clinic-based setting, either individually or in a group, rather than exercising in the home environment. Apparently, the hypothesized benefits that home treatment could bring to patients, for example, reduced transportation issues and easier translation of acquired skills, do not outweigh the disadvantages perceived by our study sample. Previous research with chronic pain patients demonstrated that a clinical environment can offer a more motivating environment for the patient and it creates an opportunity to get out of the house and meet other patients [47]. In addition, feelings of intrusion could be underlying the preference to exercise outside the home, since telerehabilitation brings clinical care into the "safe haven" of the home.

Limitations

With regard to the reliability of the discrete choice experiment, some limitations of the study must be emphasized. First, the results might be limited in terms of the extent to which they could be generalized. Data were collected in a specific patient population, namely chronic pain patients waiting for their conventional rehabilitation to start. In addition, perceptions of patients who did not pass the consistency tests were disregarded. Little is known about how patients' preferences regarding telemedicine change during treatment; therefore, we do not know whether patients' possible insecurity at the start of their treatment had affected their telemedicine treatment preferences and whether this could explain why home-based telerehabilitation scenarios with a focus on self-management were preferred the least. Future studies should assess patients' preferences at different points of time during rehabilitation, since preferences are likely to change over time and telerehabilitation treatments may need to be adjusted to the altering needs of patients during treatment. We also chose to include a non-option. This created a more realistic choice experiment, but also meant that we were limited in the exploration of the effect of patient demographics on patients' preferences. Data revealed that both older patients and patients with a low education were more likely to choose the opt-out

option. This could partly be attributed to the cognitive burden, for which discrete choice experiments have been criticized. In addition, we were not able to collect demographic information on nonresponders to determine whether there were systematic differences between responders and nonresponders. Future studies should further investigate the effect of patient demographics on treatment preference.

Conclusions

A central aim of this study was to assess which treatment attributes were most important to chronic pain patients and to explore which telerehabilitation treatment was the most preferred. Physician contact mode, the use of feedback and monitoring technology, and exercise location were key drivers of patients' treatment preferences. An "intermediate" treatment scenario consisting of attributes associated with both conventional rehabilitation and telerehabilitation was the most preferred. This demonstrated that patients were willing to accept less frequent physician consultation offered mainly through video communication, provided that they were offered feedback and monitoring technology and some face-to-face consultation and could exercise outside their home environment at flexible exercise hours. As such, telerehabilitation treatments that incorporate these attributes should be pursued as promising alternatives to conventional rehabilitation. Home-based telerehabilitation treatments with minimal physician supervision were the least preferred. However, offering health care premium reductions could make these treatments as attractive as conventional clinic-based rehabilitation.

Conflicts of Interest

None declared.

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Abbreviations

DCE: discrete choice experiment
FMT: feedback and monitoring technology
WTA: willingness to accept

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Review

Remote Monitoring of Patients With Heart Failure: An Overview of Systematic Reviews

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Abstract

Background: Many systematic reviews exist on the use of remote patient monitoring (RPM) interventions to improve clinical outcomes and psychological well-being of patients with heart failure. However, research is broadly distributed from simple telephone-based to complex technology-based interventions. The scope and focus of such evidence also vary widely, creating challenges for clinicians who seek information on the effect of RPM interventions.

Objective: The aim of this study was to investigate the effects of RPM interventions on the health outcomes of patients with heart failure by synthesizing review-level evidence.

Methods: We searched PubMed, EMBASE, CINAHL (Cumulative Index to Nursing and Allied Health Literature), and the Cochrane Library from 2005 to 2015. We screened reviews based on relevance to RPM interventions using criteria developed for this overview. Independent authors screened, selected, and extracted information from systematic reviews. AMSTAR (Assessment of Multiple Systematic Reviews) was used to assess the methodological quality of individual reviews. We used standardized language to summarize results across reviews and to provide final statements about intervention effectiveness.

Results: A total of 19 systematic reviews met our inclusion criteria. Reviews consisted of RPM with diverse interventions such as telemonitoring, home telehealth, mobile phone–based monitoring, and videoconferencing. All-cause mortality and heart failure mortality were the most frequently reported outcomes, but others such as quality of life, rehospitalization, emergency department visits, and length of stay were also reported. Self-care and knowledge were less commonly identified.

Conclusions: Telemonitoring and home telehealth appear generally effective in reducing heart failure rehospitalization and mortality. Other interventions, including the use of mobile phone–based monitoring and videoconferencing, require further investigation.

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KEYWORDS

systematic review; patient monitoring; mobile phone; telemedicine; heart failure

Introduction

Prior Work

Heart failure is a complex chronic condition that presents debilitating symptoms [1]. There is a high prevalence of heart failure worldwide [2] and, despite advanced medical, pharmacological, and surgical treatment, patient outcomes are poor and hospital readmissions are high [1].

Heart failure clinical outcomes depend largely on how well people self-manage their condition between face-to-face office visits with health care providers. Hence, lack of symptom monitoring and seeking treatment when necessary, particularly between their visits, may result in hospital readmissions in this population. To avoid heart failure exacerbation, patients are encouraged to modify their lifestyle and constantly monitor symptoms related to their condition [1]. Providing patients with the tools to take an active, participatory role in their disease progression and management is important [3].

The high health care costs and poor quality associated with heart failure have led to the development of remote patient monitoring (RPM) systems and cost-effective disease management strategies. RPM uses devices to remotely collect and send data to a health care facility for diagnostic interpretation or monitoring purpose. Such applications might monitor specific vital signs, such as blood pressure, heart rate, or electrocardiogram (ECG), or a variety of indicators for housebound patients. Such systems can be used to facilitate health care by nurses who visit patients at home [4]. RPM comprises a range of noninvasive and patient monitoring approaches that could improve quality of life (QOL) of patients with heart failure who are at high risk of deterioration [5].

The current literature contains research results from numerous trials investigating the clinical, structural, behavioral, or economic effects of RPM interventions on patients with chronic diseases [6]. Recent evidence suggests that RPM component systems have beneficial effects on mortality and hospitalization of patients with heart failure [5]. However, the scope, methods of analysis, results, and quality of systematic reviews are varied and this may cause uncertainty for policy makers, health professionals, and others regarding utilization of the information from existing evidence. Investigating the effect of a wide range of RPM systems on heart failure outcomes is a key aspect in improving such technology-based interventions, but taking it in isolation fails to consider the strength, weakness, and implications for future research.

Objectives

We undertook this overview to systematically gather, evaluate, and organize the review-level evidence. The aim of this study was to report the highest level of evidence and to identify the RPM intervention that is most effective in improving the clinical outcomes of patients with heart failure. It also aimed to identify existing gaps in this area and to recommend avenues for future research.

Methods

Inclusion and Exclusion Criteria

The included records were assessed for eligibility against the study's inclusion criteria including types of reviews, participants, interventions, and outcomes.

Types of Reviews

Previous systematic reviews and meta-analyses evaluating the effects of RPM on heart failure and published in peer-reviewed journals or the Cochrane Library were considered eligible for inclusion. Key characteristics of inclusion criteria outlined by the Cochrane Collaboration [7] were used to determine the types of reviews. Depending on the method for analyzing the evidence from primary studies, systematic reviews can be classified as qualitative or narrative reviews and quantitative reviews. We included only quantitative systematic reviews. Conference proceedings, review summaries, editorials, and unpublished studies were excluded.

Types of Participants

Patients with a diagnosis of heart failure regardless of age, sex, or ethnicity were considered in this review. However, the diagnostic criteria should have been established in the included reviews using standard criteria and New York Heart Association functional classification. Reviews with mixed population were also excluded from this study.

Types of Interventions

We considered systematic reviews and meta-analyses that investigated the effectiveness of RPM interventions for patients with heart failure. These interventions applied information and communication technology (ICT) for mentoring, supporting physical or mental health, and/or monitoring of any vital signs, biometric and/or data related disease (signs and symptoms) from patients to health care providers. The systematic reviews that only investigated the effect of telediagnosis were excluded. We also excluded structured telephone support from this overview because the definition of RPM used in this overview considered structured telephone support distinctly different from RPM interventions.

Types of Outcomes

We sought data for outcomes in the following categories:

- Patient-oriented outcomes, such as knowledge and self-care, health status, and well-being
- Health service–oriented outcomes, which include rehospitalization, emergency department visits, and length of stay

Reviews were included if the primary or secondary outcomes from included studies were related to the clinical or behavioral effects of RPM on patients with heart failure. Systematic reviews and meta-analyses that investigated only the cost, feasibility, or uptake of RPM systems were excluded.

Search Methods for Identification of Studies

A comprehensive and systematic search was performed using the electronic sources PubMed, EMBASE, CINAHL

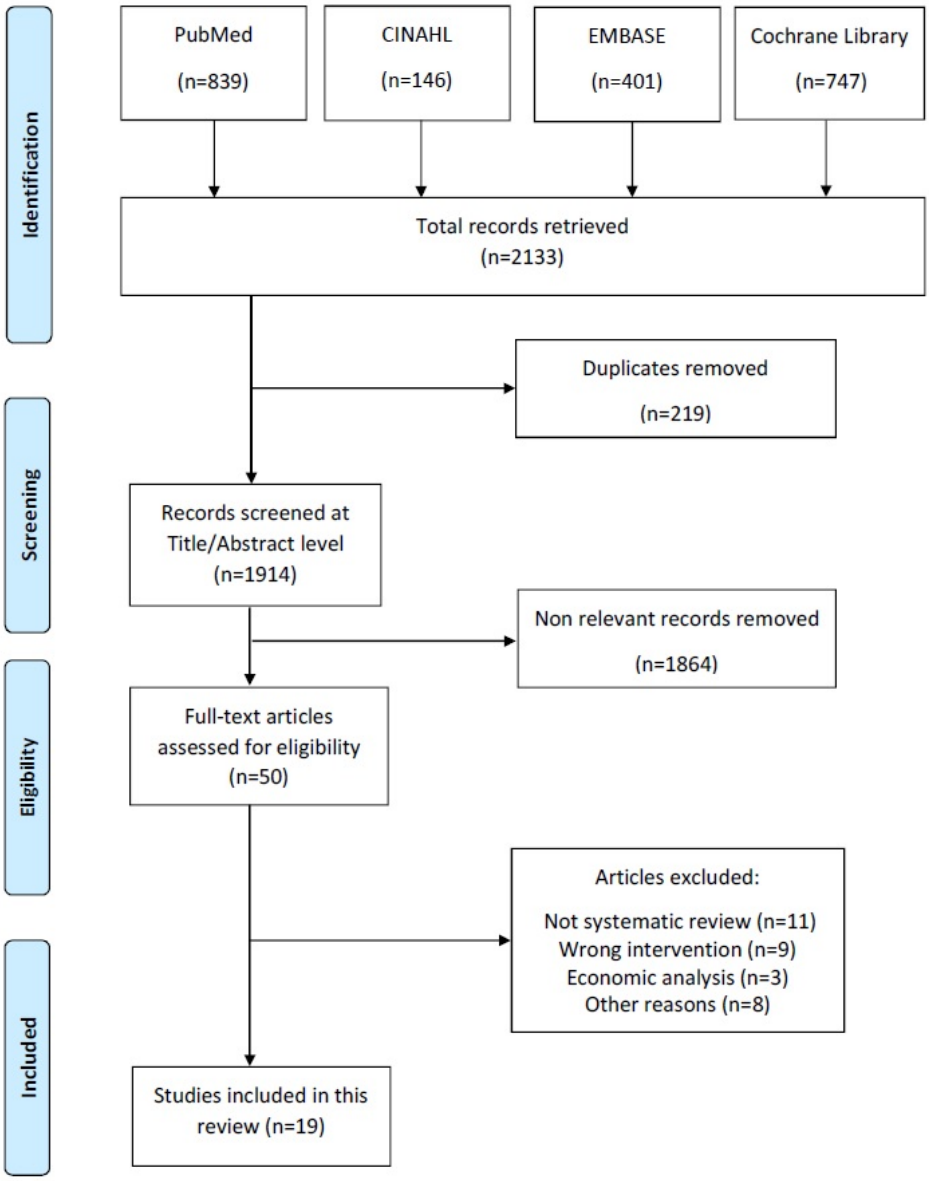
(Cumulative Index to Nursing and Allied Health Literature), and the Cochrane Library from 2005 to 2015. A sensitive search strategy was developed and refined by an experienced medical information specialist. A combination of MeSH (Medical Subject Headings) terms as well as key terms related to telemedicine, heart failure, and systematic reviews were used to search PubMed for all relevant studies. This search strategy was modified for searching the other databases according to their user guide. Details of the search strategy are presented in Multimedia Appendix 1.

Data Collection and Analysis

Selection Procedure

Studies reviewing telemonitoring, telehealth, and remote monitoring outcomes in patients with heart failure were selected by 2 independent reviewers. Records that did not clearly meet the inclusion criteria were excluded. Studies were excluded if they investigated the effects of RPM on patients with mix of chronic diseases. As shown in Figure 1, our initial search resulted in 2133 records. The reviewers read all titles and abstracts to remove duplicate studies (219). On the basis of the inclusion criteria, nonrelevant records were excluded (1864). If there was any discrepancy, the reviewers discussed the issues and reached a consensus. Because of resource limitation, reviews published in languages other than English were excluded from the analysis. A number of records (11) were excluded as they were not systematic reviews, and 20 systematic reviews were excluded because of the following reasons: wrong interventions, economic analysis, or other reasons. This yielded a final number of 19 systematic reviews included in this study.

Figure 1. Study flow diagram.



Summaries of Reviewed Systematic Reviews

To allow consistent reporting of results across reviews, we extracted and descriptively summarized each study's results using standardized language. Then we summarized and narratively reported results of the reviews to enable identification of broad conclusions within and across reviews. A table was developed to extract key characteristics of each review (Table 1). The information sought included general details related to systematic reviews (eg, authors and year of publication) and more specific details about the types of interventions, outcome variables, sample (number of included studies in each review), results, and methodological shortcomings.

Methodological Quality of Reviewed Studies

The methodological quality of included systematic reviews and meta-analyses was examined by using the Assessment of Multiple Systematic Reviews (AMSTAR) tool [27]. The tool is a validated instrument and assesses the degree to which review methods avoided bias by evaluating the methods against 11 distinct criteria. The process of scoring was performed by independent assessors. Each AMSTAR item was rated as yes (clearly done), no (clearly not done), can't answer, or not applicable, based on the published review report. A review that adequately met all of the 11 criteria was considered to be a review of the highest quality. The quality rating was as follows: AMSTAR score (out of 11 criteria) rating 8 to 11 as high quality, 4 to 7 as moderate quality, and 3 or lower as low quality.

As reported by the authors of this overview, systematic reviews included studies that ranged from high (well-designed and well-conducted studies) to low quality (studies with serious methodological limitations; Table 2). A small number of reviews were highly selective about the quality of the studies they included; for example, 3 systematic reviews [9,17,21] specified that only randomized controlled trials (RCTs) were eligible for inclusion. However, these measures did not ensure that included studies were of high quality.

Question 1: A Priori Design

Only 3 reviews [9,11,18] included in this study established inclusion criteria and a priori design before commencing with the literature search, data collection, and abstraction. The rest of the systematic reviews did not frame their research inclusion criteria and lacked a priori design.

Question 2: Duplicate Study Selection and Data Extraction

Of 19 reviews, in 10 reviews [8-11,13,14,16-18,20] the process of screening was performed by 2 independent authors. In 8 reviews the authors did not clarify this process [12,15,19,22-26].

Question 3: Comprehensive Search

The analysis of this question, which required at least two electronic sources and one supplementary strategy in order to be scored as comprehensive search, showed that all reviews used at least two electronic databases to search primary studies. The frequently used databases were MEDLINE, CINAHL, and EMBASE. Although all reviews reported the years and databases searched, only 12 reviews had comprehensive literature review based on the AMSTAR criteria [8,9,11,12,14,16,17,19-22,25].

Question 4: Inclusion of Gray Literature

Among 19 reviews included in this overview, only 5 reviews reported searching for gray literature regardless of their publication type [8,9,11,21,25]. Most reviews focused on primary studies that were published in English-language journals.

Question 5: Included and Excluded Studies Provided

Most reviews presented a list of included studies. However, only 2 reviews [19,22] reported a list of excluded studies in their article or as a supplementary material.

Question 6: Characteristics of the Included Studies

Characteristics of the original studies with respect to the participants, intervention, and outcomes were presented in 15 reviews in the form of a table or illustration [8-11,13,15,16,18-25]. A range of characteristics from primary studies such as the mean age of patients, duration of follow-up, and severity of disease was reported in the reviews.

Question 7: Quality Assessment of the Primary Studies

The methodological quality or risk of bias of primary studies included in the reviews was appraised in 10 reviews [8,9,11,12,14,18,20-22,25] out of the 19 reviews. These 10 systematic reviews provided their methods to assess included studies either using a quality scale (such as checklist with composite scores) or predefined risk of bias criteria. Furthermore, the quality of individual studies was reported in a meaningful format of a grade or score by these reviews.

Question 8: Scientific Quality of Included Studies Used Appropriately in Formulating Conclusions

Out of the 19 reviews, 7 reviews [8,9,11,14,21,22,25] formally assessed the scientific rigor of the primary studies and integrated the results of the methodological quality into the final conclusions and made recommendations for future studies.

Question 9: Appropriateness of Methods Used to Combine Studies' Findings

There were 7 reviews [8-10,13,18,19,21] that used a specific method such as chi-square test to combine the results.

Question 10: Publication Bias

The risk of publication bias was reported in 2 reviews [9,13]. As shown in Table 2, the rest of the systematic reviews did not assess publication bias.

Table 1. Characteristics of the included systematic reviews.

Author	Population (mean age, disease severity)	Type of study[a]	Intervention (length of follow-up)	Outcome variables	No. of studies (sample size)	Results	Methodological shortcomings
Kotb et al [8]	10,193 patients (mean age 44-80 years, NYHA[b] class I-IV, most II-III)	30 RCTs[c]	Telemonitoring, structured telephone support, video monitoring (6-26 months)	HF[d] mortality, all-cause hospitalization, HF hospitalization	30 (10,193)	Reduced mortality and HF hospitalization in telemonitoring and STS.	Not reported.
Inglis et al [9]	Mean age 57-78 years, NYHA class I-IV, most II-IV	25 RCTs and 5 abstracts	Telemonitoring and structured telephone support (3-15 months)	All-cause mortality, hospitalization (all-cause, HF), cost, QOL[e], and LOS[f]	30	Telemonitoring reduced all-cause mortality. Both telemonitoring and STS reduced HF hospitalizations, cost, and improved QOL.	Not reported.
Nakamura et al [10]	3337 patients (mean age 65 years, NYHA class I-IV)	13 RCTs	RPM[g] including PDAs and mobile phones	Mortality, medication management	13 (3337)	RPM significantly reduced the risk of mortality.	Types of control groups were varied among reviewed studies. Patients' medications were different among studies.
Pandor et al [11]	6561 patients, 1918 patients recently discharged (mean age 57-78 years, NYHA class I-IV, most II-IV)	20 RCTs	RPM including telemonitoring and structured telephone support (3-12 months, recently discharged patients; 6-22 months, patients with stable HF)	All-cause mortality, hospitalization (HF, all-cause), QOL, system acceptability, and LOS	20	Reduction in mortality and all-cause hospitalization in recently discharged patients, improvement in QOL.	Reviewed studies were heterogeneous in terms of monitored parameters, HF selection criteria, sample size, and follow-up duration.
Smith [12]		20 (RCTs and observational studies)	Telemonitoring and structured telephone support	Readmission to hospital for any reason	20	HF readmission reduced but evidence for all-cause readmission is inconclusive.	Studies were heterogeneous.
Xiang et al [13]	7530 patients (mean age 69 years, NYHA class I-IV, most II-IV)	33 RCTs	Telemonitoring (6-26 months)	All-cause mortality, HF hospitalization, HF-related LOS	33 (7530)	Significant reduction in all-cause mortality, HF hospitalization, HF-related LOS.	In some studies, sample was small and underpowered to detect a significant association.
Ciere et al [14]	Not reported (mean age 61-78 years, mild or moderate class of HF)	12 (11 RCTs and 1 pre-post study)	Telehealth (6-12 months)	Knowledge, efficacy, and self-care	12	Associations between telehealth and knowledge, and telehealth and self-care were mixed. TH had no effect on self-efficacy.	Limited number of studies, poor methodological quality, and mixed findings.
Radhakrishnan and Jacelon [15]	20-214	14 (12 RCTs, 8 pre-post designs, 2 quasi-experimental, and 1 pilot control)	Telehealth (1-12 months)	Self-management	14	Some level of improvement in self-care.	Studies had small sample size or low power for statistical analyses. There was a risk of recall bias.
Giamouzis et al [16]	57-710 (mean age 44-86 years, NYHA class I-IV)	12 RCTs, 2 multinational	Telemonitoring (6-26 months)	All-cause mortality, all-cause rehospitalization, cardiovascular hospitalization, ED[h] visits, bed days, days lost due to death	12 (57-710)	Mixed results.	Some studies had small sample size and, therefore, were underpowered to detect significant associations.

Author	Population (mean age, disease severity)	Type of study[a]	Intervention (length of follow-up)	Outcome variables	No. of studies (sample size)	Results	Methodological shortcomings
Clarke et al [17]	3480 (mean age range 55-85 years, NYHA class I-IV)	13 RCTs	Telemonitoring (3-15 months)	All-cause mortality, all-cause emergency hospital admission, LOS	13 (3480)	Overall reduction in all-cause mortality and HF hospital admission, no significant effects were found in all-cause emergency and hospital admission, LOS, medication adherence, or cost.	Small sample sizes, diverse control groups, interventions, and approaches in interpreting data and contacting patients.
Polisena et al [18]	3082 patients (mean age 52-75 years, NYHA class I-IV)	17 (8 RCTs and 9 observational studies)	Telemonitoring (1-12 months)	Mortality (all-cause, HF, or cardiovascular), hospitalization (HF, all-cause), ED visits (HF, all-cause), primary care or specialist visits, and home visits	17 (3082)	The number of ED visits, all-cause hospitalizations, and mortality reduced in telemonitoring group. Results related to the number of primary care or specialist visits and home visits were inconclusive.	Diverse patient population and length of follow-up, lack of proper blinding and randomization, and the wide range of home telemonitoring interventions.
Klersy et al [19]	8612 (age range 54-81 years, NYHA III-IV)	32 (20 RCTs, 12 cohort studies)	RPM (3-18 months)	Mortality, hospitalizations (all-cause, HF)	32 (8612)	The rate of mortality, hospitalizations for any cause, and hospitalizations for HF in both RCTs and cohort studies were reduced.	Not reported
Chaudhry et al [20]	Mean age 67.7 years, NYHA I-IV	9 RCTs (2 single-site and 7 multicenter)	Telephone or automated symptom monitoring	All-cause mortality, hospitalizations (all-cause, HF), event rate, and ED visits	9	Results were mixed. Telephone-based monitoring was less expensive.	High-quality trials regarding the effectiveness of automated forms of telemonitoring are scarce.
Clark et al [21]	4264 (mean age range 57-75 years, NYHA II-IV)	14 RCTs (not reported)	Telemonitoring or structured telephone support (3-16 months)	Mortality (all-cause), readmission (all-cause, HF), QOL, cost, adherence, patient acceptability	14 (4264)	QOL improved and all-cause mortality reduced. No significant effect was found on all-cause readmission and HF readmission.	Small number of trials, short-term follow-up.
Dang et al [22]	Mean age range 53.2-79 years, NYHA II-IV	9 RCTs (not reported)	Home telehealth remote monitoring (3-12 months)	All-cause mortality, readmissions (all-cause, HF), ED visits, LOS, clinic visit (scheduled, unscheduled)	9	The impact of telemonitoring on health care utilization, mortality, and cost is positive. The results for other outcome variables were mixed.	Interventions were varied in terms of technology, duration, and the process of data analysis. The patient populations were heterogeneous in terms of NYHA class, HF duration, and socioeconomic status.
Hughes and Granger [23]	Mean age 63.75 years	4 RCTs, pre-post survey	Technology-based intervention to promote self-management (30 days to 12 months)	Self-management, rehospitalization, satisfaction, QOL, and cost	4 (733)	Technology-based interventions resulted in improved outcomes related to self-management, rehospitalizations, costs, and QOL.	The number and quality of the studies are low.

Author	Population (mean age, disease severity)	Type of study[a]	Intervention (length of follow-up)	Outcome variables	No. of studies (sample size)	Results	Methodological shortcomings
Maric et al [24]	3184 (NYHA I-IV)	RCT, pre-post survey	Telemonitoring interventions (1-18 months)	Hospitalization, emergency room costs, QOL, bed days, home visits, combined events (hospital admissions, ED access/visits, mortality, left ventricular ejection fraction, and psychological moods	56	The reviewed studies showed a general trend toward improvement of outcome measures such as QOL, self-efficacy, hospitalization, and ED visits.	The majority of studies were not randomized and many had small sample sizes.
Martinez et al [25]	Mean age range 48-83 years, NYHA I-IV	RCT, descriptive, noncontrolled clinical series	Home telemonitoring (3-24 months)	Mortality, feasibility, readmissions, QOL, LOS, and cost	42	Many studies showed reduction in mortality, hospital readmissions, and length of hospital days and improved QOL.	Not reported.
Schmidt et al [26]	Not reported	19 RCTs	Telemonitoring	Mortality and rehospitalization, QOL, health-economic benefits, acceptance of home monitoring by patients, acceptance by clinicians and influence on doctor-patient relationship, significance of telemonitoring for patient compliance	19	The available scientific data on vital signs monitoring are limited, yet there is evidence for a positive effect on some clinical end points, particularly mortality. Nonetheless, any possible improvement in patient-reported outcomes, such as QOL, still remains to be demonstrated.	Not provided.

[a]Type of study: RCT, cohort study, or case study and multicenter or single-center study.

[b]NYHA: New York Heart Association.

[c]RCT: randomized controlled trial.

[d]HF: heart failure.

[e]QOL: quality of life.

[f]LOS: length of stay.

[g]RPM: remote patient monitoring.

[h]ED: emergency department.

[i]STS: structured telephone support

Question 11: Conflicts of Interest

Interestingly, 10 reviews [9-11,13,16,18,21,22,24,25] provided information related to the project's source of funding and conflict of interest. Assessing the methodological quality of included systematic reviews and meta-analyses revealed that the quality of 12 systematic reviews [8,10,11,13,14,16,18-22,25] was moderate as they were scored between 4 and 7. A total of 6 systematic reviews [12,15,17,23,24,26] had a very low quality (scored 3 and less) and only 1 systematic review was identified as highest quality (scored 10) [9]. Overall, many of the reviews displayed important limitations. For example, only 3 systematic reviews [9,11,18] had referred to their a priori design, such as a published protocol, and 2 systematic reviews [9,13] assessed the likelihood of publication bias of reviewed studies.

Table 2. Methodological quality of systematic reviews based on AMSTAR (Assessment of Multiple Systematic Reviews) scores.

Author	Q1[a]	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Total
Chaudhry et al [20]	No	Yes	Yes	No	No	Yes	Yes	No	No	No	No	4
Ciere et al [14]	No	Yes	Yes	CA[b]	No	CA	Yes	Yes	No	Yes	No	5
Clarke et al [17]	No	Yes	Yes	No	CA	No	No	No	No	No	No	2
Clark et al [21]	No	Yes	Yes	Yes	CA	Yes	No	No	Yes	No	Yes	6
Dang et al [22]	No	CA	Yes	No	Yes	Yes	Yes	Yes	No	No	Yes	6
Giamouzis et al [16]	No	Yes	Yes	No	No	Yes	No	No	No	CA	Yes	4
Hughes and Granger [23]	No	No	No	No	No	Yes	No	No	No	No	CA	1
Inglis et al [9]	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	10
Klersy et al [19]	No	No	Yes	No	Yes	Yes	No	No	Yes	No	No	4
Kotb et al [8]	No	Yes	Yes	Yes	CA	Yes	Yes	Yes	Yes	No	No	7
Maric et al [24]	No	No	No	No	No	Yes	No	No	No	No	Yes	2
Martinez et al [25]	No	No	Yes	Yes	No	Yes	Yes	Yes	CA	No	Yes	6
Nakamura et al [10]	CA	Yes	No	No	No	Yes	No	No	Yes	No	Yes	4
Pandor et al [11]	Yes	No	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes	7
Polisena et al [18]	Yes	Yes	No	No	No	Yes	Yes	No	Yes	No	Yes	6
Radhakrishnan and Jacelon [15]	No	No	No	CA	No	Yes	No	No	No	No	No	1
Schmidt et al [26]	No	No	No	No	No	No	No	No	No	No	No	0
Smith [12]	No	No	Yes	No	No	No	Yes	No	No	No	No	2
Xiang et al [13]	No	Yes	No	No	No	Yes	CA	No	Yes	Yes	No	4

[a]Q: question.

[b]CA: can't answer.

Table 3. Taxonomy of interventions and examples of outcomes reported.

Intervention	Example of outcome
Telemonitoring	Mortality, hospitalization (all-cause, HF[a]), QOL[b], length of stay, emergency department visits
Home telehealth	Mortality, hospitalization (all-cause, HF), QOL, self-care, knowledge
Mobile phone	Self-management, QOL, cost
Video monitoring	Mortality, HF hospitalization
Personal digital assistant devices	Mortality

[a]HF: heart failure.

[b]QOL: quality of life.

Synthesis of Results and Rating the Evidence of Effectiveness

We applied 4 steps in developing the data integration tables based on the study by Ryan et al [28]. These were first identifying, extracting, and summarizing relevant information from each review for a comprehensive picture of the characteristics of the systematic review. Second, results for the outcomes of the review were assessed and translated to standardized statements. Third, results including RPM interventions and heart failure outcomes were mapped onto a taxonomy (Table 3) using language specific to the field of RPM interventions. Fourth, the implications of the review were assessed after the mapping step clarified the level of evidence available for each intervention. These steps were taken to assist with synthesizing and rating the evidence across systematic reviews with complex and diverse interventions [28].

Results

Types of Interventions

This overview appraised and summarized 19 systematic reviews that consisted of a broad range of RPM interventions such as telemonitoring (telemonitoring includes the collection and transmission of clinical data between a patient at a distant location and a health care provider through a remote interface

so that the provider may conduct a clinical review of such data or provide a response relating to such data) [29], home telehealth (home telehealth comprises remote health care delivery or monitoring between a health care professional and a patient outside of clinical settings, in their home or assisted living residence) [29], and integration of electronic transfer of physiological data via mobile phones, wearable electronic devices, or implantable electronic devices. Table 1 provides a summary of the reviews' characteristics that focused on RPM in heart failure outcomes. Studies were published from 2006 to 2015 and consisted of a minimum of 4 [23] and a maximum of 56 original studies [24] with the methodology of RCT, cohort studies, and/or pre-post studies. The follow-up period ranged from 1 to 26 months.

Table 4 shows that 13 systematic reviews investigated the effect of telemonitoring and home telehealth. Among these, 4 reviews [9,11,12,21] investigated the effect of structured telephone support but as mentioned earlier, the results related to structured telephone support excluded from this review. One systematic review included 3 RCTs that examined the effect of videoconferencing and compared the intervention with usual care or telephone support [8]. One RCT and 1 pre-post study cited by 2 systematic reviews [10,23] examined mobile phone interventions. In 1 systematic review [10], 11 RCTs investigated the effect of PDAs. The devices used in those RCTs were widely varied. A total of 4 systematic reviews investigated the effect of home telehealth on heart failure clinical outcomes.

Table 4. Interventions' effectiveness.

Intervention category	Types of interventions	Examples of interventions	Reviews mapped to this category	Statements of effectiveness
Telemonitoring	14 SRs[a] examined the effect of telemedicine including telemonitoring and home telehealth. Among these, there were 4 reviews that also investigated the effect of structured telephone support.	Telephone-based symptom monitoring, automated monitoring of signs and symptoms, automated physiological monitoring (such as body weight, heart rate, arterial blood pressure, ECG[b] recordings), and other data.	[8,9,11-13,16-21,23,24,26]	There is sufficient evidence that telemonitoring interventions have an effect on clinical outcomes of HF[c] including a reduction in mortality, HF hospitalization, and all-cause hospitalization and improvement in QOL[d].
Video monitoring	One SR covering 3 RCTs[e] that implemented videoconferencing as main intervention and compared it with usual care or telephone support.	Monitoring patients' body weight, blood pressure, heart rate, and/or ECG. Some systems also included consultations.	[8]	There is not enough evidence to support conclusions about the effect of video monitoring on HF outcomes as the number of trials is small.
Mobile phone monitoring	Two SRs including 1 RCT and 1 pre-post study examined mobile phone–based interventions.	Monitoring body weight, blood pressure, heart rate, or ECG. Patient consultation.	[10,23]	Based on this review, there is insufficient evidence to determine the effect of mobile phone–based monitoring on HF clinical outcomes.
PDA devices	One SR of 11 RCTs investigated the effect of PDA devices. The devices used in those RCTs were varied.	Monitoring body weight, blood pressure, heart rate, or ECG. Patient consultation.	[10]	There is some evidence that the use of PDA devices is effective in reducing HF mortality. There is not enough evidence to make decisions about the effect of PDA interventions on the other clinical outcomes of HF.
Home telehealth	Four SRs investigated the effect of home telehealth on the clinical outcomes of HF.	Monitoring vital signs and/or ECG, individualized education, medication reminder.	[14,15,22,25]	Based on the results of this review there is some level of evidence from trials that home telehealth has an effect on HF clinical outcomes such as mortality, health care utilization, and QOL.

[a]SR: systematic review.

[b]ECG: electrocardiogram.

[c]HF: heart failure.

[d]QOL: quality of life.

[e]RCT: randomized controlled trial.

Population

Among 19 reviews, 16 reviews [8-11,13,14,16-25] reported the mean or range of participants' age and/or New York Heart Association heart failure classification. The highest reported mean age was 86 years [16] and the lowest was 44 years [16]. Of the reviews, 10 systematic reviews [8-11,13,16-18,20,25] documented the New York Heart Association classes I-IV, 2 systematic reviews reported classes II-IV [21,22], 1 systematic review reported classes III-IV [19], and 1 systematic review described participants as having a mild or moderate class of heart failure [14]. The rest of the reviews did not report heart

failure classification (Table 1). One systematic review investigated studies focused on patients with heart failure following discharge after a recent episode of hospitalization [11].

Effect of Interventions or Clinical Outcomes

Statements related to intervention effectiveness were determined using the evidence rating scheme for each review and summarized within each intervention category (Table 4). Out of 19 systematic reviews, 9 reviews showed a reduction in all-cause mortality [8-11,13,16,17,20,21] and 5 reviews showed a reduction in all-cause hospitalizations [11,18,19,23,25]. A total of 6 reviews reported a reduction in heart failure hospitalization [8,11,17,20-22], 2 reviews reported a reduction in length of hospital stay [9,11], and 1 systematic review reported a reduction in emergency department visits [18]. Improvement of QOL was reported in 3 reviews [11,21,23] and self-care in 1 review [15].

Telemonitoring has been shown to reduce mortality (risk ratio, RR, 0.66, 95% CI 0.54-0.81, P<.001) [9]. Also, 24 hours telemonitorirng over 7 days (hazard ratio 0.76, 95% CI 0.49-1.18), and telemonitoring during office hours (hazard ratio 0.62, 95% credible interval 0.42-0.89) [11], (risk ratio 0.77, 95% CI= 0.61-0.97, P ≥.01) [21], (odds ratio 0.53,CI 0.36-0.80) [8] has reduced the rate of HF mortality. The significant effect of telemonitoring on health care utilization was also reported in several systematic reviews (risk ratio 0.72, 95% CI 0.61-0.85) [13], (odds ratio 0.64, 95% CI 0.39-0.95) [8], (risk ratio 0.79, 95% CI 0.67-0.94, P>.001) [21], (RR 0.93, 95% CI 0.87-0.99, P ≥.01) [19].

Discussion

Principal Findings

This overview reports evidence from 19 unique systematic reviews that have synthesized trials and other studies evaluating the effects of RPM interventions on heart failure outcomes. Information on a wide range of outcomes was sought. The most commonly measured and reported outcomes were mortality [9,11,17,20,21] and heart failure rehospitalization [9,17-20], but many others (Table 5) reported and helped to inform RPM outcomes [15-17,19]. Limitations in the quality of the systematic reviews included in this overview (Table 2) demonstrate that there is a lack of high-quality evidence of RPM interventions. This could be due to the fact that several of the articles were not designed and structured as systematic reviews based on validated assessment tools such as AMSTAR.

The results of this overview demonstrate that telemonitoring has beneficial effects on clinical outcomes of heart failure, including a reduction in mortality, heart failure hospitalization, and all-cause hospitalization and an improvement in QOL [8,9,12,14,16-18,20,21,24]. It can be concluded that key elements of telemonitoring including physiological monitoring of blood pressure, heart rate, weight, and ECG must form an integral part of the routine care of patients with heart failure.

Although the number and quality of systematic reviews that examined the impact of home telehealth interventions on heart failure outcomes were limited, the collected evidence suggests that home telehealth interventions have positive effects of reduced health care utilization [25] and improved QOL [15]. However, these interventions do not appear to have any effect on knowledge and self-care [19].

Despite recent advances in telecommunications technology that have facilitated clinical use of videoconferencing, the results of this overview (Table 4) suggest that there is a lack of evidence to support the effectiveness of mobile phone–based monitoring and video monitoring. This may be due to the limited number of studies investigating the effects of these interventions on patients with heart failure [8,13,23]. Although mobile phone–based monitoring and videoconferencing have not shown to be as effective as telemonitoring in improving heart failure outcomes, these are accessible, convenient, and widely acceptable to patients [30,31]. Furthermore, mobile phones have the capacity to assist patients to receive feedback from and communicate with health care professionals. With the high penetration of mobile phones in most countries and rapid advancement of the wireless network, these interventions have the potential to be incorporated into highly interactive ICT-based platforms to deliver health care and disease self-management programs [31].

This overview has a number of strengths including a comprehensive search strategy, duplicate screening, data extraction, and the use of a validated instrument (AMSTAR) to assess the methodological quality of included reviews. Mapping the evidence using the validated assessment tool and synthesizing the results of included systematic reviews, rather than reporting results of individual primary studies, helped us to differentiate between outcomes where there was sufficient evidence related to the heart failure RPM interventions and identify the gap in the evidence.

There are a number of limitations that must be kept in mind when interpreting the results of this overview. This overview only reported articles published in English. In addition, the information related to the RPM interventions and their outcomes has not been retrieved from primary studies; therefore, the results of this overview are limited by the data reported in the systematic reviews. Furthermore, all systematic reviews are prone to publication bias and, therefore, such bias may have been transferred to our overview. There is also a possibility that individual studies were included in more than one systematic review; therefore, double counting is inevitable and this may affect the results [32].

Considering the lack of high-quality reviews in the current literature, we recommend that more robust methods are utilized in conducting and reporting systematic reviews. This will lead to less evidence but higher quality and, therefore, result in a well-organized field of literature that is more interpretable by researchers.

Table 5. Clinical outcomes reported by the systematic reviews.

Author	Clinical outcome[a]											
	1	2	3	4	5	6	7	8	9	10	11	12
Kotb et al [8]		Yes	Yes	Yes								
Inglis et al [9]	Yes			Yes		Yes				Yes		Yes
Nakamura et al [10]	Yes								Yes			
Pandor et al [11]	Yes		Yes	Yes		Yes				Yes		
Smith [12]			Yes								Yes	
Xiang et al [13]	Yes			Yes						Yes		
Ciere et al [14]							Yes	Yes				
Radhakrishnan and Jacelon [15]								Yes				
Giamouzis et al [16]	Yes		Yes	Yes	Yes					Yes		
Clarke et al [17]	Yes				Yes				Yes	Yes		Yes
Polisena et al [18]	Yes	Yes	Yes	Yes	Yes							
Klersy et al [19]	Yes		Yes	Yes								
Maric et al [24]												
Chaudhry et al [20]	Yes		Yes	Yes								
Clark et al [21]	Yes		Yes	Yes		Yes						Yes
Dang et al [22]	Yes		Yes	Yes	Yes	Yes				Yes	Yes	Yes
Hughes and Granger [23]						Yes					Yes	Yes
Martinez et al [25]	Yes					Yes				Yes		Yes
Schmidt et al [26]	Yes		Yes			Yes						

[a]Clinical outcomes: 1, all-cause mortality; 2, heart failure mortality; 3, all-cause hospitalizations; 4, heart failure–related hospitalizations; 5, emergency department visits; 6, quality of life; 7, knowledge; 8, self-care; 9, medication adherence or medication management; 10, length of stay; 11, readmission; 12, costs.

Implications for Practice

The overview of systematic reviews demonstrates telemonitoring to be effective in reducing mortality and rehospitalization of patients with heart failure [8,9,12,14,16-18,20,21,24]. This required key elements of telemonitoring such as monitoring of blood pressure, heart rate, weight, and ECG. Health care professionals who seek a more rigorous and stronger RPM intervention that is evidenced to improve clinical outcomes of patients with heart failure may adopt telemedicine key elements. Additionally, the intervention taxonomy may assist health care providers to identify a range of interventions available in relation to specific outcomes.

Implications for Research

Despite the evidence of effectiveness that resulted from the studies included in this overview, many areas of uncertainty remain, and interventions using mobile phone and video monitoring require further rigorous assessment [8,10,23]. Rapid advances and the ubiquitous availability of mobile phones have created new perspectives on ICT-based health care delivery systems [31]. Although the current evidence is not sufficient to support the effect of mobile phone and video monitoring on heart failure mortality or health care utilization, it is evident that their uptake and adherence is high [30,31]. This is because these interventions can be delivered anywhere at any time and for extended periods and consequently facilitate regular communication and behavioral maintenance. Lack of sufficient information in the current evidence indicates a clear need for further high-quality research on mobile phone–based and videoconferencing interventions. Hence, we recommend further investigation of the effects of these interventions in future. There is also a need to determine the intensity and duration of telemonitoring and home telehealth interventions.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy.

[PDF File (Adobe PDF File), 45KB - jmir_v19i1e18_app1.pdf]

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Abbreviations

AMSTAR: Assessment of Multiple Systematic Reviews
CINAHL: Cumulative Index to Nursing and Allied Health Literature
ECG: electrocardiogram
ICT: information and communication technology
QOL: quality of life
RCT: randomized controlled trial
RPM: remote patient monitoring

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Original Paper

Developing Nutrition Label Reading Skills: A Web-Based Practice Approach

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Abstract

Background: Nutrition labels offer the information needed to follow Dietary Guidelines for Americans, yet many individuals use labels infrequently or ineffectively due to limited comprehension and the effort required to use them.

Objective: The objective of our study was to develop and test a Web-based label-reading training tool to improve individuals' ability to use labels to select more healthful foods. We were particularly interested in determining whether practice can lead to increased accuracy using labels as well as decreased effort, together reflecting greater efficiency. We compared a basic and an enhanced, prior-knowledge version of the tool that contained an additional component, a brief nutrition tutorial.

Methods: Participants were 140 college students with an average age of 20.7 (SD 2.1) years and education 14.6 (SD 1.2) years, who completed 3 sets of practice that were designed to teach them, through repetition and feedback, how to use nutrition labels to select more healthful products. Prior to training, participants in the prior-knowledge group viewed a multimedia nutrition presentation, which those in the basic group did not receive. Mixed-effects models tested for improvement in accuracy and speed with practice, and whether improvements varied by group.

Results: The training led to significant increases in average accuracy across the 3 practice sets (averaging 79% [19/24 questions], 92% [22/24], 96% [23/24] respectively, $P<.001$), as well as decreases in time to complete with mean (SD) values of 8.7 (2.8), 4.6 (1.8), and 4.1 (1.7) seconds, respectively. In block 3, the odds of a correct answer for the prior-knowledge group were 79% higher (odds ratio, OR=1.79, 95% CI 1.1-2.9) than those for the basic group ($P=.02$). There was no significant difference between the groups in block 2 ($P=.89$).

Conclusions: Practice led to improvements in nutrition label reading skills that are indicative of early stages of automatic processing. To the extent that automatic processes are at the core of healthy habit change, this may be an efficient way to improve dietary decision-making.

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KEYWORDS

nutrition labeling; dietary habits; automatic information processing; food selection; choice behavior

Introduction

The Dietary Guidelines for Americans are designed to support eating patterns that promote health and reduce the risk of diet-related chronic diseases [1,2]. The guidelines also call for manufacturers to include the Nutrition Facts panel (ie, nutrition label) on food labels to help individuals make informed choices. Deciding which foods are healthy when shopping for oneself

or one's family can be a daunting task, particularly when simultaneously factoring in price and convenience. Thus, it is not surprising that grocery shopping is considered to be the least enjoyable (tied with house cleaning) of 28 daily activities [3]. Although nutrition labels can facilitate decision-making, many individuals do not use nutrition labels effectively or at all [4-6]. Underutilization may be due to a lack of understanding of the information as well as an unwillingness to invest the time to understand them, which renders labels too effortful to use [7,8]. For example, individuals often have difficulty understanding the numerical information [9] and what amounts constitute a meaningful difference in calories or other nutrients when comparing products [10]. These challenges can lead individuals to avoid using nutrition labels.

Although many agree that more work is needed to increase education related to label use [5,6,11], there is no clear consensus on teaching individuals how to use nutrition labels, resulting in a wide range of approaches. Label reading tasks have been incorporated into a larger set of nutrition education goals in face-to-face delivery mode [12,13]. Using a randomized pretest-posttest design, for example, older women (n=98) with diabetes completed a series (10) of weekly sessions on nutrition, some of which included demonstrations on how to compare food labels [14]. The intervention led to increases in nutrition knowledge, self-efficacy, and label reading accuracy. Another approach has been to focus more directly on label reading. For example, researchers conducted a pretest-posttest intervention on food label reading across 9 weeks (n=43 women) and found greater gains on label reading outcomes in the intervention than in the control group [13]. In a single training session, consumers (n=19) attended a 2-hour lecture at a grocery store, followed by reading label practice [15]. The results showed improvements in self-reported knowledge and confidence using labels; however, improvements in label reading abilities were not reported. However, other studies using a small-group format within a single training session have reported improvements in label comprehension [16,17]. Evidence linking label reading training with dietary intake is scarce, but a 10- to 15-minute training session on how to read nutrition labels was insufficient to affect sodium intake 3 months later (label reading ability was not assessed) [18].

In addition to face-to-face nutrition interventions, there has been a rapid increase in the number of Web-based interventions [19], which have the advantage of delivering relatively low-cost, interactive nutrition interventions to a large number of consumers [19-21].

Some evidence suggests that individuals value Web-based educational tools as a way to guide food choices in the long run [22]. Web-based programs have shown success in improving the understanding of nutrition as well as dietary quality [19,23], even though they do not consistently surpass other methods [24,25]. However, we are aware of only a few studies that have examined label reading skills [26,27]. In one study that compared face-to-face and Web-based training, researchers taught participants 3 nutrition topics, 1 of which was label reading [26]. The results showed that participants in the face-to-face training showed greater improvements in label reading accuracy than those in the Web-based training. However, for the other 2 topics, both delivery formats improved nutrition-related behaviors to the same extent. Specific details surrounding the nature of label reading activities (eg, focus and process) were not provided; however, the researchers suggested that label reading may be relatively more difficult and therefore participants may benefit more from in-person education delivery [26]. In this study, we examined the impact of a Web-based label reading tool to increase label reading accuracy and decrease time to read labels. The tool was specifically designed to promote skill acquisition [28] through deliberate practice [29] and to promote efficiency, that is, increase accuracy and reduce time due to greater automaticity. Automatic processes are desirable because they are relatively fast and effortless compared with more controlled processes [30,31] and can be developed through intense practice, or repetition [29,32,33] using tasks that provide meaningful content and feedback [34].

We examined a basic version of the training as well as an enhanced version that provided prior nutrition information, in the form of self-paced slides. Past work has shown that prior knowledge supports the acquisition of new knowledge and skills [35], and correlational studies have shown associations between prior nutrition knowledge and label comprehension [36]. Thus, participants were assigned to the basic group or an enhanced, prior-knowledge group to determine whether label reading accuracy increased, and time to read labels decreased, with practice and whether prior knowledge affected practice effects.

Methods

Recruitment

Participants were 140 college students with an average age of 20.7 (SD 2.1) years and education 14.6 (SD 1.2) years, who were enrolled in 1 of 2 consecutive quarters of an introductory psychology course. Recruitment occurred through a Web-based portal that listed the following eligibility criteria: ability to read from a computer screen and use a computer mouse, and English language fluency. To balance the number of participants within groups, assignment occurred through a Web-based system by alternating between the 2 conditions at sign-up, with the first participant each quarter randomly assigned to a group. Ethical approval was obtained from the Institutional Review Board at the University of California, Davis.

Measures of Demographics and Prior Food Label Experience

Participants completed a demographic survey, followed by measures assessing prior food label experience including self-reported food label use and nutrition label numeracy. Self-reported food label use was assessed using the question: "I'd like you to think about the labels on many food products that list ingredients and provide nutrition and other information. When you buy a product for the first time, how often do you read this information?" [37]. Responses were made on a scale of 1 (never) to 5 (always). Nutrition label numeracy was assessed using multiple-choice questions (n=7) requiring participants to manipulate quantitative information, for example, "Roughly how many servings of this product would you need

to get 100% of the recommended daily value of iron?" [38,39]. Scores were the total number of questions answered correctly.

Enhancement (Prior-Knowledge) Manipulation

Those in the prior-knowledge group received a 7-minute nutrition overview using PowerPoint slides that taught basic nutrition information (eg, definition of nutrients and energy, sources of nutrients, diet-health relations). Those in the basic group did not receive the nutrition overview. Both groups were then given a multiple-choice nutrition knowledge quiz (18 items), designed to assess learning from the overview for the prior-knowledge group compared with the basic group.

Nutrition Label Training Task

Two of the most common reasons for using nutrition labels are to compare foods and select healthful options [40]; however, individuals lack awareness of what constitutes an important nutrient difference between 2 products [7,10]. For example, individuals who were asked to compare 2 similar products paid attention to nutrients that differed insignificantly across the products or were not particularly salient for the food type, for example, paying attention to sodium levels in cold cereals while ignoring added sugar and fiber [10]. Thus, the task we designed to develop label-reading skills provided an opportunity to identify meaningful nutrient differences that signify relative healthfulness of a variety of foods (eg, cereals, and soups). We included to-be-limited as well as to-be-encouraged nutrients, which are often overlooked [6]. Because nutrition label reading is a complex skill, we targeted the underlying processes supporting healthfulness decisions and removed other food label components (eg, pictures of food, claims) that could potentially slow the early stages of skill acquisition.

The nutrition labels for the training task were based on actual foods from different meal types (breakfast, lunch, dinner, snacks, and beverages) and included examples of more and less healthful foods within each meal type (eg, potato chips, carrot sticks, brown rice vegetable bowl, fried fish sandwich). From these foods, we manipulated the nutrition information to create 200 pairs for the comparison task. Correct answers were operationalized in terms of large nutrient differences between pairs, referred to as *large-consistent* differences. We also manipulated small differences, which were made in the opposite direction, and thus referred to as *small-inconsistent* differences. Finally, in addition to the size of the difference, we manipulated the type of nutrient to include micronutrient only (eg, calcium), to-be-encouraged only (eg, fiber), to-be-encouraged and to-be-limited (eg, fiber and sodium), and to-be-limited only (eg, sodium) differences. In general, we expected greater accuracy for pairs with large-consistent to-be-limited nutrient differences relative to to-be-encouraged nutrient differences. On the contrary, pairs with only small-inconsistent to-be-encouraged differences would be relatively easier than the others because this information would be less likely to be used [6], and therefore less likely to mislead individuals. We included 3 introductory label tasks prior to the focused practice comparing nutrition labels. The first task described the information available on a food label (eg, the different types of nutrients, metric types). The second task (Figure 1) required participants to locate a specific piece of information on 1 of 3 areas of the food label (nutrition label, ingredient list, or front of package). The third task consisted of a set of 4 sample comparisons tasks, followed by the correct answer and answers to any follow-up questions.

The label reading training task provided practice using nutrition labels (pre-2018 format) to compare the relative healthfulness of pairs of foods. Participants completed 3 blocks, each containing 24 nutrition label comparisons, followed by feedback after each comparison (correct/incorrect) as well as their percent correct at the end of each block. For each comparison, 2 nutrition labels were presented side by side, with instructions to select the label that represented the more healthful option within the context of their daily diet (Figure 1). The location of the more healthful product was counterbalanced across the left and right sides of the screen. At the end of the training, participants rated their perceptions of the training task on a 5-point scale. The tasks were completed in roughly 60-90 minutes.

Figure 1. Samples of training materials for locate task (top) and comparison task (bottom).

Perceptions of Training

We obtained feedback from participants regarding their experience with the training tool, drawing on past research on Web-based training [41]. We assessed participants' perceptions of the label comparison task to determine whether they felt they had increased their accuracy and decreased their time to respond with practice, and whether they felt their skills would improve with more practice. We used 2 items: "Regarding nutrition label comparisons you just completed, to what extent did they help you: i) compare foods more accurately, ii) compare foods more quickly?" and responses were made on a 5-point scale: 5=very helpful; 1=not very helpful. In addition, we asked 2 questions about the entire session to assess perceptions of overall utility: "Regarding the entire session, to what extent were the tasks: i) easy to complete, ii) useful to you?" We also asked participants whether they felt they would improve their food label reading skills with additional practice. Responses were made on a 5-point scale.

Statistical Analyses

All statistical analyses were performed using SAS software version 9.4 (SAS Institute). We tested for differences between prior-knowledge and basic groups in age, food label use, numeracy, and education using the Wilcoxon rank-sum test, as well as sex and Hispanic ethnicity using the chi-square test.

Accuracy

At the comparison level (accuracy=correct or incorrect for each comparison), we fitted a mixed-effects hierarchical logistic regression model to test for the effects of prior knowledge on training improvement, controlling for sex, self-reported food label use, numeracy, and comparison type (ie, large-consistent versus small-inconsistent differences for each pair). Quarter enrolled was also included to control for possible differences between the 2 samples. We tested for interactions between training block and prior-knowledge group to test for the effects of knowledge on training improvement. We also tested for interactions between training block and comparison type to determine where the benefits of training were the most evident. Bivariate associations were also tested for each covariate using mixed-effects logistic regression models, so that both raw and adjusted odds ratios (OR) could be obtained.

Time to Complete Blocks

In addition to accuracy, we explored the amount of time individuals took to complete blocks to determine whether there was evidence for initial stages of automaticity. Block *duration* was defined as the average time to complete each block. Duration was log10-transformed to achieve normality of the residuals and analyzed using mixed-effects regression models that tested for a downward trend in duration with block. We also tested for the effects of sex, quarter enrolled, self-reported food label use, numeracy, and prior-knowledge group and its interaction with block to test for whether prior knowledge affected duration with practice. Bivariate associations were also tested for each covariate, so that both raw and adjusted effects could be assessed.

Results

Enrollment

The initial enrollment included 151 participants; 11 (8 from the prior-knowledge group and 3 from the basic group) were eliminated because their very low accuracy (at or below the chance performance level of 50%) indicated that they were unable or unwilling to follow instructions. The characteristics of the remaining 140 participants by group are shown in Table 1.

Table 1. Bivariate associations of baseline characteristics with treatment group.

Effect (units)	Estimates (SD or SE)[a]		*P* value
	Prior-knowledge (n=67)	Basic (n=73)	
Age (years)	20.5 (2.1)	20.9 (2.2)	.31
Education (years)	14.4 (1.3)	14.7 (1.2)	.18
Numeracy (number correct out of 7)	4.5 (1.9)	4.5 (2.1)	.86
Self-reported food label use (Likert scale, 1-5)	3.5 (1.1)	3.9 (1.1)	.04
Female	60% (4.4)	60% (4.6)	.92
Hispanic	16% (4.6)	16% (4.4)	.99

[a]Estimates are mean (SD) except for “Female” and “Hispanic,” which are in percent (SE).

There was a significant difference between the groups in their self-reported food label use, with those in the basic group reporting slightly higher label use than those in the prior-knowledge group. There were no significant differences in age, numeracy, or education. As a manipulation check, we examined the effects of prior-knowledge group on nutrition quiz scores to determine whether the overview of nutrition increased nutrition knowledge. There was a significant difference between groups on the nutrition quiz such that the prior-knowledge group had an average of 64% correct and the basic group had an average of 51% correct ($P<.001$). Numeracy had a significant effect on the average score ($P<.001$), but there were no significant differences in quiz score due to sex, quarter, or self-reported food label use ($P=.66$, .26, and .14, respectively).

Accuracy

The effects of predictors on accuracy (odds of answering a comparison correctly) are shown in Table 2 as univariate unadjusted and model-adjusted ORs, CIs, and *P* values. Both the adjusted and unadjusted analyses on accuracy showed that on average individuals increased markedly in their accuracy with practice. Accuracy increased on average from 79% in the first block to 92% and 96% in the second and third blocks, respectively ($P<.001$) in the bivariate association. In the full model, the interaction between prior knowledge and block was significant ($P=.02$). In block 3, the odds of a correct answer for the prior-knowledge group were 79% higher than those for the basic group ($P=.02$). There was no significant difference between the groups in block 2 ($P=.89$).

Accuracy depended on the type of comparison. As expected, accuracy was higher for pairs with to-be-limited large-consistent differences relative to other large-consistent differences (micronutrients, to-be-encouraged only, both to-be-encouraged and to-be-limited) ($P<.001$). To illustrate, in block 1, predicted accuracy was 80% for the to-be-limited large-consistent differences compared with 53% for the micronutrient large-consistent differences. On the contrary, accuracy was the lowest for the combined to-be-encouraged and to-be-limited small-inconsistent differences (relative to micronutrients or to-be-encouraged only) types ($P<.001$). For example, in block 1, participants had a predicted accuracy of only 78% for the

combined small-inconsistent differences, but 86% for the micronutrient small-inconsistent differences.

The magnitude of improvement also varied by comparison type, as reflected in significant interactions between training block and small-inconsistent differences (P<.001), and between training block and large-consistent differences (P<.001). Pairs with to-be-limited large-consistent differences showed the highest proportion of correct responses but were similar to pairs with to-be-encouraged and combined to-be-encouraged and to-be-limited differences. Accuracy for the micronutrient large-consistent differences remained significantly lower across blocks. In contrast, the pairs with micronutrient small-inconsistent differences had the highest proportion of correct responses across all blocks, while the pairs with to-be-encouraged and to-be-limited small-inconsistent differences had lower and similar levels of accuracy. Figure 2 shows average, model-adjusted accuracy differences across comparison types, by block.

Numeracy significantly predicted accuracy (P<.001), such that, for every unit increase in numeracy, the odds of a correct response increased by 11%. However, gender (P=.06), self-reported food label use (P=.40), and quarter enrolled (P=.12) all showed nonsignificant effects.

Figure 2. Model-adjusted accuracy for large-consistent (top) and small-inconsistent (bottom) nutrient differences by block. Micro=micronutrients; TBE: to be encouraged; TBL: to be limited.

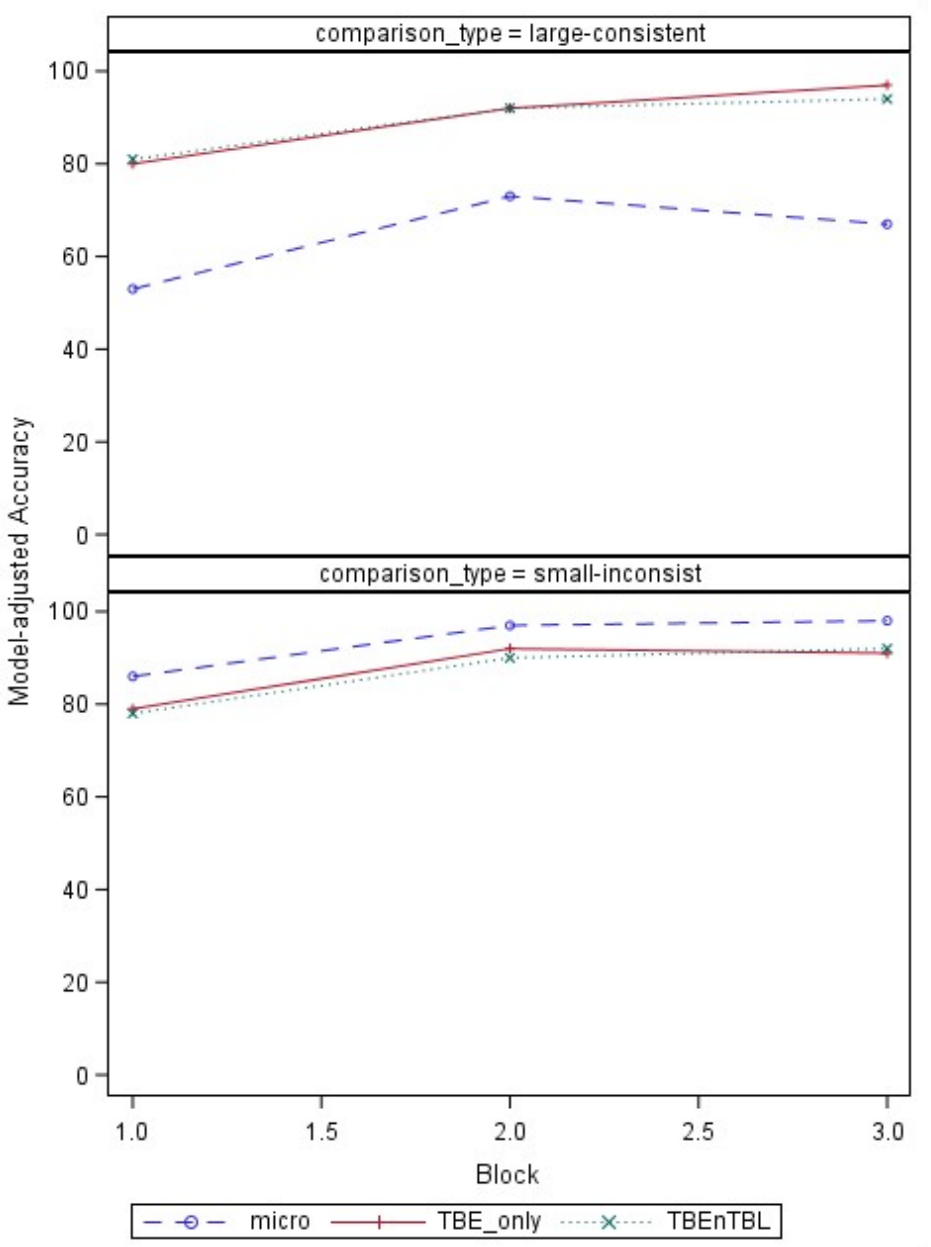

Table 2. Effects on accuracy, univariate unadjusted (raw) and adjusted.

Effect		Unadjusted (raw)			Adjusted		
		Odds ratio	95% CI	*P* value	Odds ratio	95% CI	*P* value
Manipulation							
Prior-knowledge group (reference=basic)		1.03	.77-1.4	.85	1.03	0.76-1.4	.84
Block							
3		5.74	4.7-7.1		4.2	1.6-10.9	.003
2		2.86	2.4-3.4		2.1	0.79-5.7	.14
1		1	-	<.001	1	-	-
Sm[a] inconsistent differences							
TBE[b] and TBL[c]		.30	.25-.37		.45	0.33-0.61	<.001
TBE only		.43	.32-.58		.58	0.37-0.90	.01
Micro[d]		1	-	<.001	1	-	-
Lg[e] consistent differences							
TBE and TBL		2.9	1.9-4.3		2.18	1.12-4.22	.02
TBE only		2.9	2.0-4.2		2.47	1.2-5.0	.13
TBL only		4.8	3.3-7.2		3.23	1.6-6.3	<.001
Micro		1	-	<.001	1	-	-
Interactions							
Block	*Prior-knowledge group*						
3	Knowledge				1.79	1.1-2.9	.02
2	Knowledge				.97	0.66-1.4	.89
(ref) 1	Basic				-	-	-
Block	*Sm Inconsistent*						
3	TBE and TBL				.42	0.23-0.78	.006
3	TBE only				.17	0.08-0.36	<.001
2	TBE and TBL				.60	0.33-0.93	.03
2	TBE only				.37	0.17-0.78	.009
(ref) 1	Micro				-	-	-
Block	*Lg Consistent*						
3	TBE only				4.6	2.1-10.6	<.001
3	TBL only				18.2	6.1-58.8	<.001
3	TBE and TBL				10.8	4.2-29.0	<.001
2	TBE only				1.34	0.58-3.1	.49
2	TBL only				1.80	0.78-4.7	.21
2	TBE and TBL				1.22	0.46-2.9	.67
(ref) 1	Micro				-	-	-
Participant characteristics							
Sex (ref=female)		1.4	1.04-1.9	.03	1.55	1.1-2.2	.01
Self-reported food label use		1.2	1.02-1.4	.02	1.04	0.89-1.21	.62
Numeracy		1.2	1.1-1.3	<.001	1.11	1.01-1.21	.03
Nutrition overview quiz		1.3	1.2-1.4	<.001	1.24	1.11-1.40	<.001
Quarter enrolled (ref=2nd)		1.1	.81-1.5	.52	.77	0.55-1.07	.12

[a]Sm: Small.

[b]TBL: To be limited.

[c]TBE: To be encouraged.

[d]Micro: Micronutrients.

[e]Lg: Large.

Table 3. Time (log duration) to complete blocks with practice, raw and adjusted with back-transformed (exponentiated) coefficients.

Effect (reference level)	Raw coefficient	SE	Exponentiated coefficients	*P*	Adjusted coefficients	SE	Exponentiated coefficients	*P*
Block (ref) 1	-				-			
2	–0.28	0.009	0.53	<.001	–0.28	0.01	0.52	<.001
3	–0.34	0.009	0.46	<.001	–0.34	0.01	0.46	<.001
Prior-knowledge group (control)	0.015	0.023	1.04	.53	0.015	0.024	1.04	.54
Quarter enrolled (2nd)	0.011	0.024	1.03	.63	0.028	0.027	1.07	.27
Sex (female)	0.043	0.025	1.10	.67	0.052	0.026	1.13	.04
Self-reported food label use	0.006	0.011	1.01	.61	0.006	0.012	1.01	.65
Numeracy	–0.003	0.006	0.99	.60	–0.001	0.007	1.002	.85

Time to Complete Blocks

As shown in Table 3, the speed at which individuals completed the blocks increased with practice. The mean duration of comparisons was 8.7 (SD 2.8) seconds for the first block, compared with 4.6 (SD 1.8) and 4.1 (SD 1.7) seconds for the second and third blocks (*P*<.001), respectively. Females, 6.0 (SD 3.1), took longer than males, 5.4 (SD 2.6), on average across blocks (*P*=.04). Numeracy (*P*=.85), self-reported food label use (*P*=.65), prior-knowledge group (*P*=.54), and quarter enrolled (*P*=.27) were all nonsignificant in the adjusted model.

Perceptions of the Training

Data on perceptions of training were available for only 101 of the 140 participants due to a programming error. Within this subset, the majority of respondents rated the training positively, stating that the training was helpful or very helpful in comparing foods more accurately, 77% (78/101), and more quickly, 85% (86/101). Similarly, most participants indicated that the entire session was easy or very easy to complete, 79% (80/101), and was useful or very useful, 77% (78/101). Participants also felt that they were likely or very likely to improve their food label reading skills with additional practice, 76% (77/101).

Discussion

Principal Findings

There has been a paucity of research on nutrition label skill development. Drawing on the cognitive literature [29], we developed and tested a Web-based label training tool that focused heavily on practice. Participants were asked to make repeated nutrition label comparisons (72 in all) to learn what constitutes a meaningful difference between 2 products. After each comparison, we provided accuracy feedback so individuals could track their performance and adjust their approach. The findings showed significant improvements in label reading accuracy as well as decreased time to read the labels. Despite the high number of practice trials, participants viewed the training tasks as useful and easy to complete.

Most of the past research focusing on nutrition label training has been conducted face to face. These findings generally show that training increases label reading accuracy [16,17]. Research on label reading effects on dietary intake is scant, with 1 study showing no effects of training on sodium intake; however, the training lasted 10-15 minutes and no assessments of training efficacy were reported [18]. A handful of Web-based educational studies have been conducted, but details surrounding label tasks are often not reported [26,27]. For example, Park et al [27] used interactive, self-assessment quizzes with immediate feedback as part of a Web-based nutrition intervention for college students. One quiz topic focused on label reading; however, the nature of the task and the extent of improvement were not reported.

The results of this study shed light on the components of nutrition label training that may support long-term skill development. With practice, individuals were able to identify important or large nutrient differences between the 2 products without getting distracted by misleading minor nutrient differences (ie, those pointing them toward the less healthful option). Consistent with past research suggesting that to-be-encouraged nutrients are less likely to be considered [6], large-consistent to-be-encouraged differences were harder to evaluate but small-inconsistent to-be-encouraged differences were easier to ignore (less distracting). These findings build on earlier work showing that individuals are often unable to differentiate between insignificant and meaningful differences when comparing food products [10] and extend it by showing that the type of nutrient can exacerbate this problem. Importantly, individuals were able to identify these critical differences in nutrient levels with less time, suggesting that automatic processes supported skill development. Participants' subjective experience of the training was consistent with these

objective measures as reflected in perceptions of increased accuracy and speed.

The findings surrounding the prior-knowledge manipulation were consistent with the expectation that nutrition knowledge supports label reading skills [36]. Participants who received the nutrition overview showed significantly greater improvement across blocks relative to those in the basic condition. It is important to point out, however, that the effect of prior knowledge was small relative to the improvements across blocks (ie, the main effect of practice). Nevertheless, it was significant after controlling for past experience, as reflected in self-reported food label use (frequency) and numeracy skills. The additional nutrition knowledge likely supported comprehension of the various nutrients, daily values, and in turn what constitutes large versus small differences across products. It could also be that additional nutrition information motivates individuals to try to understand and learn new nutrition information [42]. Prior knowledge did not have a similar effect on increases in speed with practice. Although this was somewhat surprising, past work has shown that prior knowledge is sometimes more closely associated with accuracy than with speed [43].

The results of this study also indicate that the effects of prior knowledge, past experience, and numeracy on skill development differ. Specifically, self-reported frequency of use had little effect on accuracy; however, food label numeracy was significantly related to accuracy. This finding is consistent with research showing that self-reported frequency of label use is not necessarily indicative of how well food labels are understood [44].

The potential for nutrition labels to communicate nutrition information is widely acknowledged, as is the need for more experimental research to determine how the potential can be actualized [45]. Training for automaticity offers another avenue to increase nutrition awareness and improve dietary decision making. Although somewhat distinct from approaches based on habit theory, which sometimes downplay the role of nutrition education and information seeking [46], there is overlap. Both habit theory and the skill development approach in this study support the role of automaticity in behavior change. For some areas of behavior, skill development and knowledge acquisition may be necessary to establish the foundation of new habits, as well as the instigation and execution of habits within the complexities of daily life [47].

Limitations and Future Directions

Although the sample size was small, it was consistent with other studies [18]. The sample was also young and well educated, making it unclear whether the findings generalize to middle-aged and older adults, and those with lower literacy and numeracy. College students are at risk of making poor dietary choices [48]; however, consumers with lower literacy and numeracy are also at risk [9] and require attention in future label training research. Another limitation was a ceiling effect on the last block, which might have prevented us from finding greater improvements on the last block. Interestingly, participants felt they would continue to improve their label reading skills if they were to continue to practice beyond the 3 blocks offered in the training session. Thus, despite the fact that performance was high, there was some understanding that skill development could continue with sustained practice. More work is needed to develop more challenging comparisons for educated consumers and examine dose-response training factors to better understand skill maintenance over time. Although we isolated the nutrition label from the rest of the package to allow individuals to focus on the most informationally dense part of the food label, the nutrition labels, future research is needed to examine nutrition label skill development as it occurs within the context of other parts of the package and in other settings (eg, Web-based or in-store grocery shopping).

Conclusions

Consumers may not bother using nutrition labels if reading them is too difficult or time-consuming [49]. The findings of this study indicate that nutrition label-reading skills can become more efficient using a scalable, Web-based tool to provide focused practice. To the extent that continued practice will build automatic and efficient processes, additional training sessions may promote habitual and effective use of nutrition labels. Additional work is needed to determine whether efficient skills are more likely to be used when selecting foods to eat, and will in turn support the initiation and maintenance of healthful food choices in the long run.

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Conflicts of Interest

None declared.

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Review

Personal Health Records: A Systematic Literature Review

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Abstract

Background: Information and communication technology (ICT) has transformed the health care field worldwide. One of the main drivers of this change is the electronic health record (EHR). However, there are still open issues and challenges because the EHR usually reflects the partial view of a health care provider without the ability for patients to control or interact with their data. Furthermore, with the growth of mobile and ubiquitous computing, the number of records regarding personal health is increasing exponentially. This movement has been characterized as the Internet of Things (IoT), including the widespread development of wearable computing technology and assorted types of health-related sensors. This leads to the need for an integrated method of storing health-related data, defined as the personal health record (PHR), which could be used by health care providers and patients. This approach could combine EHRs with data gathered from sensors or other wearable computing devices. This unified view of patients' health could be shared with providers, who may not only use previous health-related records but also expand them with data resulting from their interactions. Another PHR advantage is that patients can interact with their health data, making decisions that may positively affect their health.

Objective: This work aimed to explore the recent literature related to PHRs by defining the taxonomy and identifying challenges and open questions. In addition, this study specifically sought to identify data types, standards, profiles, goals, methods, functions, and architecture with regard to PHRs.

Methods: The method to achieve these objectives consists of using the systematic literature review approach, which is guided by research questions using the population, intervention, comparison, outcome, and context (PICOC) criteria.

Results: As a result, we reviewed more than 5000 scientific studies published in the last 10 years, selected the most significant approaches, and thoroughly surveyed the health care field related to PHRs. We developed an updated taxonomy and identified challenges, open questions, and current data types, related standards, main profiles, input strategies, goals, functions, and architectures of the PHR.

Conclusions: All of these results contribute to the achievement of a significant degree of coverage regarding the technology related to PHRs.

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KEYWORDS

personal health records; patient access to records; mobile health; electronic health records; taxonomy

Introduction

Overview

The physician-patient relationship traditionally consists of the total dependence of the patient on the physician. Physicians need to keep accurate record systems to store information about patients and use the records to make diagnoses and recommendations [1]. In this sense, one important milestone is the use of the electronic health record (EHR). Health records are collections of patient health data, and the EHR is defined as a digital repository of the health status of patients [2-4]. The EHR evolved from a number of electronic methods of storing patients' health data that became a structured and interoperable approach [5,6]. However, EHRs have some limitations because their records are based entirely on data reported by health care providers [3]. One trend is allowing patients to have access to their own health data, making them the owner of such data [7,8]. Therefore, personal health records (PHRs) emerged from the EHR and are defined as health records related to patient care that are controlled by the patient [6,9]. The PHR can also be defined as a representation of the health information, wellness, and development of a person [10]. The main advantages of the PHR refer to the ability of patients to maintain data on their health. However, many challenges need to be overcome to promote widespread PHR adoption, including how to achieve interoperability using the EHR, implementation costs, privacy, security, and the assessment of the effective benefits that the patient may have [1].

PHRs allow patients to maintain information on their medical conditions, drugs, and behaviors related to self-care and self-monitoring of their health [11]. Nevertheless, access controlled by the patients represents an ever-present concern because it requires a free but safe balance between system customizations, privacy, and security controls [12]. In particular, without the application of security practices, no privacy is available for the data [13-15]. Another possibility is that the PHRs accept data obtained from health-related equipment, such as accelerometers, gyroscopes, wireless scales, wristbands, and smartwatches. The proliferation of these technologies is called the Internet of Things (IoT) [16,17]. Among IoT application domains, health care is one of the most attractive, giving rise to many health-related devices [18]. Data collected from these objects can complement the PHRs and help detect risks to the patients' health [16]. Nonetheless, existing PHRs have limited intelligence and can only inform a small subset of users' health care needs [19]. In addition, processing PHR data automatically and combining data from sensors with stored records for transformation into useful knowledge is another challenge [20].

The PHR works as a platform for patients' and health care providers' use, enabling the exchange of information with health care systems [21]. PHR has also emerged as a mechanism for patients to make appointments with their health care providers. The aim is to address patients' evolving needs by using specific methods to improve their care and foresee health issues. The technologies used to process health-related data include machine learning, pattern recognition, applied mathematics, statistics, expert systems, data sharing, and artificial intelligence algorithms [22-24]. Moreover, advances in information and communication technology (ICT) have allowed both the storage and easy access of large amounts of data, allowing the release of physical space, facilitating research and the correlation of data within hospitals. However, the increasing number of patients who need care, especially with the increased life expectancy of people in several countries, has been an obstacle to managing huge databases of medical records.

The health community is constantly facing global epidemics and issues that transcend countries, such as cancer, influenza, AIDS, diabetes, and obesity. Patients who migrate or travel from one country to another could make use of their own PHR to obtain faster and more efficient health services. With the increase in the adoption of wireless technology and mobile devices, this creates opportunities to deliver health care services to patients through a world-standard PHR, although many challenges remain in achieving these benefits [25].

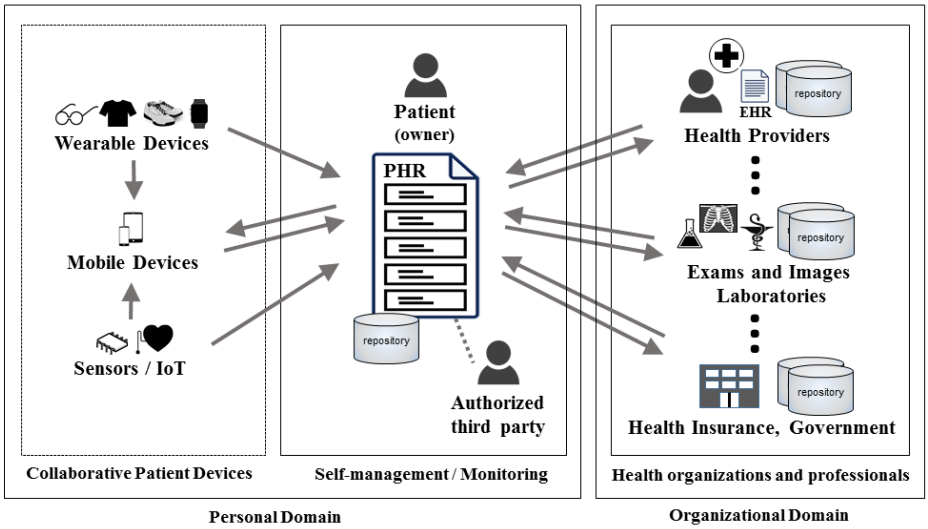
Electronic Health Records

The EHR, also called the electronic medical record, refers to a structure in digital format of patients' health data that is maintained throughout their life and is stored accurately in a repository [2]. Health care providers use EHRs, whose data can vary greatly and can include vital signs (such as body temperature, pulse, respiration, and blood pressure), age, weight, medications, allergies, medical examination results, and radiology images that are used to diagnose conditions [2,4]. The EHR is used to support health care professionals and health organizations (eg, hospitals, laboratories, or clinics) for the improved management of patient health data [26]. However, these health records are usually not stored with the same structure in different health organizations. These factors hinder the interoperability of health information among hospitals, clinics, and laboratories [27]. To address some of these problems, the PHR concept was proposed in 2006 [6] and was defined as an ISO (International Organization for Standardization) standard (ISO/TR 14292) in 2012 [10].

Personal Health Records

The PHR refers to a representation of health records related to the care of a patient that is managed by the patient [6]. In other words, the PHR refers to archives containing health data about each patient, but, unlike the EHR, it is managed by the patient [1,10]. With a PHR, patients can choose to share their health data with health care providers or keep them private [6]. Figure 1 illustrates how the PHR and EHR differ in their goals, although they can be integrated to exchange information that is relevant to the patient's health [10].

Figure 1. Personal health record (PHR) and electronic health record (EHR) relationships. IoT: Internet of Things.



Multiple EHRs for the same patient can coexist, but only one PHR would exist. The PHR can integrate data from many sources, ranging from devices connected to the patient to health data from EHRs stored in health care provider systems [6].

Although the term PHR may refer to records regardless of format (and can be on paper), the records are implemented electronically and are accessible through mobile devices (mHealth). In this sense, PHRs have allowed patients to self-monitor and manage their own health conditions [23]. Another alternative is medical-oriented PHR, which includes features that are not patient-centered [11,28]. This PHR can be "tethered" (tied) to where the data subsets are provided, including organizations that maintain patient data electronically [6]. In this case, PHRs may be stored in a stand-alone computer or service portal to which only the user has access [29].

Some variant names for PHR appeared in the literature, such as ePHR (electronic PHR) [7] or UHR (universal health record) [30]. The first concept refers to the use of PHR in an electronic format, while the second proposes PHR-sharing data with health care providers. Another term is intelligent PHR (iPHR), which uses medical knowledge to anticipate the health needs of patients and promote tools to guide searches for diseases and recommendations for nursing activities or medical products [19]. Although these different nomenclatures are used, we use the term PHR throughout this work.

To identify the technology for the PHR and to discuss the main open issues, this work surveyed the main contributions of the scientific community over the last decade. The purpose was to review the PHR literature and describe the existing models. As a way of mapping this scenario, we used the systematic literature review methodology to choose the studies [31-33]. As a result, we propose an updated and wide taxonomy for PHRs and indicate further directions for study.

Methods

Study Design

This section focuses on describing the study protocol, which introduces the adopted procedures and outlines the main subsequent decisions. As previously mentioned, this study presents a systematic literature review designed to provide a wide overview of the PHR research area, establish whether research evidence exists on a topic, and provide quantitative evidence [31,34]. We selected this type of literature review approach because our goal was to summarize the technology regarding PHRs and identify promising directions, which do not require an in-depth analysis and synthesis. With this in mind, we followed widely recognized empirical guidelines [31,34] to plan and run systematic mapping studies. Moreover, to mitigate threats to validity, we followed the well-documented study protocol available in the studies by Biolchini et al [35] and Qiu et al [36].

The presented systematic literature review method was carried out by defining the following activities:

1. Research questions—introduce the research questions investigated;

2. Search strategy—outline the strategy and libraries explored to collect data;

3. Article selection—explain the criteria for selecting the studies;

4. Distribution of studies—present how studies are distributed chronologically;

5. Quality assessment—describe the quality assessment of the selected studies;

6. Data extraction—compare the selected studies and research questions.

The following sections describe how this process of mapping the study was carried out.

Research Questions

According to Kitchenham and Charters [31] and Petticrew and Roberts [34], the definition of research questions is the most important part of any systematic review. Therefore, we seek to identify and classify the technology related to PHRs; the features, problems, challenges, and solutions that are currently being considered; and the research opportunities that exist or are emerging. In this sense, we have defined general and specific

research questions. The general research questions have been refined into more specific questions to better provide a thorough classification and thematic analysis, as well as to pinpoint promising research directions for further investigation. Our research questions are classified into two categories: general question (GQ) and specific question (SQ). Table 1 lists all the research questions investigated.

The GQ group of research questions concerns a broader classification and some challenges concerning PHRs. GQ1 refers to the question of classifying and defining the taxonomy for PHRs. This research question focuses on the interoperability capacity that a PHR can have. This question highlights integration issues of a PHR that is created and maintained by systems that are developed using heterogeneous technologies. GQ2 refers to the key challenges and issues in using PHRs. This is the main factor that will serve as a direct influence in the PHR survey. The purpose is to identify the types of issues that have been raised in the literature in the last decade. The research focuses on identifying the main problems affecting the spread of PHR adoption by patients and health care providers. For this question, we are able to reason with regard to the issues and factors that consequently influence PHR adoption.

With the general research questions, we have also explored some derived specific research questions (SQ group) to improve the study filtering process. These questions have been proposed to pinpoint questions surrounding the adoption of the PHR. SQ1 seeks to identify the data types that a PHR can contain. SQ2 investigates the types and profiles of users who interact with a PHR. SQ3 examines the types of standards that are used in PHR implementations. SQ4 seeks to show the interaction types that a patient has with a PHR. SQ5 concentrates on evaluating the techniques or methods used to input data into a PHR. SQ6 investigates the purposes of a PHR. Finally, SQ7 concentrates on the types and models of PHR architecture.

Table 1. Research questions.

Group and identifier	Issue
General questions (GQ)	
GQ1	How would the taxonomy for PHR[a] classification appear?
GQ2	What are the challenges and open questions related to PHRs?
Specific questions (SQ)	
SQ1	What are the data types that are included in a PHR?
SQ2	What are the standards that apply to PHRs?
SQ3	What are the user types and profiles that interact with a PHR?
SQ4	What are the interaction types of a patient with a PHR?
SQ5	Which are the techniques or methods used to input information into a PHR?
SQ6	What are the goals of a PHR?
SQ7	What are the types or models of architecture of PHRs?

[a]PHR: personal health record.

Search Strategy

The next step was to find a complete set of studies related to the research questions. This process involved the designation of *search keywords* and the *definition of search scope* [34]. In the *construction of search keywords* phase, we defined keywords to obtain accurate search results. In their report, Kitchenham and Charters [31] suggest breaking down the research question into individual facets as research units, where their synonyms, acronyms, abbreviations, and alternative spellings are all included and combined by Boolean operators. In addition, Petticrew and Roberts [34] propose the PICOC (population, intervention, comparison, outcome, and context) criteria, which can be seen as guidelines to properly define such research units.

In focusing on defining the PHR technology, we defined broader PICOC criteria based on the general research questions. Our goal was to refine and answer the specific research questions, which are derived from the general research questions with a restricted focus. Therefore, under the PHR scenarios, we defined the PICOC criteria as follows.

Population

The populations involve keywords, related terms, variants, or the same meaning for the technologies and standards on PHRs. Therefore, the following search string in Textbox 1 was defined for the selection.

Intervention

We used the following terms to better filter studies in line with the purposes: health data, health services monitoring and reporting, patient monitoring devices, remote health monitoring, and mobile health care devices.

Comparison

This case refers to the comparison of different architecture types and models of implementation of the PHR. In addition, we compared the different PHR types regarding coverage and localization.

Outcome

The outcomes related to factors of importance to practitioners (eg, improved reliability) and, in particular, to the patient. With respect to PHRs, this might refer to reducing the cost of collecting data, improving health information quality, anticipating potential problems, and allowing the patients to interact with their health data.

Context

In this regard, we analyzed the context of PHR information coverage in terms of content such as standardization, information grouping, and security and privacy in the relationships between patients and health care providers.

Hence, the final keyword set is displayed in Textbox 2.

Textbox 1. Search string. PHR: personal health record; PHA: personal health application; PHM: personal health management; PHI: private health information.

((("personal" or "patient" or "private") and ("health") and ("record" or "application" or "management" or "information")) or ("patient" and ("access" or "portal")) or ("PHR" or "PHA" or "PHM" or "PHI"))

Textbox 2. Final keyword set.

Keywords = PICOC = Population AND Intervention AND Comparison AND Outcome AND Context

In the *definition of search scope* phase, the source studies were obtained from selected electronic databases by searching using the constructed research keywords.

Article Selection

Once we found all the related articles, we proceeded to remove the studies that were not as relevant and kept only those that were the most representative. Therefore, we removed the studies that did not address PHR specifically. To apply the exclusion criteria, we used the terms of population and intervention criteria as follows:

- Exclusion criterion 1: article does not address PHR or related acronyms (population criterion I).
- Exclusion criterion 2: article does not address "health data" or "health services" (intervention criterion II).

The steps of the filtering process are as follows: (1) impurity removal, (2) filter by title and abstract, (3) removal of duplicates, and (4) filter by full text.

First, the impurities of the search results were removed. Some impurities, for example, the names of conferences correlated to the search keywords, were included in the search results because of the characteristics of the different electronic databases.

Second, we analyzed the title and abstract of the articles and excluded those that did not address PHR as a subject.

Third, all the remaining studies were grouped and the duplicates were removed because some studies were in more than one database.

Some studies remained that were not particularly related to this survey. We analyzed the full text to remove those that were not relevant.

Quality Assessment

Since it is important and essential to assess the quality of the selected studies, the quality criterion is intended to verify that the article is really a relevant study [31]. We evaluated the selected articles with regard to the purpose of research, contextualization, literature review, related work, methodology, the results obtained, and the conclusion in accordance with objectives and indication of future studies. For this purpose, the quality was evaluated according to Table 2, where the questions to which the articles were submitted to validate that these studies met the quality criteria are listed.

Data Extraction

We also developed an evaluation form for the selected articles in order to gather information about the studies and the sections where we found answers to general and specific research questions, which are presented in Table 3. This table shows each item of the study related to the research question, allowing us to assess and extract details of the articles and understand how the studies have addressed the issues related to the proposed research questions. The aim was to direct the survey to specific points that would answer the research questions.

Table 2. Quality assessment criteria.

Identifier	Issue
C1	Does the article clearly show the purpose of the research?
C2	Does the article adequately describe the literature review, background, or context?
C3	Does the article present the related work with regard to the main contribution?
C4	Does the article have an architecture proposal or research methodology described?
C5	Does the article have research results?
C6	Does the article present a conclusion related to the research objectives?
C7	Does the article recommend future works, improvements, or further studies?

Table 3. Review articles related to the research questions.

Section	Description	Research questions
Open content		
Title	Title of the scientific article	GQ1[a], GQ2, SQ1[b], SQ2, SQ7
Abstract	Summary of paper's purpose, method, and results	GQ1, GQ2, SQ1, SQ2, SQ7
Keywords	Words representing the text content	GQ1, GQ2, SQ1, SQ2, SQ7
Article content		
Introduction	Introduction specifies the issue to be addressed	All questions
Background	Section includes concepts and is related to the proposal	All questions
Method	Presents and describes the scientific methodology	All questions
Results	Performs an evaluation according to the proposed methodology	All questions
Discussion	Data that were quantified compared with the literature	GQ2, SQ2-SQ7
Conclusion	Findings related to the objectives and hypotheses	GQ2, SQ2-SQ7

[a]GQ: general question.

[b]SQ: specific question.

Results

Recruitment

In this section, we present the results obtained from the 48 fully assessed studies related to the research topic. We seek to answer each proposed research question in the following subsections through elaborative information synthesis. As a result, aside from answering the research questions, we have also proposed contributions in the PHR field from the study of related works, which are an updated taxonomy and an updated vision about main challenges and issues, as well as an updated survey about data types, standards, user types, profiles, and input techniques.

Conducting the Search Strategy

To cover as many related studies as possible, we selected 12 electronic databases as our search scope, which are listed in Multimedia Appendix 1. These portals cover the most relevant journals and conferences within the computer science and health care field. In Multimedia Appendix 2, we present the publishers or organization editors and the respective publications of the selected studies. Duplicated results produced from different databases were excluded by manual filtering in the study selection. To limit our search, we set the years to range from 2006 to 2016.

Proceeding With Article Selection

The selection process is summarized in Figure 2, which shows the filtering process.

We found 5528 articles in the initial search before applying the exclusion criteria; of these, 3237 (58.55%) articles were identified as impurities. We applied the first exclusion criterion to the studies that remained after we withdrew these articles. Continuing the process, 1429/2291 (62.37%) articles were filtered through a title review, and 453/862 (52.5%) articles were filtered through abstract analysis. We grouped the studies that remained, and 205/409 (50.1%) articles were identified as duplicates and were removed. After this stage, exclusion criterion 2 was applied to the full text and only 97/204 (47.5%) remained.

When analyzing the 97 candidate articles in the list, we noticed that some of these studies were from the same author or research group and were similar in many respects. Some of these articles had been more recent or were even more complete versions but they remained essentially the same methods and techniques. For articles that were repeated, the most representative article was selected. Thus, 49 (50%, 49/97) articles were excluded at this stage. Finally, 48 articles were selected as the baseline for the study. An overview of all primary studies is presented in Table 4 with the identifier, reference, publication year, publisher, and type, which are sorted in ascending order by publication year.

Table 4. List of articles.

Identifier	Study, year	Publisher	Type
A01	Bricon-Souf and Newman, 2006 [37]	Elsevier	Journal
A02	Tang et al, 2006 [6]	Oxford[a]	Journal
A03	Frost and Massagli, 2008 [38]	JMIR[b]	Journal
A04	Kaelber et al, 2008 [39]	Oxford	Journal
A05	Huda et al, 2009 [40]	IEEE[c]	Conference
A06	Kim et al, 2009 [41]	JMIR	Journal
A07	Brennan et al, 2010 [3]	Elsevier	Journal
A08	Castillo et al, 2010 [5]	BioMed[d]	Journal
A09	Horan et al, 2010 [23]	JMIR	Journal
A10	Hudson and Cohen, 2010 [22]	IEEE	Conference
A11	Jones et al, 2010 [42]	MLA[e]	Journal
A12	Nazi et al, 2010 [43]	Springer	Journal
A13	Patel et al, 2010 [44]	Elsevier	Journal
A14	Reti et al, 2010 [45]	Oxford	Journal
A15	Wen et al, 2010 [46]	JMIR	Journal
A16	Williams, 2010 [47]	ACM[f]	Conference
A17	Wynia and Dunn, 2010 [7]	Wiley	Journal
A18	Archer et al, 2011 [29]	Oxford	Journal
A19	Baird et al, 2011 [1]	ACM	Conference
A20	Caligtan and Dykes, 2011 [26]	Elsevier	Conference
A21	Lafky and Horan, 2011 [14]	SAGE	Journal
A22	Liu et al, 2011 [48]	ACM	Conference
A23	Siek et al, 2011 [49]	Springer	Journal
A24	Zulman et al, 2011 [50]	ACP[g]	Journal
A25	Carrión Señor et al, 2012 [51]	JMIR	Journal
A26	Emani et al, 2012 [52]	JMIR	Journal
A27	Fuji et al, 2012 [11]	Springer	Journal
A28	Kharrazi et al, 2012 [53]	Elsevier	Journal
A29	Luo et al, 2012 [19]	Springer	Journal
A30	Steele et al, 2012 [54]	Wiley	Journal
A31	Sunyaev and Chornyi, 2012 [55]	ACM	Journal
A32	Agarwal et al, 2013 [56]	JMIR	Journal
A33	Li et al, 2013 [13]	IEEE	Journal
A34	Nazi, 2013 [57]	JMIR	Journal
A35	Woods et al, 2013 [58]	JMIR	Journal
A36	Ancker et al, 2014 [59]	Springer	Journal
A37	Bouri and Ravi, 2014 [60]	JMIR	Journal
A38	Cahill et al, 2014 [21]	Springer	Journal
A39	Chrischilles et al, 2014 [61]	Oxford	Journal
A40	Ozok et al, 2014 [15]	Elsevier	Journal
A41	Spil and Klein, 2014 [62]	IEEE	Conference

Identifier	Study, year	Publisher	Type
A42	Wells et al, 2014 [25]	Oxford	Journal
A43	Czaja et al, 2015 [63]	SAGE	Journal
A44	Liu et al, 2015 [12]	Elsevier	Journal
A45	Price et al, 2015 [64]	BioMed	Journal
A46	Spil and Klein, 2015 [9]	Elsevier	Journal
A47	Sujansky and Kunz, 2015 [65]	Springer	Journal
A48	Ford et al, 2016 [66]	JMIR	Journal

[a]Oxford: Oxford University Press.

[b]JMIR: JMIR Publications.

[c]IEEE: Institute of Electrical and Electronics Engineers.

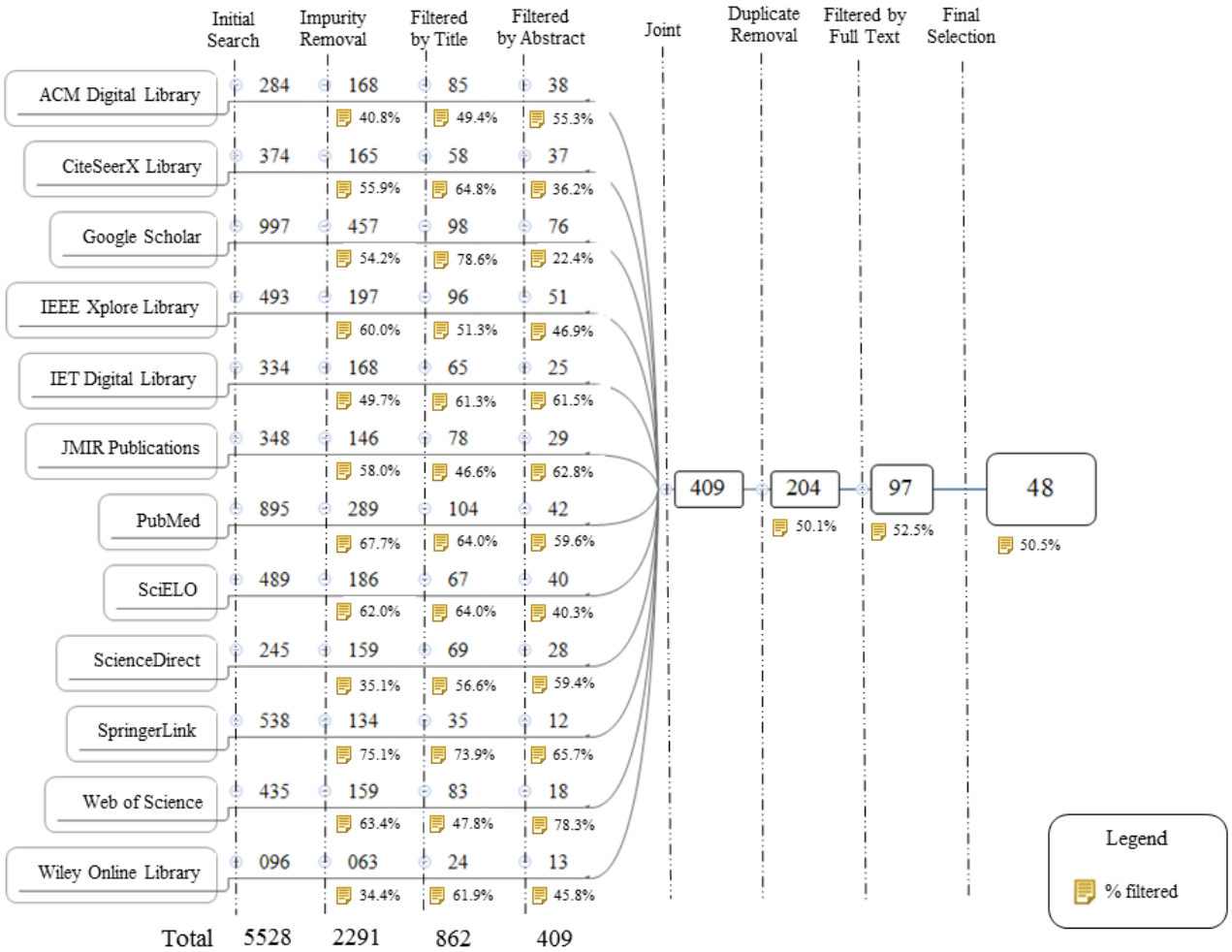
[d]BioMed: BioMed Central.

[e]MLA: Medical Library Association.

[f]ACM: Association for Computing Machinery.

[g]ACP: American College of Physicians.

Figure 2. Systematic mapping study—article selection. SciELO: Scientific Electronic Library Online.



In Figure 3, we present the evolution of the selected publications over the years, ranging from 2006 to 2016. The studies were analyzed according to the main objectives, as seen in the figure legend, where the articles were divided into the groups "Structures," "Architectures," and "Functions." Above each year, the number of articles published in that year is shown. Each item label includes the publisher of the work, and the journal and conference articles are distinguished by the box format.

Performing the Quality Assessment

In Figure 4, we present the quality criteria score of the articles based on the quality assessment criteria proposed in Table 2.

The quality criteria score each article obtained is shown on the vertical axis and the studies themselves on the horizontal axis, from 1 to 48. Upon analysis, most articles met all the criteria for evaluation, responding positively to at least 6 out of 7 quality assessment criteria. For instance, several articles do not comment on or cite possible future studies in general because they are conclusive articles, with a conclusion on its assessment.

Figure 3. Publication chronology. The numbers above years indicate the number of articles published. Oxford: Oxford University Press; JMIR: JMIR Publications; IEEE: Institute of Electrical and Electronics Engineers; BioMed: BioMed Central; MLA: Medical Library Association; ACM: Association for Computing Machinery; ACP: American College of Physicians.

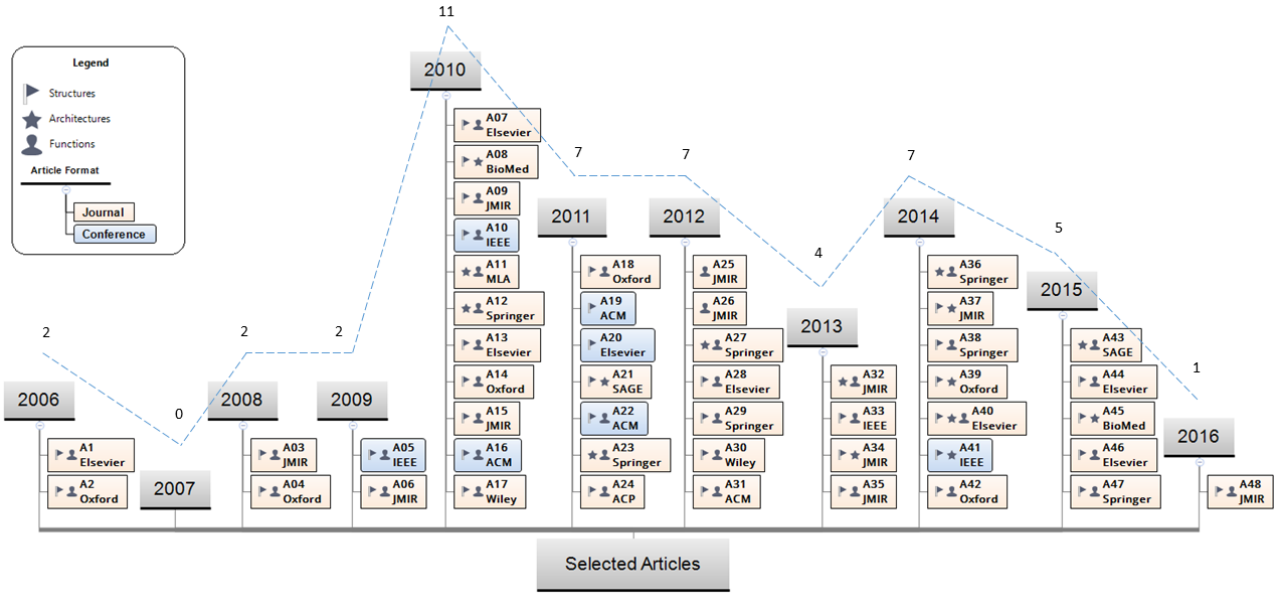
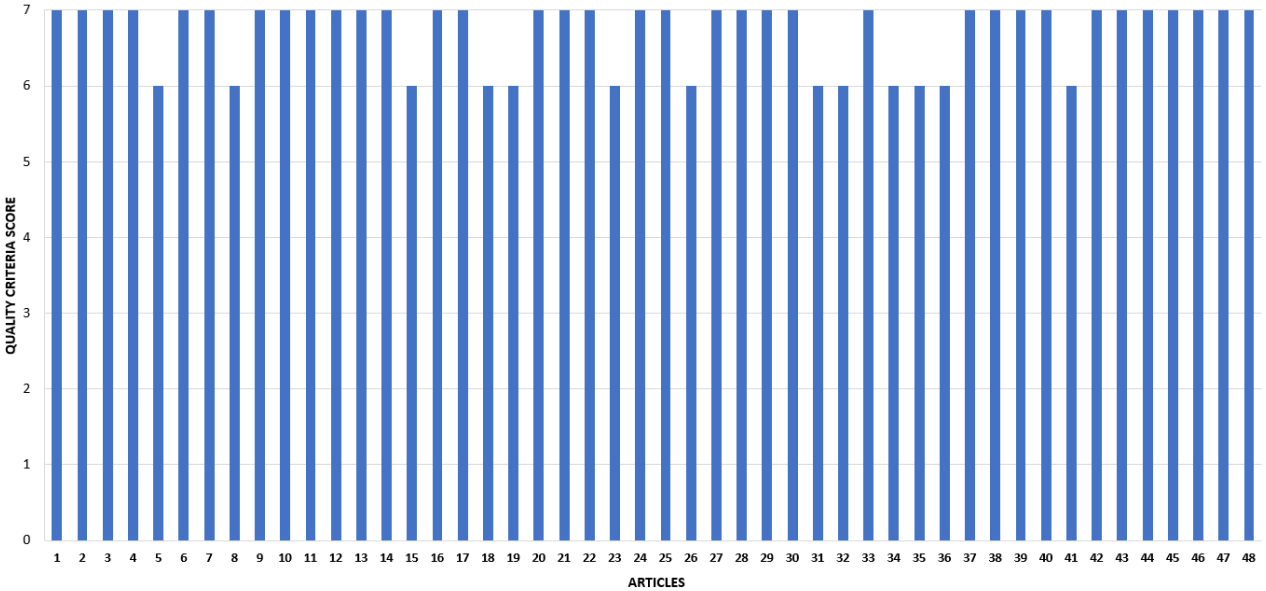


Figure 4. Quality assessment of the articles.



Data Extraction and Answers to the Research Questions

Finally, to address the *general research questions*, we have identified the following.

GQ1: How Would the Taxonomy for PHR Classification Appear?

We identified studies that investigated a number of current issues that were addressed in the PHR field. Therefore, we managed to build the proposed taxonomy to gather and organize the various possibilities for PHRs. By analyzing the selected articles and seeking to answer this general research question,

we propose a taxonomy for PHR based on important characteristics of the models, and we believe that this taxonomy could help to classify, compare, and evaluate different PHR types. Moreover, this classification can provide an overview of possible alternatives in terms of aims, content, and architectures. The proposed taxonomy for the PHR classification is summarized in Table 5, which is broadly divided into three groups: (1) Structures, (2) Functions, and (3) Architectures. Beside each item in Table 5 is a brief description of each classification. The specific research questions (SQ1 to SQ7) are included in the taxonomy, which was developed through analysis of the selected articles.

GQ2: What Are the Challenges and Open Questions Related to PHRs?

To answer this question, we listed and identified challenges, open questions, aspects, issues, and common concerns in the adoption of PHR among the analyzed studies. These aspects were collected and are presented in Table 6. As seen, the content is split to group some of the common characteristics of challenges and concerns (GCC, group of challenges and concerns) related to collaboration and communication (GCC1), privacy, security, and trust (GCC2), infrastructure (GCC3), and integration (GCC4). The subject matter that is most commonly cited is separated by item, with the identifiers ranging from CC01 to CC15.

Table 5. Personal health record taxonomy.

Group and item	Description
Structures	Main data types and standards used in health records
Data types	Data types found in PHRs[a] (see subsection SQ1[b])
Standards	Standards to which PHRs can adhere (see subsection SQ2)
Functions	Depicts the main goals and features present in the PHRs
Users profiles	User types and profiles that interact (see subsection SQ3)
Interaction	Patient's interaction types with a PHR (see subsection SQ4)
Data source	Techniques for input of information (see subsection SQ5)
Goals	Represents the aim of the PHR (see subsection SQ6)
Architectures	Architecture types and scopes (see subsection SQ7)
Models	Describes the main architecture models
Coverage	Has a physical location division for data

[a]PHR: personal health record

[b]SQ: specific question

Table 6. Personal health record challenges and concerns.

Group and identifier	Challenge and concern	Reference articles
GCC1[a]: collaboration and communication		
CC01[b]	Context-aware computing	A01, A41
CC02	Wearable computing, IoT[c]	A01, A28
CC03	AI[d] applied to health	A01, A10, A16
CC04	Personalization, usability, familiarity, comfort	A02, A07, A19, A22, A29, A40, A42, A45
CC05	Manage medications	A23, A29
CC06	Patient-generated data	A22, A42, A44, A45, A47
GCC2: privacy, security, and trust		
CC07	Confidentiality and integrity	A07, A08, A19, A29, A42, A45, A46
CC08	Data repository ownership	A13, A16, A19, A45, A47
CC09	Authorization and access control technologies	A02, A07, A11, A16, A21, A22, A31, A40, A42
CC10	Secure transport protocol	A16, A22, A42, A47
GCC3: infrastructure		
CC11	Portability—devices, equipment, hardware	A11, A18, A21, A23, A24, A28, A30, A42, A43, A44
CC12	Efficiency and scalability	A01, A40, A41, A44, A45, A46
GCC4: integration		
CC13	Patterns in collecting medical data	A13, A17, A42, A47
CC14	Terminology	A22, A29
CC15	Interoperability	A13, A16, A21

[a]GCC: group of challenges and concerns.

[b]CC: challenge and concern.

[c]IoT: Internet of Things.

[d]AI: artificial intelligence.

In GCC1 group, there are challenges and issues related to collaboration and communication, ranging from data types to be stored and made available in the PHR to policy barriers to limit the provided information type. Some articles mention the PHR data that are available according to the context awareness, such as CC01, and some articles discuss wearable computing and IoT, such as CC02. Other articles examine artificial intelligence that is applied to the health sector in CC03. The customization, usability, familiarity, and comfort when using the PHR is the subject matter of several articles in CC04, and the management of medications contained in the PHR is reviewed in CC05. The GCC2 group presents issues related to privacy, security, and reliability that are presented in PHRs: CC07 addresses confidentiality and integrity issues. CC08 refers to data repositories and their owners. CC09 examines access control technologies. CC10 includes a discussion on data transport protocols. The GCC3 group treats issues related to the infrastructure of PHRs, in which CC11 discusses the portability of devices and equipment used with a PHR. In CC12, issues on the efficient construction of computer systems and the scalability of the infrastructure used to support PHR solutions are discussed. Finally, in the GCC4 group, concerns about integration are examined, such as in CC13, which concerns patterns in collecting medical data. CC14 presents concerns about the terminology used to collect and store PHRs. Additionally, CC15 addresses issues about interoperability.

Regarding the *specific research questions*, we have identified the following:

SQ1: What Are the Data Types That Are Included in a PHR?

To answer this research question, we analyzed all selected studies that involved research of the data types used in PHRs, which are summarized in Table 7. Through the analysis of proposals and references in selected articles, we were able to obtain an updated set of data types related to PHRs. The data types ranged from information cited in many studies, such as those on allergies, immunizations, and medications, to types that are not frequently mentioned, such as genetic information and home monitoring data.

Table 7. Personal health record data types.

Type	Description	Reference articles
Allergies	Allergies and adverse reactions	A02, A12, A16, A18, A20, A25, A28, A30, A35, A39, A40, A41, A46
Demographic	Patient statistics and clinical data	A03, A20, A35, A39, A40, A43
Documents	Attached files (photos, scanned documents)	A07, A20, A28
Evolution	Progress and clinic notes, care plan	A07, A14, A18, A34
Family history	Family medical history	A02, A12, A16, A18, A20, A25, A28, A37
General	Patient registration information, emergency contact	A03, A12, A16, A18, A28
Genetic	Genetic information	A16, A25
Home monitor	Home-monitored data	A02, A18, A25
Immunizations	Immunization records (vaccine), tracking immunizations	A02, A09, A12, A16, A18, A19, A20, A25, A28, A30, A32, A37
Insurance	Insurance plan information, coding for billing	A16, A18, A28
Laboratory results	Laboratory and imaging test results (laboratory tests)	A02, A12, A14, A16, A18, A19, A20, A25, A28, A32, A35, A43
Major illnesses	List of major diseases	A03, A02, A12, A18, A25
Medications	Medication list prescribed, past medicines taken	A02, A07, A12, A16, A18, A20, A25, A28, A35, A39, A41
Prescriptions	Medical prescription refills (renewing)	A04, A09, A12, A15, A17, A43, A46
Prevention	Preventive health recommendations	A12, A18, A32, A40, A46
Providers	Previous health care provider list	A02, A18, A28, A30, A37
Scheduling	Appointments, past procedures, hospitalizations	A02, A12, A16, A18, A20, A25, A28, A35, A37
Social history	Social history, lifestyle (health habits)	A02, A12, A18, A25, A40
Summaries	Admissions, permanencies, and discharges	A39, A35, A43
Vital signs	Status of bodily functions	A16, A30, A35, A37, A40

SQ2: What Are the Standards That Apply to PHRs?

Some providers use proprietary formats to organize their health records that are used only by internal applications, each of which has a different format [7,65]. Thus, to answer this question, we focused on open standards, which are summarized in Table 8 and present a vast number of data organizational patterns for health records. Table 8 lists the referenced standards (group of standards, GS) according to their goals: nomenclature and terminology (GS1), privacy (GS2), structural and semantic (GS3), and templates and technology platforms (GS4). In group GS1, standards regarding nomenclature and terminology were grouped. Group GS2 contains only one standard that addresses privacy. In the GS3 group, several structural and semantic standards are presented. Finally, the GS4 group is related to templates and technology platform standards. We were able to identify some standards from the research on integrations and related projects, such as openEHR [67], which is integrated with the DICOM (Digital Imaging and Communications in Medicine) standard and others.

Table 8. Main personal health record–related standards.

Group and standard	Description	Reference articles
GS1[a]: nomenclature and terminology		
HNA/NIC[b]	Classifications of nursing activities and interventions	A29
ICDx	Family of international classification of diseases	A11, A28, A29, A44
LOINC	Code names for identifying medical observations	A47
SNOMED CT	Terminology collection of medical terms	A11, A28, A47
UMLS	System of medical vocabularies	A11, A13
GS2: privacy		
HIPAA	USA legislation for medical information	A09, A22, A25, A35
GS3: structural and semantic		
ASC X12N	Accredited standards committee X12-INS	A45, A47
CCD	Specification for exchange clinical documents	A11, A47, A48
CCR	Specification for sharing continuity of care content	A11, A33
CDA	Specification for clinical notes	A11, A47
DICOM	Standard for medical digital imaging	A11
EN 13606	EHR[c] standards in Europe	A25
HL7/FHIR/SMART	Family of standards and platforms based on the HL7 reference model	A11, A18, A28, A42, A43, A45, A47
ISO[d]	TR (Technical Report) 14292 (PHR) and ISO/IEEE 11073 Personal Health Data (PHD)	A01, A03, A20, A23, A25, A38, A43, A47
openEHR	Open standards specification in eHealth	A11
xDT	German family of data exchange formats	A04
GS4: templates and technology platforms		
OpenMRS	Platform and reference application named Open Medical Record System	A42
OSCAR	EHR system named Open Source Clinical Application and Resource	A42

[a]GS: group of standards.

[b]HNA/NIC: Home Nursing Activities/Nursing Interventions Classification

[c]EHR: electronic health record.

[d]ISO: International Organization for Standardization.

SQ3: What Are the User Types and Profiles That Interact With a PHR?

Upon analyzing the selected articles, we identified a set of profiles or user types that have access to the electronic patient record, which vary from the physician, who is primarily responsible for the PHR information, to the patient. The types of access also include the possibility that some data may be publicly available, for example, on social networks [19]. There are multiple stakeholders involved in accessing the PHR, such as patients, providers, employers, payers, governments, and research institutions [6]. In Multimedia Appendix 3, we present the details of the profiles that have been identified. We can see that the physician is widely referenced, while the nurse and administrative profiles are not cited as often. Among the laity, the patient profile is often cited; however, the relative or guardian profile is less commonly cited. We also included a public profile because patients might share their information anonymously in some cases or for other cases in which public administration sectors provide open statistical data.

In the following section, we present a brief description of the perceived profiles:

Physician or doctor—the physician, in this assessment, is the health professional profile responsible for reporting patient data in consumer electronic records.

Nurse—according to the International Standard Classification of Occupations [68], nursing professionals provide treatment, support, and care for people who need nursing care owing to the effects of aging, injury, disease, or other physical or mental impairments or face potential risks to their health.

Administrative—this profile refers to all administrative health professionals who are not directly linked to the data generation

but have informational access for bureaucratic, statistical data gathering or financial information needs.

Patient or consumer—this profile refers to the PHR principles; some authors also refer to the patient as a consumer of health care [14,26].

Relative—this profile is composed of parents, guardians, caregivers, responsible legal individuals, or anyone who has the patient's permission to access his or her PHR.

Public or anonymous—this refers to profiles with external access in an anonymous or public way, such as institutions, the government, researchers, health plans, third parties, and even social networks.

SQ4: What Are the Interaction Types of a Patient With a PHR?

This research question seeks to describe the interaction types of a patient with a PHR, that is, the types of relationships that a patient has using the PHR. In the following section, we present a brief description of the interaction types that were identified when analyzing the articles:

Direct—in this case, the patients are the owners and manage their health data in the PHR. Reference articles: A02, A05, A09, A12, A25, A26, A31, A48.

Indirect—in this case, the patient has read-only access and cannot edit the data. The health care providers are the owners, and the patient can only download or print the health records. Reference articles: A01, A05, A22, A25, A26, A40, A41, A42.

Outsourced—in this case, the patient authorizes a third party to handle the health data or the responsible parties (eg, parents) manage the patient's health records. Reference articles: A02, A03, A04, A07, A18, A24, A25, A28, A37, A48.

SQ5: Which Are the Techniques or Methods Used to Input Information Into a PHR?

Another result was the identification of techniques and actors that interact in the process of data collection for inputting into a PHR. Table 9 presents some answers to this specific research question, summarizing the techniques of inputting the relevant data into PHRs.

Table 9. Techniques for inputting information into personal health records.

Techniques and profiles (actors)	Description	Reference articles
Data collaboration (T1[a])		
Health professionals	Collaboration between multiple health care professionals. Health care providers are the owners (paternalistic relationship).	A08, A09, A12, A15, A22, A23
Patient reports (T2)		
Patient	Patient reports data, for example, listing drugs that are being used or menstrual period data.	A23, A26, A47
Adaptive platforms (T3)		
Environment	Aggregate sources provisioning individualized personal eHealth services combined with context information, including monitoring sensors. Patient and health care providers collaborate for inputting data into PHR[b].	A01, A26, A38, A43, A44
Anonymization (T4)		
Anonymous	Anonymizing social network data.	A16, A44

[a]T: technique.

[b]PHR: personal health record.

This information follows standards and is intended to structure and standardize the data provided. We list the main actors that provide the data, including health professionals and the patients themselves, which are gathered from the environment, including anonymously. The techniques (T) identified for inputting data range from data collaboration (T1), to patient reports (T2), adaptive platforms (T3), and anonymization (T4). Table 9 also includes articles in which these techniques and actors are cited. In short, this was the actors' group that was identified with a relevant interaction in collecting data for inputting data into the PHR.

SQ6: What Are the Goals of a PHR?

This research question includes the main goals of the PHR. This question is intended to identify the purpose that a PHR has in a broad context and that applies to any profile that has access.

In the following section, we present a brief description of the interaction types:

Consult—in this case, the purpose is to allow the profile to only consult (in read-only mode). Reference articles: A01, A03, A07, A10, A13, A15, A16, A17, A21, A39, A47.

Maintain—in this case, the user profile is allowed to maintain and control the health records. Reference articles: A09, A16, A18, A22, A29, A33, A37, A46.

Monitor—in this case, the PHR is in monitoring mode and can send alerts or warnings for one or more profiles; the goal is to help the patients monitor their health. Reference articles: A01, A07, A10, A20, A23, A25, A29, A40, A43, A45.

SQ7: What Are the Types or Models of Architecture of PHRs?

The purpose of this question is to identify the types or models of architecture in which a PHR can be implemented. When analyzing the articles, as seen in Table 10, the architecture types (architecture group, AG) were split into two groups: model (AG1) and coverage (AG2). The first group, AG1, describes the main architecture models. The second group, AG2, divides the data based on the physical location, that is, the scope of the PHR.

Table 10. Personal health record architecture types or models.

Group and item	Description	Reference articles
AG1[a]: model		
On paper	Health records are kept on paper	A08, A20, A22
Inside	PHR[b] is kept in local repositories, inside the provider, for example	A02, A03, A16, A20, A31
Outside	PHR is distributed or shared between servers outside the provider	A01, A03, A24, A35
Hybrid	PHR is distributed inside and outside the provider	A02, A10, A28, A35, A47
AG2: coverage		
Stand-alone	Data coverage is used only in the provider area	A11, A26, A45, A46
Local	Area is at the city level	A03, A11, A20, A29, A35
Regional	Data are used in the state or province	A02, A04, A25, A37, A45
National	Coverage encompasses the nation	A09, A12, A28, A34, A35
International	Coverage transcends the nation	A09, A16, A28, A30

[a]AG: architecture group.

[b]PHR: personal health record.

Discussion

Principal Findings

In this study, we sought to identify a quantitative and qualitative sample of studies that enabled us to obtain a clear overview of the technology regarding PHRs in the last 10 years from a number of candidate articles. This research sought to highlight some of the most relevant studies of the field according to certain systematic selection criteria. The survey sought to identify several common aspects of studies by answering a number of research questions. As a result, we were able to propose a PHR taxonomy and identify gaps to be further researched that represent challenges and issues that have been detected in recent years. These aspects range from patients' concerns to providers' problems regarding PHR adoption. In addition, we have identified the data types included in PHRs, an updated tabulation of the data standardization, access profiles and their characteristics, and, finally, a classification of input techniques. We also identified other common and related aspects. These opportunities are discussed as follows.

GQ1: How Would the Taxonomy for PHR Classification Appear?

For the *GQ1 research question*, we sought to define a PHR taxonomy, which is presented in Table 5. Our proposed taxonomy illustrates the PHR types and their organization according to several studies that were analyzed. We primarily identified three major groups of PHR organization types: (1) Structures, (2) Functions, and (3) Architectures. From these groups, we were able to examine the PHR types in depth to understand each one of them. These groups also showed that there are PHR application initiatives on several fronts with concerns that range from features and content to architectural format in terms of PHR implementation [54].

GQ2: What Are the Challenges and Open Questions Related to PHRs?

For the *GQ2 research question*, we sought to define the main challenges and issues regarding the use of PHRs. There are many open questions to be further researched in the area of PHR. The challenges and constraints in the adoption of PHRs are diverse. Some research results indicate problems of usability, privacy, security, and complexity in the use of PHRs, ranging from fears of including erroneous data to the difficulty of interpretation as the main difficulties [1,48]. In Table 6, we describe some challenges and issues that may give rise to future studies. According to the number of items in each group in the table, we notice a greater concern with the first three groups, although we cannot claim this assessment as being definitive. One possibility that we touch upon for this observation is that the integration of standards and interoperability, as well as the nomenclatures and terminologies, are already in a stage of stability and consolidation. This leads us to reinforce the thesis that the concerns of the authors at this time are the issues raised by the first three groups of problems. That is, the concerns and challenges are more focused on discussions regarding confidentiality, integrity, authorization, access control, portability, efficiency, scalability of solutions, and issues related to user experience.

SQ1: What Are the Data Types That Are Included in a PHR?

With respect to the *SQ1 research question*, we sought to define an updated ranking on data types in PHRs. Upon analyzing the studies, we observed that PHR data types have evolved since the first PHRs [6,37]. The data types found include groups that are not usually included in EHRs. Among the EHR stored data are medications, prescriptions, scheduled appointments, vital signs, medical history, laboratory information, immunizations, summaries, scanned documents, billing information, and progress notes about changes in the patient's health [4]. However, in PHRs, new data types have emerged, including genetic information [47,51], medical advice (recommendations), and prevention concerning the patient's health, as well as data types with recommendations for prevention and home monitoring data [9,15]. Other data types that appear in PHRs are allergies, patient registration data, and insurance plan information, including demographic data such as age, sex, and education. Furthermore, information on the patient's family, social history, lifestyle, food, diet, daily activities, and a list of providers who treated the patient previously are included in PHRs.

SQ2: What Are the Standards That Apply to PHRs?

For the *SQ2 research question*, we sought to define a current view of PHR standards. The result was the identification of the current list of existing data standards used in PHRs. We observed several standards that were maintained by various stakeholders that were located in different countries and regions. We were also able to observe a consolidation of some patterns in the articles' citations, such as ISO [4,10] and HL7 (Health Level Seven) [29], which are used to define and establish interoperability between the systems. When analyzing the articles, it was observed that all the standards listed can be used directly or indirectly with a PHR. However, their purposes are diverse. Some standards have specific goals, for example, DICOM [42] and SNOMED CT [65], while others have broader purposes, for example, HL7 [29] and openEHR [67], which can be integrated with other specific standards to render the solution. Finally, we identified some open systems or platforms that serve as templates, which use some of the listed standards to propose management solutions for patients' health data.

SQ3: What Are the User Types and Profiles That Interact With a PHR?

In the *SQ3 research question*, we sought to define the PHR user types and profiles that address PHR. The result was the identification of updated profiles as well as their characteristics. For the security and privacy of the health data, the answer to this research question offered a clear definition of the profiles that are allowed access to the PHR and what their responsibilities are [11]. In terms of access profiles, although the PHR is focused on personal use, the idea is that a patient can also delegate access to third parties by choice or necessity, as in the case of children or people who need special care. These third parties can access all or only specific parts of the PHR dataset. Patients can share their PHR for various purposes. Such patients may be minors whose parents need to share their health data with physicians, people with special needs who require constant monitoring, or even patients who wish to share their health data with other physicians. By analyzing the selected articles, it was possible to find multiple profiles that have access to the PHR. We can therefore highlight the following profiles: patients, physicians, nurses, relatives, administrators, and the public. A physician's tasks include recording the health information and medical history of the patients as well as exchanging information with practitioners and other health care professionals [68].

In cases where patients need emergency care, a primary care physician usually treats them. If more specialized care is needed, the physician indicates the need for a specialist. Furthermore, physicians must report births, deaths, and notifiable diseases to the government. Because the PHR is composed of health data that are stored for a lifetime, many physicians edit the PHR over time. Otherwise, in the case of an administrative profile, these professionals usually have limited and controlled access to the medical records. This profile is considered internal access, which is not to be confused with external access institutions. With the patient profile, the user can manage the information provided in his or her repository. The purpose is for patients to have access to their health data and use them throughout their lives [65]. This set of information is established at different moments over time, for example, for each medical consultation, laboratory test, and hospital admission. Nevertheless, there is a clear distinction between what was reported by health professionals and what the patient reports. Thus, the PHR offers an exact distinction between what was reported from each profile in its repository. In the case of a relative profile, some authors distinguish these profiles in terms of accessing the PHR with some limitations or full access with the permission of the patient [5,23,65]. Additionally, in the case of public or anonymous profiles, the health data can be accessed in a limited or shared way, in which the PHR has a public and social nature to help other patients [47].

SQ4: What Are the Interaction Types of a Patient With a PHR?

In the *SQ4 research question*, we were able to identify three types of patient interactions with the PHR. In the first type, according to the definition of the PHR in ISO 14292 [10], the patient manages and controls the health data directly. In the second case, the patient only acts in a supporting role as a complementation of EHRs but does not have effective control. Finally, in the third type the patient outsources the management of the health data to a responsible person.

SQ5: Which Are the Techniques or Methods Used to Input Information Into a PHR?

Regarding the *SQ5 research question*, we sought to define the main techniques to input data into the PHR. As a result, with the analysis of the selected articles presented in Table 9, we can identify the techniques and profiles of the actors who use them. In the data collaboration (T1) technique, different health professionals access the PHR aside from the patient. The patient remains the PHR owner, but health professionals collaborate on input records in an identifiable and controlled way. In the second case, patient reports (T2), patients alone are in charge of inputting their medical record data without any support. In

the third form, adaptive platforms (T3), the reported data and the data collected from the EHR are integrated with the PHR data. In this case, data obtained from different sources and contexts are combined. The purpose is to provide better management of the patient's condition. For instance, it would be possible to provide real-time access to sensitive patient information and ease communication among patients and providers. In the case of the anonymization (T4) technique, medical data can be integrated with a social network, where the patient can share his or her status anonymously and receive contributions from other users.

SQ6: What Are the Goals of a PHR?

In the *SQ6 research question*, we sought to identify the PHR use purposes. This research question is related to the specific question SQ3, which aims to identify the objectives of the user profiles when accessing the PHR. We have identified three objective types. In the first case, the user profile accesses the PHR to only verify the health data without manipulating them. One example here includes health professionals or administrators who have permission to only view the data. In the second case, the user profile has permission to manipulate the data. In this situation, it is important to highlight the need to identify and control the profile that has changed the data and which data have been changed. In the third case, the user profile only monitors the records. An example of this might be a case in which the PHR receives data from sensors (IoT) and can send alerts depending on a situation.

SQ7: What Are the Types or Models of Architecture of PHRs?

Finally, in the *SQ7 research question*, we identified the architectures related to PHRs. We divided them into two groups: types (AG1) and coverage areas (AG2), as seen in Table 10. In the case of architecture models, some articles state that health data are still stored on paper in many places, and other institutions have evolved into the proposed hybrid architectures with the PHR distributed inside and outside the health care organizations. In the case of the possibilities of coverage areas, we identified types ranging from a stand-alone PHR on a single machine to PHRs that can be taken from one country to another following an open international standard.

Limitations

This research is limited to aspects related only to PHRs rather than also including EHRs or electronic medical records, for example. In this sense, the review focused exclusively on articles addressing the inherent PHR concepts. This research sought to answer the research questions that were proposed in order to obtain an outline of the current literature related to PHRs without specifically assessing any computer system that refers to the use of PHR. The research was limited to obtaining articles published in a number of scientific portals related to ICT and health. Our research was reduced to studies found from these websites when we implemented the steps of the systematic literature review methodology. We focused our work on scientific articles and did not address commercial or more technological approach solutions.

Conclusions

This study aimed to raise and discuss the main issues regarding PHRs and identify the concepts of the technology in this area. To answer the research questions in this paper, we sought first to systematize and qualify the information that served as a source for the survey. For the completion of the work, we were able to identify and propose a broad taxonomy for the scope of work, which was created after an analysis of the relevant articles in the last decade. In the taxonomy, we were able to identify and group a number of types and PHR classifications ranging from “Structures” and types associated with “Functions” to the types of “Architectures” applied to PHRs. Having established the taxonomy, it was possible to observe other important relationships to understand PHRs. We noticed aspects regarding concerns and challenges in the adoption of PHRs as well as the main data types. In addition, we were able to identify several standards regarding PHR, where it was possible to verify those that were most important in the current scenario. Regarding user profiles, we identified the main users representing these types of profiles, as well as their responsibilities when they access PHRs. We were able to identify the techniques and methods used in the input of information into PHRs.

Finally, aside from answering all the specific research questions and relating them in the taxonomy, we can also rank the PHR with regard to goals, negotiation types, and architectures. The answers and classifications obtained contribute to the achievement of a coverage degree of searches that are identified in various aspects regarding the PHR. The physician-patient relationship traditionally consists of total dependence of the patient on the physician. In addition, the fragmented nature of the health system can impose a costly burden on physicians. The PHR can be a solution to this problem, although obstacles still persist, including support for reaching this paradigm, where the ownership of the data belongs to the patient.

In future studies, we envision a focus on the challenges and issues related to security, privacy, and trust, which directly affect the users’ confidence in adopting the PHR. Although these questions have existed for a long time, they do not have definitive answers yet. Other aspects that can be studied and that are important to improving the user experience are questions about usability, personalization, familiarity, and comfort. Another aspect that can serve as a future study is to explore the models of architecture and the implementation of PHR following the expansion of the use of technologies such as wearable computing, IoT, and artificial intelligence that are applied to health.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Selected portals.

[PDF File (Adobe PDF File), 107KB - jmir_v19i1e13_app1.pdf]

Multimedia Appendix 2

List of editors.

[PDF File (Adobe PDF File), 15KB - jmir_v19i1e13_app2.pdf]

Multimedia Appendix 3

List of users and profiles access.

[PDF File (Adobe PDF File), 55KB - jmir_v19i1e13_app3.pdf]

Multimedia Appendix 4

Presentation of study.

[PDF File (Adobe PDF File), 1MB - jmir_v19i1e13_app4.pdf]

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Abbreviations

AG: architecture group
DICOM: Digital Imaging and Communications in Medicine
EHR: electronic health record
ePHR: electronic personal health record
GQ: general question
HL7: Health Level Seven
ICT: information and communication technology
IoT: Internet of Things
ISO: International Organization for Standardization
iPHR: intelligent personal health record
GS: group of standards
PHR: personal health record
PICOC: population, intervention, comparison, outcome, and context
SQ: specific question
UHR: universal health record

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Review

The Use of Motion-Based Technology for People Living With Dementia or Mild Cognitive Impairment: A Literature Review

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Abstract

Background: The number of people living with dementia and mild cognitive impairment (MCI) is increasing substantially. Although there are many research efforts directed toward the prevention and treatment of dementia and MCI, it is also important to learn more about supporting people to live well with dementia or MCI through cognitive, physical, and leisure means. While past research suggests that technology can be used to support positive aging for people with dementia or MCI, the use of motion-based technology has not been thoroughly explored with this population.

Objective: The aim of this study was to identify and synthesize the current literature involving the use of motion-based technology for people living with dementia or MCI by identifying themes while noting areas requiring further research.

Methods: A systematic review of studies involving the use of motion-based technology for human participants living with dementia or MCI was conducted.

Results: A total of 31 articles met the inclusion criteria. Five questions are addressed concerning (1) context of use; (2) population included (ie, dementia, MCI, or both); (3) hardware and software selection; (4) use of motion-based technology in a group or individual setting; and (5) details about the introduction, teaching, and support methods applied when using the motion-based technology with people living with dementia or MCI.

Conclusions: The findings of this review confirm the potential of motion-based technology to improve the lives of people living with dementia or MCI. The use of this technology also spans across several contexts including cognitive, physical, and leisure; all of which support multidimensional well-being. The literature provides evidence that people living with dementia or MCI can learn how to use this technology and that they enjoy doing so. However, there is a lack of information provided in the literature regarding the introduction, training, and support methods applied when using this form of technology with this population. Future research should address the appropriate introduction, teaching, and support required for people living with dementia or MCI to use the motion-based technology. In addition, it is recommended that the diverse needs of these specific end-users be considered in the design and development of this technology.

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KEYWORDS

dementia; mild cognitive impairment; technology; review

Introduction

Dementia is a collective term used to describe a range of symptoms associated with neurodegenerative conditions such as Alzheimer's disease. Characteristic signs of dementia involve marked impairment in the areas of cognitive functioning such as memory, attention, executive function, comprehension, judgment, and communication [1]. Mild cognitive impairment

(MCI) can be defined as a condition in which an individual has mild but measurable changes in thinking abilities; however, these changes do not affect the person's ability to carry out all activities of daily living [2]. MCI can be classified as amnestic or nonamnestic based on the thinking abilities affected [2]. For example, people with amnestic MCI predominantly experience memory challenges and may begin to forget important information that he or she would have previously recalled easily (eg, appointments, conversations, or recent events). In contrast, memory is spared among people with nonamnestic MCI, with changes greater than those expected for their age in one other cognitive domain such as language, visuospatial skills, or executive functioning [2]. As the population ages and life expectancy continues to increase [3], progressive cognitive disorders such as dementia or MCI have become a major age-related health concern, with the number of people living with dementia expected to reach 1.4 million in Canada by 2031 [4]. Although there are many research efforts directed toward the prevention and treatment of dementia and MCI, it is also important to learn more about supporting a good life for people currently living with these conditions [5].

People living with dementia or MCI often have reduced opportunities for engagement and face progressive barriers when trying to participate in activities they once enjoyed with ease [5]. For individuals with dementia or MCI, engaging in pleasant and meaningful activities can promote a good quality of life and support overall well-being [6]. Recent publications have shown that there are many ways in which people with dementia can engage in pleasant activities and live well, including the use of novel technology devices such as touchscreen tablets and personal computers [5,7-10].

More recently, the use of motion-based technology has become a popular topic of interest in many areas of care [11-16]. Recent research involving the motion-based technology has revealed positive benefits for healthy older adults [11-13], as well as populations with stroke [14], Parkinson's disease [15], and traumatic brain injury [16]. Motion-based technology can be described as a natural user interface (NUI) device that operates through intuitive actions similar to natural, everyday gestures. When used for activity promotion, games presented through motion-based technology may also be referred to as "exergames" as physical actions are required to interact with the technology and play the games. In addition, games presented on this type of technology can provide an accessible source of fun and meaningful engagement. However, the literature on the use of motion-based technology for people living with dementia or MCI is currently quite limited and undefined. Therefore, the purpose of this literature review is to identify and synthesize the current knowledge on this topic, while highlighting gaps that require further investigation. In addition, this review aims to add to the body of knowledge supporting the use of novel technologies to promote a good life for people living with dementia or MCI.

The current review presents an overview of the ways in which motion-based technology has been used with people living with dementia or MCI. This review aims to address the following questions:

1. In what contexts has motion-based technology been used with people living with dementia or MCI?

2. Were these studies focused on people with dementia or people with MCI?

3. What forms of hardware and software were used?

4. Was the technology utilized in a group or individual setting?

5. What methods were used to introduce, teach, and support people living with dementia or MCI to use motion-based technology?

Methods

A systematic review of the literature was conducted on the use of motion-based technology for people living with dementia or MCI.

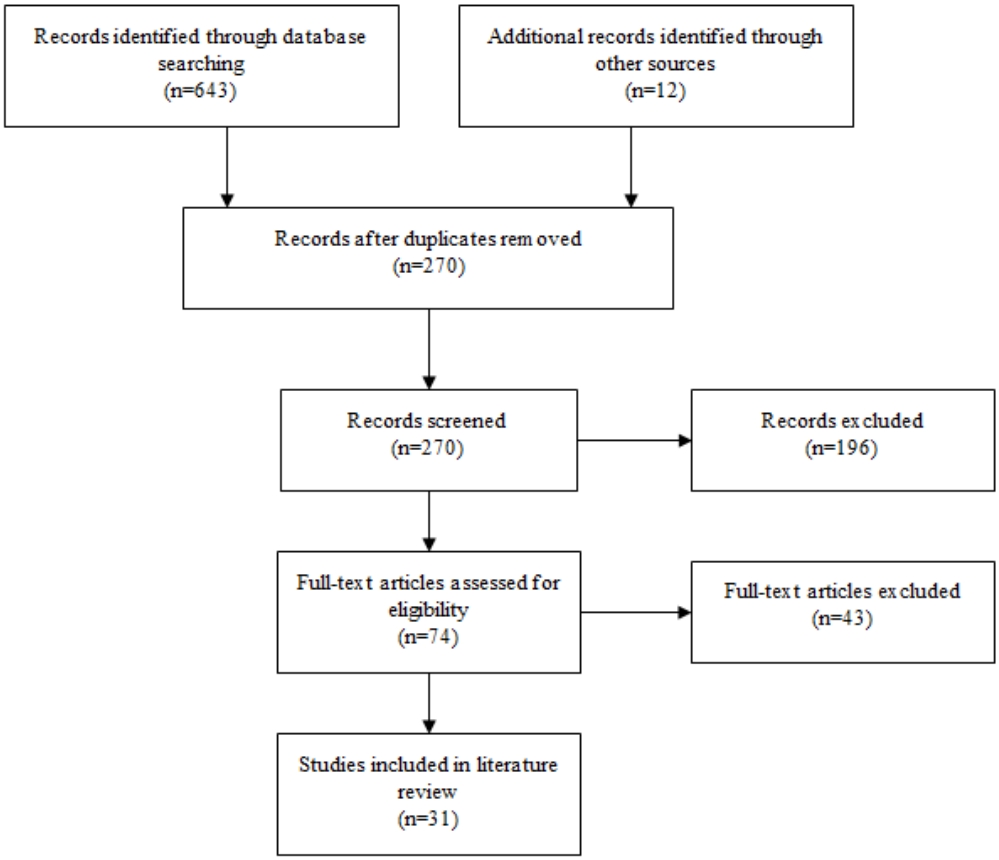
The following search terms were used for this review: (dementia) OR (Alzheimer*) OR (mild cognitive impairment) OR (MCI) AND (exergam*) OR (motion-based) OR (virtual reality) OR (gesture-based) OR (Nintendo Wii) OR (Xbox Kinect) OR (interactive console) AND (activit*) OR (gam*).

The following electronic databases were accessed for this review: Medline (Ovid), PsycINFO (Ovid), Cochrane (Ovid), PubMed (NCBI), and CINAHL (EBSCO). The search was extended to include references of relevant articles.

Articles were included or excluded based on the following criteria: (1) language: English; (2) participants: human, living with dementia or MCI; and (3) technology: any interface requiring physical movement for interaction.

The search protocol defined above originally resulted in the identification of 643 references through database searching and an additional 12 references through hand searching, amounting to a total of 655 initial returns. After the removal of duplicate documents, a total of 270 articles remained which were then screened for eligibility criteria. Articles that did not meet the inclusion criteria based on their title or abstract were subsequently removed, resulting in a total of 74 articles identified for full-text analysis. After reading each article, an additional 43 articles were excluded, resulting in a total of 31 full-text articles included in the final review (Figure 1) [17].

Figure 1. Flow diagram of search procedure.



Results

Overview of Findings

Thirty-one articles met the final inclusion criteria and were included in this review. Table 1 shows the synthesized results of the search procedure that provides an overview on this topic, organized as per the questions identified above.

Context of Use

Three broad categories describing the context in which the motion-based technology was used for people living with dementia or MCI were identified during the review: (1) cognitive function (21 articles); (2) physical function or activity promotion (12 articles); and (3) leisure activities (13 articles). Thirteen articles contained information pertaining to one or more categories that suggests the motion-based technology has the potential to span across several contexts. Articles addressing more than one context of use include: 6 articles [21,24,32,34,46,47] focused on cognitive function and leisure activities, 3 articles [23,37,38] pertaining to both cognitive and physical function, 2 articles [30,44] relevant to both physical function and leisure activities, and 2 articles [26,45] encompassing all 3 categories. These articles were counted under both or all categories as appropriate (Table 1).

Cognitive Function (n=21)

Cognitive function was the most prevalent category identified within the literature regarding the use of motion-based technology for people with dementia or MCI. Articles categorized in this section used the motion-based technology to present cognitive exercises to people with dementia or MCI with the aim of assessing, measuring, restoring, maintaining, stimulating, or improving various aspects of cognitive function. The articles included in this section used a technology that is commercially available (eg, Nintendo Wii) [24,26,28,31,32,34-38,45-47], or the one that was specifically created for study purposes by the researcher (eg, a stationary bicycle merged with a graphical interface) [18,21-23,27,29,43,48].

The main focus was general cognitive function rather than focusing on specific domains (eg, memory, executive function) [18,24,29,31,45,46,48]. Articles included in this category used the motion-based technology with the aim of assessment and screening for early signs of dementia in people living with MCI [37,43]; reducing the risk or rate of progression in people currently living with dementia [21,23,32,38]; assessing or improving procedural learning ability in people with either dementia or MCI [28,34,35]; providing cognitive stimulation for people with dementia [26-28]; prompting people with dementia through occupational tasks [22]; increasing the attention span and concentration during tasks for people with MCI [47]; and improving reaction time (ie, how fast the brain responds to stimuli) and comprehension in people with MCI [36].

Table 1. Summarized results of literature review.

Publication author	Purpose of technology	Study population	Hardware and software	Individual or group use	Introduction, teaching, and support methods used
Bamidis et al [18]	Cognitive function	Dementia and MCI[a]	Touchscreen interface, Nintendo Wii-mote, and Wii Balance Board (FitforAll); SketchUp (Google, Mountain View), 3Ds Max Studio (Autodesk Inc), and XNA game software (Microsoft Corp)	Group	-
Benveniste et al [19]	Leisure activities	Dementia	TV, PC, sensor bar, and Nintendo Wii-mote (MinWii); unspecified software	Group	Staff would sit with participants and offer as much support as needed
Billis et al [20]	Physical function or activity promotion	Dementia and MCI	Touchscreen interface, Nintendo Wii-mote and Wii Balance Board (FitforAll); SketchUp (Google, Mountain View), 3Ds Max Studio (Autodesk Inc), and XNA game software (Microsoft Corp)	Group	Psychologist or therapist was present during all sessions to train the participants in using the program
Boulay et al [21]	Cognitive function and leisure activities	Dementia	TV, PC, sensor bar, and Nintendo Wii-mote (MinWii); unspecified software	Group	Participants were given 1 training session to become familiar with the interface; psychologists gave instructions and help during test sessions
Chang et al [22]	Cognitive function	Dementia	Microsoft Kinect sensor, PC, and TV screen; Kinempt software (custom-built)	Individual	Verbal instructions, task breakdown, gesture demonstrations, support as required
Chilukoti et al [23]	Cognitive function and physical function or activity promotion	Dementia	Mini stationary bike with graphical user interface; unspecified software	Individual	-
Colombo et al [24]	Cognitive function and leisure activities	Dementia and MCI	EyeToy for PlayStation 2; Bubble-pop game (Sony Corp)	Individual	-
Cutler et al [25]	Leisure activities	Dementia	Nintendo Wii; Wii Sports, and Nintendo Wii Fit (Nintendo Co Ltd)	Group	Repeated demonstrations
Cutler et al [26]	Cognitive function, physical function or activity promotion, and leisure activities	Dementia	Nintendo Wii; Wii Fit (Nintendo Co Ltd,), and Microsoft Kinect; Kinect Sports (Microsoft Corp)	Group	Initial support, reduced as participants became competent with the technology
De Urturi Breton et al [27]	Cognitive function	Dementia	Microsoft Kinect; KiMentia software (custom-built)	Individual	-
Fenney and Lee [28]	Cognitive function	Dementia	Nintendo Wii; Nintendo Wii Sports (Nintendo Co Ltd)	Group	Physical guidance, verbal prompts as required
González-Palau et al [29]	Cognitive function	MCI	Touchscreen interface, Nintendo Wii-mote, and Wii Balance Board (FitforAll); SketchUp (Google, Mountain View), 3Ds Max Studio (Autodesk Inc), and XNA game software (Microsoft Corp)	Individual	Participant met with a therapist every 2 weeks to discuss progress
Higgins et al [30]	Physical function or activity promotion and leisure activities	Dementia and MCI	Nintendo Wii; Nintendo Wii Sports (Nintendo Co Ltd)	Group and individual	Introduced in a one-on-one session before transitioning to a group environment
Hughes et al [31]	Cognitive function	MCI	Nintendo Wii; Nintendo Wii Sports (Nintendo Co Ltd)	Group	Initial training for 6 weeks on how to use the technology
Kayali et al [32]	Cognitive function and leisure activities	Dementia	Nintendo Wii; Nintendo Wii Fit (Nintendo Co Ltd)	Group	-

Publication author	Purpose of technology	Study population	Hardware and software	Individual or group use	Introduction, teaching, and support methods used
Konstantinidis et al [33]	Physical function or activity promotion	Dementia	Touchscreen interface, Nintendo Wii-mote, and Wii Balance Board (FitforAll); Google SketchUp (Google, Mountain View), 3Ds Max Studio (Autodesk Inc), and XNA game software (Microsoft Corp)	Individual	Technology gives instructions, prompts, praise, notifications, and guidance; therapists can add or modify games
Leahey and Singleton [34]	Cognitive function and leisure activities	Dementia	Nintendo Wii; Nintendo Wii Sports (Nintendo Co Ltd)	Group	Verbal and physical cues, vanishing cues, task breakdown
Legouverneur et al [35]	Cognitive function	Dementia and MCI	Nintendo Wii; Nintendo Wii Sports (Nintendo Co Ltd)	Individual	Simple introduction, repeated demonstrations, verbal prompts, physical assistance when required
Liou et al [36]	Cognitive function	MCI	Microsoft Kinect; Kinect Sports, Kinectimals and Fruit Ninja (Microsoft Corp)	Group	-
McCallum and Boletsis [37]	Cognitive function and physical function or activity promotion	Dementia and MCI	Nintendo Wii; Nintendo Wii Fit, and Nintendo Wii Sports (Nintendo Co Ltd)	Group and individual	-
McCallum and Boletsis [38]	Cognitive function and Physical function or activity promotion	Dementia and MCI	Nintendo Wii; Nintendo Wii Fit and Nintendo Wii Sports (Nintendo Co Ltd)	Group and individual	-
McEwen et al [39]	Physical function or activity promotion	Dementia	Interactive rehabilitation exercise (IREX) hardware and software (GestureTek, Silicon Valley)	Individual	-
Padala et al [40]	Physical function or activity promotion	MCI	Nintendo Wii; Nintendo Wii Fit (Nintendo Co Ltd)	Individual	-
Padala et al [41]	Physical function or activity promotion	MCI	Nintendo Wii; Nintendo Wii Fit (Nintendo Co Ltd)	Individual	-
Siriaraya and Ang [42]	Leisure activities	Dementia	Microsoft Kinect; software created through Unity3D (Unity Technologies)	Group and individual	Prompts provided as required based on each person
Tarnanas et al [43]	Cognitive function	Dementia and MCI	PC, Microsoft Kinect sensor, treadmill and LEAP motion sensor (Leap Motion Inc); Microsoft Kinect software development kit (Microsoft Corp)	Individual	-
Tobiasson [44]	Physical function or activity promotion and leisure activities	Dementia	Nintendo Wii; Nintendo Wii Sports (Nintendo Co Ltd)	Group	Gesture demonstrations, verbal cues, physical support when required, personalizing introduction, teaching, and support methods
Tobiasson et al [45]	Cognitive function, physical function or activity promotion and leisure activities	Dementia	Nintendo Wii; Nintendo Wii Sports (Nintendo Co Ltd)	Group	Initial support, reduced over time as users became more competent with the technology
Ulbrecht et al [46]	Cognitive function and leisure activities	Dementia and MCI	Nintendo Wii; Nintendo Wii Sports (Nintendo Co Ltd)	Group and individual	Therapists received training in introducing and supervising the intervention prior to the study
Weybright et al [47]	Cognitive function and leisure activities	MCI	Nintendo Wii; Nintendo Wii Sports (Nintendo Co Ltd)	Individual	One-on-one introduction session to learn the technology and play the games; prompts and cues provided as needed prior to and during the sessions

Publication author	Purpose of technology	Study population	Hardware and software	Individual or group use	Introduction, teaching, and support methods used
Yamaguchi et al [48]	Cognitive function	Dementia	XaviX hardware—base-machine, TV screen, sensor mat and sensor ball; Hot-plus software (SSD Co Ltd)	Group	Caregivers support participants through communication and praise

[a]MCI: Mild cognitive impairment.

Whereas there were many different ways in which motion-based technology was applied as a cognitive intervention for people living with dementia or MCI, the rationales behind the choice to use this technology were quite similar. Many studies chose to use motion-based technology as evidence supports combined mental and physical training for cognitive health promotion [18,23,27,29,32,34,36,38,45-47]. This type of technology was also chosen due to the fact that it provides cognitive [21,24,26,28,35], mental and social [31,48], and physical and social [37] stimulation for people living with dementia or MCI. In additional, motion-based technology is intuitive and has the unique ability to perform tasks such as assessment and screening and task prompting for individuals with dementia or MCI [22,43].

Physical Function or Activity Promotion (n=12)

Physical function or activity promotion was the category least focused on in respect to people living with dementia or MCI. Articles included in this category [20,23,26,30,33,37-41,44,45] used the motion-based technology to target areas of physical functioning, remove or reduce risk of disability, provide a targeted rehabilitation approach for those already living with existing physical challenges, and promote games presented on the motion-based technology as an engaging, attainable, and accessible way to encourage people living with dementia or MCI to participate in physical activity. Articles included within this context also featured commercially available technology [26,30,37,38,40,41,44,45] and technology designed by researchers specifically for study purposes [20,23,33,39].

One common theme to emerge was gait, balance, and fall risk [37-41]. Additional areas of focus within this emerging theme included general motor function [37,38] and mobility in people with either dementia or MCI [30,39], as these measures can be indicative of an increased risk for falls. The literature also placed a great deal of focus on using the motion-based technology as an interactive, accessible, and fun way to encourage motivation to participate in and enjoy physical activity in general [20,23,26,30,33,44,45]. People with dementia or MCI face many challenges that can make it increasingly difficult to engage in regular physical activity or rehabilitation regimens. Unsurprisingly, this technology was mainly utilized as a tool for activity promotion.

Leisure Activities (n=13)

Leisure activities can be described as fun and enjoyable pastimes that contribute to a higher quality of life [5]. In this review, it was found that only 42% (13/31) studies used the motion-based technology to provide meaningful leisure activities for people with dementia or MCI [19,21,24-26,30,32,34,42,44-47] compared with the 68% (21/31) studies that used the motion-based technology for cognitive purposes [18,21-24,26-29,31,32,34- 38,43,45-48]. Interestingly, a review of the use of touchscreen technology for people living with dementia [9] highlighted that supporting leisure activities has received significantly less focus compared with the context of cognitive function. This is echoed in the current review of the motion-based technology, which has been used more as a cognitive tool than a leisure device. Indeed, there are areas of the leisure technology industry dedicated to this, but their emphasis has tended to be on the younger generations as their target consumers [49]. For example, it has been well established that compared with younger people, older adults have lower access to and usage of recent technologies [49].

The articles within the leisure category used the motion-based technology with the primary aim of providing a source of enjoyment and engagement for people living with dementia or MCI [19,25,26,30,32,34,42,44,45]. In addition, the articles examined the use of the motion-based technology for other aspects of leisure such as acceptability and pleasure of games presented on the motion-based technology for people with dementia or MCI [24,46], self-esteem in people with dementia [19,21], positive affect and mood in people with MCI [47], and reminiscing in people with dementia [42]. Interestingly, in many of the articles that did not address leisure, it was still reported that the participant dropout rate was relatively low, and that they enjoyed interacting with the technology and playing the games. This suggests that the motion-based technology has the ability to provide an inadvertent source of enjoyment, even if it is technically being utilized as a cognitive or physical tool.

Two of the reviewed articles in the leisure category described “gaming technology groups” specifically for people with dementia that aimed to use games presented on motion-based technology to provide cognitive and physical stimulation, as well as meaningful leisure activities within an interactive social setting [25,26]. The authors ran these group activities with various subsets of the target population including people living with dementia within the community, people living in assisted-living facilities, male-only groups, and groups combining men and women. Investigators behind the “gaming groups” used the knowledge acquired to create “how to” guides for implementing, managing, and supporting gaming technology groups for people living with dementia [50,51].

Study Population

The second research question, which aims to identify the study population included in the interventions (ie, people with dementia or people with MCI) have been discussed here. Of note is that 9 of the 31 articles included in this review focused on both people with dementia and people with MCI [18,20,24,30,35,37,38,43,46]; therefore, these studies have been counted under both categories.

People With Dementia (n=25)

Of the 31 studies included in the review, 25 of them focused on people with dementia. This shows a clear trend toward the use of the motion-based technology for people with dementia rather than people with MCI. In addition, it is unsurprising that the category of cognitive function received the greatest attention in studies involving people with dementia, with 17 of 25 articles addressing an aspect of cognition.

Of interest, a majority of the studies involving people with dementia were conducted in a group setting, whereas those focusing on people with MCI were conducted as an individual activity. The reasoning behind this was not clear. In addition, 16 of the 25 articles focusing on people with dementia conveyed information regarding the methods used to introduce, teach, and support people with dementia to use the motion-based technology. In contrast, only 7 of 15 articles focused on the use of the motion-based technology for people with MCI offered all the information regarding the introduction, teaching, and support methods. Again, the reasoning behind this was not exactly clear. Finally, studies looking at these 2 groups, whether together or separately, all chose to utilize more commercially available hardware and software than custom-built.

People With Mild Cognitive Impairment (n=15)

Of the 31 studies included in this review, only 15 focused on people living with MCI. Of note is that none of these articles specified whether participants had amnestic or nonamnestic MCI. Furthermore, only 6 of these 15 studies focused specifically on people with MCI, with the remainder focusing on people with MCI in conjunction with people living with dementia. This highlights the lack of focus on people living with MCI specifically within the motion-based technology literature.

In studies looking specifically at people with MCI, cognitive function also received the most attention, similar to the studies focusing on people with dementia. However, there was much less focus on the use of the motion-based technology to provide meaningful leisure activities for people with MCI (27%, 4/15 studies) than there was for people with dementia (48%, 12/25 studies). In addition, the number of studies looking at physical function or activity promotion for people with MCI was higher than those looking at physical function or activity promotion in people with dementia. This indicates that interventions for people with MCI specifically were used more for improving cognition or physical function, whereas studies involving people with dementia specifically tended to focus more on cognition and leisure, with physical function or activity promotion receiving the least amount of focus.

Hardware and Software

The hardware (ie, console used) and software (ie, gaming interface) utilized in the review articles have been discussed here. Of note is that multiple articles within the cognitive function, leisure activities, and physical function or activity promotion contexts all used similar hardware and software (Table 1), suggesting that the existing motion-based technology has the ability to span across several contexts.

Hardware Selection

An analysis of the literature revealed that a majority of the research involving the motion-based technology and people with dementia or MCI utilized commercially available hardware. The most commonly chosen motion-based technology hardware, used in 16 studies [25,26,28,30-32,34,35,37,38,40,41,44-47], was the Nintendo Wii (Nintendo Co Ltd), which features a base console and a remote control with built-in motion sensors. The player holds the remote control (also known as the “Wii-mote”) while performing physical movements, which are transformed into actions on the screen (Figures 2 and 3). However, holding and operating the Wii-mote requires manual dexterity, fine motor control, grip strength, and may be difficult to use for populations with age-related physical impairments, as well as people with dementia or MCI. In one instance, Tobiasson et al, 2015 [45] had to modify the Wii-mote by covering most of the buttons with a thermoplastic splint to make it easier to hold and prevent players with dementia from unintentionally pressing the wrong buttons or pressing too many buttons. This was echoed in studies by Benveniste et al, 2010 [19] and Boulay et al, 2011 [21], where subjects used a Wii-pistol (a small plastic gun that holds the Wii-mote) to make holding and using the controller easier. In addition, participants with dementia or MCI both reported having difficulty remembering which buttons on the Wii-mote were associated with which movements, therefore, this issue was mitigated by covering most of the buttons [19,21,30,45].

The Xbox Kinect (Microsoft Corp) was the second most common commercially available hardware device featured within the literature [26,27,36,42]. The Kinect sensor, used in conjunction with a base console, is embedded with gesture-recognition equipment including an infrared projector and a camera that tracks motion in 3 different dimensions. Movements made by the player are mimicked by a virtual avatar on the screen. Due to the fact that there is no handheld remote or controller required, the user controls the entire gaming interaction through the use of physical motions, allowing for an immersive and user-friendly experience (Figures 4 and 5).

Colombo et al’s study (2012) [24] was the only one to utilize the EyeToy for PlayStation2 hardware (Sony Corp) that features a small USB camera connected to the main console that displays the image of the person in view on the TV screen. Similar to the Microsoft Kinect, interaction requires no handheld controller, allowing the user to naturally interact with the game (Figures 6 and 7). However, participants’ perceptions of the usability or acceptability of this hardware was not mentioned in the article, and there was no other mention of this specific device within any of the other articles.

About eleven articles featured custom-built hardware [18-23,29,33, 39,43,48]. The hardware designs varied, including a personal computer merged with a Microsoft Kinect sensor and a TV screen [22]; a mini stationary bike with an attached graphical user interface [23]; a TV screen merged with a PC, a sensor bar, and a Wii-mote controller [19,21]; a personal computer merged with a Microsoft Kinect sensor, a treadmill, and a LEAP sensor (Leap Motion Inc) [43]; a base-machine combined with a television screen, a sensor mat, and

motion-sensor wrist bands [48]; green screen hardware [39]; and a touchscreen interface compatible with a Nintendo Wii-mote controller and a Nintendo Wii balance board [18,20,29,33]. Notably, 9 of these 11 papers featuring custom-built hardware have addressed either cognitive function or physical function or activity promotion, with only 2 articles concerned with leisure. It was also noted that only 7 of these articles provided detailed information regarding the introduction, teaching, and support methods used during the intervention.

Figure 2. Nintendo Wii controller (left) and Nintendo Wii base console (right).

Figure 3. Nintendo Wii interaction.

Figure 4. Xbox One base console (bottom) and Microsoft Kinect sensor (top).

Figure 5. Microsoft Kinect interaction.

Figure 6. PlayStation2 EyeToy hardware.

Figure 7. PlayStation2 EyeToy interaction.

Software and Game Selection

A majority of the articles utilizing commercially available hardware paired it with commercially available software. Articles that chose to utilize the Nintendo Wii hardware also paired it with the Nintendo Wii software (Nintendo Co Ltd) including Nintendo Wii-Fit [25,26,32,37,38,40,41] or Nintendo Wii-Sports [25,26,28,30,31,34-38,44-47], with some articles utilizing both software packages. These software applications

were used across all 3 contexts, namely, cognitive, physical, and leisure activities.

Of the articles featuring Microsoft Kinect hardware, only 2 used commercially available Kinect software (Microsoft Corp): Kinect Sports [26,36], Kinectimals [36], and Fruit Ninja [36]. The remaining studies created their own custom-built software for the Microsoft Kinect including the Kimentia software [27] and software created through a program called Unity3D (Unity Technologies) [42]. In the only study that featured the commercially available PlayStation EyeToy hardware, the corresponding EyeToy software was used, exclusively the Bubblepop game (Sony Corp) [24].

The 11 articles that created custom-built hardware also paired it with custom software programs, including unspecified commercially available software [19,21]; SketchUp (Google, Mountain View), XNA game software (Microsoft Corp), and 3Ds Max Studio software (Autodesk Inc) [18,20,29,33]; Kinempt (custom-built) [22]; Microsoft Kinect software development kit (Microsoft Corp) [43]; XaviX (SSD Co Ltd) [48]; and interactive rehabilitation exercise (IREX) software (GestureTek) [39]. The remaining study designed a graphical user interface, but made no mention of the software used for development [23]. These 11 studies tended to focus more on cognitive and physical use and provided very limited, if any information regarding the introduction, teaching, and support methods used during the activity, which were mostly delivered on an individual basis.

Four of the reviewed articles [18,20,29,33] utilized a custom-built motion-based technology platform called FitforAll, which consisted of an integrated touchscreen interface used in conjunction with the Nintendo Wii-mote and the Nintendo Wii balance board. This platform featured a physical and cognitive training program with the aim of assessing the impact of combined training on cognition and physical activity promotion in people living with dementia or MCI [18,20,29,33]. In addition, 2 studies looked at a bespoke motion-based technology music therapy program called MinWii [19,21], which was created by merging a television screen, a personal computer, and motion-based technologies such as the Nintendo Wii-mote and an infrared sensor bar. The technology allowed participants to play familiar songs or improvise a scale of their choice, and was used to promote positive self-esteem and reminiscing among people living with dementia.

Individual or Group Use

The following section addresses the fourth research question, which explores the use of the motion-based technology for people living with dementia or MCI as a group or individual activity. Five of the studies implemented the motion-based technology in both a group and individual setting [30,37,38,42,46], and therefore these articles were counted under both categories.

Individual Use

Seventeen articles presented the motion-based technology to people with dementia or MCI as an individual activity (Table 1). These articles primarily addressed cognitive [22,24,29,35,37,38,43,46,47] and physical measures [23,33,38-41,44,45], with leisure activity receiving the least amount of focus [24,30,42,46,47]. Although the reasoning behind this was not clear, it can be suggested that perhaps it is easier to track and measure cognitive and physical variables among individuals rather than groups. In addition, only 8 of these 17 articles provided all the information regarding the methods used to introduce, teach, and support people living with dementia or MCI to interact with the technology [22,29,30,33,35,42,46,47].

Group Use

Nineteen articles used the motion-based technology in a group setting (Table 1). Of these articles, 12 studies addressed a cognitive variable [18,21,26,28,31,32,34,36-38,45,48], 11 addressed an aspect of leisure [19,21,25,26,30,32,34,42,44-46], and 7 addressed a physical measure [20,26,30,37,38,44,45]. This suggests that using the motion-based technology in a group setting has the ability to support several aspects of well-being for people living with dementia or MCI. In addition, the research in 8 of the 13 articles addressing leisure was conducted within a group setting [19,21,25,26,32,34,44,45], with the remaining articles focusing on individual activity [24,47], or a combination of both [30,42,46]. This suggests that the group dynamic may have contributed to the positive leisure experience.

Several articles included the feedback from researchers, staff, caregivers, and participants living with dementia or MCI, reporting that the group dynamic added an extra social component to the gaming activity. Presenting the motion-based technology as a group activity was reported to promote social interaction among people with dementia and MCI [26,30,32,45,48], maintain social skills among people with dementia [34], and reduce social barriers for people with MCI [31]. The group dynamic also created an opportunity to promote teamwork and socialization [20,26,28,30-32,44,45]. It was also reported that using the motion-based technology in a group setting encouraged friendly competition [44,45] and intergenerational connections for people living with dementia [19,21,26].

Introduction, Teaching, and Support

The fifth and the final research question aimed to identify the methods used to introduce, teach, and support people living with dementia or MCI when engaging with the motion-based technology. This is particularly important as people with dementia are indeed able to learn new things with the right support and prompting, which can help prolong independence and support a good quality of life [5]. However, this proved to be the most significant gap in the literature. Of the 31 articles included in the final review, only 19 made a reference to the way in which participants were introduced, taught, and supported to use the technology. In addition, there was major variation in the amount of information and level of detail provided.

Introduction Methods

Information related to the introduction of the motion-based technology with people living with dementia or MCI as discussed in the literature elsewhere has been analyzed here (Table 1). The way a technology is introduced to a person with dementia or MCI (ie, what it is, what it does, why it would be

beneficial to them, and so on) is crucially important as the introduction of such devices could potentially influence the individual's choice or desire to learn to use it [52]. In other words, introduction essentially sets the tone for teaching. For example, people with dementia or MCI are less likely to adopt a technology if they are unable to figure out what it does or how it is relevant to them [52].

Tobiasson, 2009 [44], who conducted their study as a group activity, gradually introduced participants living with dementia to the technology one at a time to give their full attention to teaching the person to handle and interact with the console system before transitioning to a group environment. Legouverneur et al, 2011 [35] provided participants with dementia or MCI with a 1-h introduction session where they were instructed to create their own virtual player (avatar) to teach them to handle and use the Nintendo Wii-mote. In addition, they suggested that the technology should be initially presented in a simple and understandable way [35]. Furthermore, Cutler et al, 2015 [26] highlighted the importance of considering the interests of people with dementia when first introducing new technology to choose activities that are relevant, meaningful, and achievable for the individual.

Weybright et al, 2010 [47] provided participants with MCI with an initial introduction session before the data collection phase where they were taught how to use the Nintendo Wii controller, how to navigate the system, and how to play the games. This approach was similar to that of Boulay et al, 2011 [21], who gave participants with dementia an introduction session to familiarize themselves with the interface. Higgins et al, 2010 [30] also provided an individual introduction session to participants with dementia or MCI prior to the study, but this was done to increase the person's confidence and competency with the technology before transitioning into a group environment.

Chang et al, 2011 [22] introduced their gesture recognition system to a participant with dementia using verbal instructions. If the participant did not understand how to interact with the system, the researchers would provide the person with a less-intrusive prompt (verbal) followed by a more-intrusive prompt (gesture) if the user was still finding it difficult [22]. In addition, Ulbrecht et al, 2012 [46] stated that therapists, which included general nurses, geriatric nurses, or occupational therapists, received training in introducing and supporting people with dementia or MCI to engage in activities presented on the motion-based technology prior to the intervention, but they did not elaborate on what this training entailed. Through further investigation, it was found that only 9 articles [18,20,21,30,33,34,39,45,46] used trained therapists (occupational therapists, physiotherapists, recreational therapists, psychologists, nurses, diversional therapists, and physical educators) to lead the interventions. Of further interest, many of these studies focused on an aspect of cognitive or physical function.

Teaching Methods

The cognitive challenges faced by people with dementia or MCI such as working memory difficulties, and impairments in attention, visuospatial abilities, and motor skills make it challenging for them to learn new information. Therefore, it is important to use teaching techniques that maximize involvement of spared abilities and avoid involvement of impaired abilities [5]. In this review, various examples of training techniques were used to teach participants to interact with the technology, illustrating the diverse and purposeful use of several techniques to accommodate the needs of people living with MCI or dementia (Table 1). For example, Leahey and Singleton, 2011 [34] mentioned about breaking the movement sequence down into small steps, which supports the conclusions of the studies [28,34,35], whose findings provide evidence of spared procedural learning capacity in people living with either dementia or MCI.

Cutler et al, 2015 [26] and Tobiasson et al, 2015 [45] both recommended providing participants with dementia initial support including verbal and physical cues, but gradually reducing these cues over time as they became more competent with the technology. In addition, both groups [26,45] suggested using positive encouragement and personalizing teaching approaches for each individual. Other training techniques for people with dementia or MCI included the use of verbal cues [35,44,45], repeated instructions [21,25,35], sounds [44], physical cues or gesture demonstrations [35,44,45], and prompts [47].

Hughes et al, 2014 [31] took a more extensive approach, providing participants with MCI with a 90-min session per week for 6 weeks to increase competence with the technology and to train participants to use the system and play the Nintendo Wii Sports games. In contrast, Chang, Chen, and Chuang, 2011 [22] designed their technology with the intent of the system training the participants, which meant that the research personnel provided no additional training after the initial introduction session. Although this study only involved 1 participant with dementia, meaning that no major conclusions can be drawn, the gesture recognition system was successful in prompting the individual through occupational tasks [22]. This approach was similar to that of Konstantinidis et al, 2016 [33], where the motion-based platform itself was designed to give instructions, prompts, praise, and guidance in order to train participants with dementia to use the technology and complete the activities.

Support Methods

Few articles mentioned the methods utilized to support people living with dementia or MCI during the interaction with the motion-based technology. Of interest is that verbal prompts and cues were often utilized as both teaching techniques and support methods [21,33]. In addition, movement cues and physical guidance were also offered as support methods for users by leading them through the sequence as required (eg, placing a hand over theirs) [35,44,47]. Fenney and Lee, 2010 [28] offered verbal prompts and cues to support participants with dementia during sessions as required, but otherwise they were encouraged to just play. By the end of the 9-week training, participants with dementia required significantly less prompting and were able to verbally explain and physically demonstrate the game instructions [28]. Furthermore, Siriaraya and Ang, 2014 [42] suggested the use of prompts to provide support to people living with dementia as required. This coincides with the

recommendations of Tobiasson et al, 2015 [45] who suggested that support methods for people with dementia regarding the game and the movements should be personalized to each individual (ie, giving the right amount and type of support that the person requires). Whereas several articles concluded that people living with dementia or MCI require less support over time while interacting with the motion-based technology [28,30,34,35,44,45], Cutler et al, 2015 [26] suggested that after a period of initial support, people with dementia may not require any ongoing support while using such technologies.

The FitforAll platform presented by González-Palau et al, 2014 [29] and Konstantinidis et al, 2016 [33] was designed to give instructions, prompts, praise, and guidance in order to support participants with dementia to use the technology and complete the activities. With this approach, the only involvement required from the therapists was meeting with participants once in 2 weeks to determine whether to raise, decrease, or maintain the current intensity level of the platform. In contrast, Billis et al, 2011 [20], who also presented the FitforAll platform, mentioned about trained therapists or psychologists who were present at every session to offer as much support to participants with dementia or MCI as needed. The reasoning behind this variation was not clear. Similar to Billis et al, 2011 [20], Benveniste et al, 2010 [19], and Boulay et al, 2011 [21], who used a motion-based music therapy platform called MinWii, also mentioned the use of trained psychologists or therapists who were present at all sessions to offer help to participants with dementia when required. However, they did not elaborate on exactly what help was offered or when.

Discussion

Principal Findings

Although the current literature supports the use of the motion-based technology for people living with dementia and MCI, this area of research is still in its infancy and requires further investigation. This review highlights the potential application of this technology across several contexts to improve the well-being of people living with dementia and MCI, including cognitive, physical, and leisure activities. As previously reported with the touchscreen technology [9], the focus of research till date has been on cognitive function rather than providing meaningful leisure pastimes. This is a particularly interesting result as participants from studies across all contexts reported that the motion-based technology, and the activities presented on this type of technology were enjoyable [19-21,24-26,30-33,39,44,45,47,48], engaging [19,20,24,25,28,30-34,41,47,48], usable [19-21,25,26,33,41], stimulating [30,31,33], empowering [24,26,34], fun [19,25,33,44], acceptable [46], motivating [28,39], encouraging [19], meaningful [34], and perceived as a positive experience overall [35,46]. This suggests that utilizing the motion-based technology to provide meaningful leisure activities for people living with dementia or MCI warrants further exploration.

The results also demonstrate that the motion-based technology can be utilized in both group and individual settings, highlighting the potential for application in a wide range of environments including personal houses, day programs, and long-term care homes. There was a relatively even distribution between the technology use in group and individual settings, although the reason for the choice was frequently not explained. From the review it appeared that technology applications relating to cognitive and physical parameters were more often conducted as individual sessions with leisure activities in groups. This may be because the group dynamics increases opportunities for social interaction and communication, while supporting teamwork, group cohesion, friendly competition, and intergenerational connections, which are more conducive to leisure use of motion-based technologies.

The majority of studies used commercially available technologies over the bespoke ones. Cases in which custom technologies were used, they had been designed to address specific cognitive and physical variables in an individual setting. The Nintendo Wii console was the most used commercially available hardware, with the Nintendo Wii Sports and Nintendo Wii Fit games (Nintendo Co Ltd) the most used activities. Although there was less research with the more recently created Xbox Kinect console (Microsoft Corp), the Kinect has significant potential for this population as the device does not use any kind of remote or controller, allowing for a more user-friendly and natural experience based purely on organic gestures. In addition, even though these commercially available devices are not specifically designed for this population, the findings suggest that this technology can still be of benefit to people living with dementia or MCI.

It is critically important for game developers to be considerate of the cognitive and physical challenges experienced by people with dementia or MCI while creating the motion-based technology software for this population. For example, the methods used within the literature to introduce, teach, and support people with dementia or MCI to interact with the motion-based technology could be integrated into aspects of the software (ie, games) to further enhance usability, enjoyment, and increase the potential of this type of technology even more. Future recommendations include collaboration with several stakeholders including people living with dementia or MCI, researchers, nonprofit organizations, day program staff, caregivers, and game developers. It is also recommended that further work involving individuals living with dementia or MCI in the design and development process is needed to fully realize the potential of this technology.

The most prominent gap in the literature related to a lack of information about how to introduce the technology, teach people with dementia or MCI to use it, and support them in continued use. Of the 31 articles included in the final review, only 19 [19-22,25,26,28-31,33-35,42,44-48] mentioned the methods used to help people living with dementia or MCI to learn and become competent with the technology. The literature shows clear evidence that people with dementia or MCI can and are willing to learn to use the motion-based technology; therefore, it is ideal to continue to discover and develop ways in which to optimally support these individuals to facilitate learning, enjoyment, and success. Further investigation is required to produce systematic guidelines for researchers, clinicians, care providers, and families to implement this technology to benefit people living with dementia and MCI.

Conclusions

Our findings have outlined several areas of knowledge regarding the use of the motion-based technology for people living with dementia or MCI, while highlighting gaps in the literature that warrant further investigation. With this, this review adds to the body of knowledge supporting the use of novel technologies to promote a good life for people living with dementia or MCI. It is clearly evident that people living with dementia or MCI can learn to use the motion-based technology and that this hardware can provide an avenue for cognitive stimulation, physical activity, and engaging leisure activities. However, further research regarding the introduction, teaching, and support of these individuals while using this type of technology is warranted, in addition to including their input in the development of hardware and software for this specific population.

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Conflicts of Interest

None declared.

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Abbreviations

MCI: mild cognitive impairment
NUI: natural user interface
PC: personal computer
TV: television

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Original Paper

Factors Associated With Weight Change in Online Weight Management Communities: A Case Study in the LoseIt Reddit Community

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Abstract

Background: Recent research has shown that of the 72% of American Internet users who have looked for health information online, 22% have searched for help to lose or control weight. This demand for information has given rise to many online weight management communities, where users support one another throughout their weight loss process. Whether and how user engagement in online communities relates to weight change is not totally understood.

Objective: We investigated the activity behavior and analyze the semantic content of the messages of active users in LoseIt (r/loseit), a weight management community of the online social network Reddit. We then explored whether these features are associated with weight loss in this online social network.

Methods: A data collection tool was used to collect English posts, comments, and other public metadata of active users (ie, users with at least one post or comment) on LoseIt from August 2010 to November 2014. Analyses of frequency and intensity of user interaction in the community were performed together with a semantic analysis of the messages, done by a latent Dirichlet allocation method. The association between weight loss and online user activity patterns, the semantics of the messages, and real-world variables was found by a linear regression model using 30-day weight change as the dependent variable.

Results: We collected posts and comments of 107,886 unique users. Among these, 101,003 (93.62%) wrote at least one comment and 38,981 (36.13%) wrote at least one post. Median percentage of days online was 3.81 (IQR 9.51). The 10 most-discussed semantic topics on posts were related to healthy food, clothing, calorie counting, workouts, looks, habits, support, and unhealthy food. In the subset of 754 users who had gender, age, and 30-day weight change data available, women were predominant and 92.9% (701/754) lost weight. Female gender, body mass index (BMI) at baseline, high levels of online activity, the number of upvotes received per post, and topics discussed within the community were independently associated with weight change.

Conclusions: Our findings suggest that among active users of a weight management community, self-declaration of higher BMI levels (which may represent greater dissatisfaction with excess weight), high online activity, and engagement in discussions that might provide social support are associated with greater weight loss. These findings have the potential to aid health professionals to assist patients in online interventions by focusing efforts on increasing engagement and/or starting discussions on topics of higher impact on weight change.

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KEYWORDS

obesity; online social media; weight loss; user behavior; topic modeling

Introduction

Obesity is a major public health problem that adversely impacts morbidity, mortality, and quality of life. According to the World Health Organization (WHO), the prevalence of obesity has nearly doubled over the last 30 years [1]. According to a survey conducted by the Pew Research Center in September 2013 [2], of the 72% of American Internet users that have looked for health information online, 22% have searched for help to lose or control weight. These numbers show that people are seeking health advice and support online, especially in topic-driven communities and forums, Q&A sites (eg, Quora), and social media, including Twitter, Facebook, and Reddit [3,4].

Along with the growth of online searches for health advice, there has been a shift of social interactions from the real to the virtual world with the popularization of online social networks [5]. Most of these networks consist of communities organized according to user interests, including obesity and weight management groups. In contrast with real-world social groups, online social networks have no time restrictions, may be accessed from anywhere at no cost, and provide a constant source of information, support, and advice [6].

Among the factors that play a major role on the success of weight loss in online social networks are individual features and social embeddedness. Social embeddedness encompasses the structure and intensity of individual connections—reflecting different forms of engagement and participation in the community [3,5]—and it has been investigated across different weight management online communities [6-8]. Although social embeddedness has shown to strongly correlate with weight loss, most studies have mainly looked at the structural connections of the networks (ie, who connects to whom) [9]. Topics discussed by engaged users may also be as important as their engagement in the community. The linguistic style and semantics associated with the topics discussed might also be important features because they provide insights on personality, attitudes, and behavior, which in turn correlate with health outcomes [10]. However, most analyses look at syntactic features of the text, including word counts or the presence of positive or negative constructs [11,12]. Concerning the semantics of the messages, only a few qualitative studies focusing on small groups of users were able to analyze it. This is mainly due to the difficulties of automatically extracting semantics from text.

Analyses focusing on the behavior of users and the syntactic meaning of their texts are becoming common practice, not only in online health communities, but also in other contexts where user behavior in online social media can provide relevant information, including customer behavior [13] and citizens' engagement with politics [14]. For instance, many marketing-related studies have proposed different theoretical frameworks to help understand the behavior of customers in virtual brand communities [15,16] or to identify the reasons for customers engaging online [17]. These frameworks and associated reasoning, despite being similar to ours, are not directly applicable to the health context. This is because the reasons for patients to engage on health communities are different from those of customers in a brand community and, most importantly, the role of the community toward users in both contexts differs significantly. Health online social network users are motivated mainly by having the opportunity to talk to users going through the same experiences without feeling pressure from society because obesity is still stigmatized. Furthermore, weight-loss communities present a large opportunity for ordinary users and health agents to perform both direct and indirect mental health and social support interventions, improving users' self-motivation to lose weight and increasing their self-esteem [18,19].

In this paper, we describe both the activity behavior and analyze the semantic content of the messages of the LoseIt (r/loseit) online Reddit weight-loss community and investigate whether these factors are associated with weight loss in this online social network using different inputs to a regression model.

Methods

Data Collection

Reddit is an online forum organized in subcommunities by areas of interest called subreddits. We used Python Reddit Application Programming Interface (API) Wrapper (PRAW) [20], a Python package that eases access to Reddit's official API, to collect the dataset from a Reddit subreddit called "LoseIt" [21], which is a community in which people interact about weight-loss issues [22]. Reddit users may submit content, such as texts or direct links to other sites, both collectively referred to as "posts." The community can then vote posted submissions up (upvotes) or down (downvotes) as a sign of "liking" or "disliking" it. Users can also reply to posts with comments. One interesting aspect of Reddit is the anonymity of user accounts. In this study, users were identified by their system log-in. Data on real-world characteristics (age, gender, anthropometric measures), online activity behavior, and linguistic style were collected in English-written posts, comments, and tags in LoseIt from August 2010 to November 2014 [23].

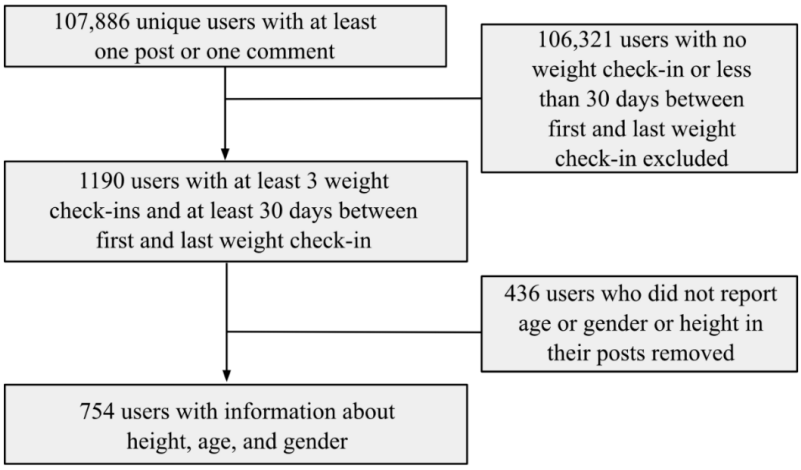
Study Measures

Self-reports of weight, known as weight check-ins, included start weight, current weight, and goal weight. To deal with multiple reports of start weight (65/1190, 5.46%) per user, we selected the ones with the longer interval between start weight and current weight. To be considered for analysis, this interval had to be at least 30 days in an attempt to minimize the effect of short-term weight variations not related to fat loss on our outcome [24]. For a subset of users with this data available (n=1190), we collected data on age, gender, and height, and

calculated body mass index (BMI) as BMI=weight (kg)/height (m^2), obtaining a final sample of 754 users, as depicted in Figure 1. We categorized BMI according to the WHO criterion [25] of normal (BMI<25 kg/m^2), overweight (25<BMI<30 kg/m^2), class I obesity (30<BMI<35 kg/m^2), class II obesity (35<BMI<40 kg/m^2), and class III obesity (BMI≥40 kg/m^2).

Measures of online activity were undertaken in relation to individual use (per user) and temporal activity. Data on the number of posts and comments (per time and per user), number of upvotes received per post and comment, number of comments received per post, and the number of weight check-ins were collected. We also computed the lifespan of a user, defined as the period of time between his/her first and last activity, and assessed the proportion of days online (days when a user posted or commented) and the number of active weeks. For assessing temporal patterns of activities, we derived a weekly temporal series for each user life span in LoseIt that estimated user participation over time (ie, we computed his/her number of activities in that week for each week in the lifespan of the user).

Figure 1. Flowchart of the user selection process.



Semantic Analysis of Text

After removal of special characters and stop words (the most common words in a language), we created a matrix of posts/comments per terms (words) using the term frequency [26]. This matrix was used as input to a semantic analysis of the messages through topics using latent Dirichlet allocation (LDA) with Gibbs sampling [27]. LDA assumes that there are hidden variables (topics) that explain the similarities between observable variables (posts or comments). The parameter for the number of topics was empirically defined as 50 and the method run for 2000 iterations. For each post/comment, LDA returns the probability of it being associated with a topic. Each topic, in turn, is represented as a set of words, in which each word is also associated with a probability of describing a topic. For each topic, we manually associated a label with the message given by its descriptive words and associated posts/comments.

Statistical Analyses

Dataset characteristics were described by mean and standard deviation (SD), median and interquartile range (IQR), or frequencies.

We performed three linear regression models to investigate the association between weight change over at least 30 days and users' real-world characteristics (model 1: age, gender, BMI), activity behaviors (model 2: number of activities, comments received, upvotes received, number of weight check-ins, lifespan, percentage of days active, number of days active, number of days offline, number of weeks active, and if the user has a verified email), and semantics extracted from text (model 3: the 26 most-discussed topics of posts and comments selected from a set of 100 topics using the Akaike information criterion) on weight change (over at least 30-day interval). For model 3, summed and normalized probabilities returned by the LDA for each user's post or comment per topic were given as input to the regression model. Regression models were compared using the coefficient of determination (R^2) and the adjusted R^2, which also accounts for the number of variables included in the model.

To evaluate the generalization power of the models, we executed a 10-fold cross-validation [28]. This method divides the data into 10 nonoverlapping folds and uses nine parts to fit the model and one (also called test set) to measure its generalization performance. This procedure is repeated 10 times, each time with a different fold as the test. At the end of this process, the mean and standard deviation over the 10 folds are reported, together with the correlation between the real and predicted values in the user test set. All data were analyzed using R (MASS and caret packages).

Results

Data Sample Analysis

Over the 4-year follow-up, 107,886 of 252,279 (42.76%) Reddit users were active (ie, users with at least one post or comment). Among these, 101,003 (93.62%) wrote at least one comment and 38,981 (36.13%) wrote at least one post. For posts, 1621 of 107,886 users (1.50%) contributed more than five times, suggesting that this group starts several discussions around weight-loss problems. These users were the ones who remained

active in the network for longer, with a median of 72 (IQR 78) active weeks versus a median of 1 (IQR 18) active weeks for the remaining users. We observed that more than 95.39% (64,281/67,387) of posts had at least one upvote. Considering the top 5.00% (3370/67,387) most upvoted posts, they all received more than 100 upvotes, suggesting that some posts do call the attention of the community and receive its support. Characteristics of the dataset are shown in Table 1.

Table 1. Overall characteristics of the LoseIt dataset.

Statistics	Median (IQR)	Mean (SD)
Posts per day	45.0 (30.0)	45.5 (22.7)
Posts per user	0 (1.0)	0.7 (1.8)
Comments per day	599.0 (333.0)	586.7 (264.3)
Comments per user	2 (4.0)	7.9 (34.4)
Upvotes per post	6.0 (16.0)	35.7 (126.7)
Upvotes per comments	2.0 (2.0)	3.1 (11.4)
Weight check-ins per user	2 (2.0)	2.7 (3.6)
Activities per user	2 (5.0)	8.5 (35.3)

For weight check-ins, 8834 of 107,886 (8.18%) users had at least one weight check-in. Among them, 6622 users declared a start weight, 6303 a current weight, and 3074 a goal weight. Among all users who declared a start weight, 65 (0.1%) declared it more than once, with 34 of 65 (52%) decreasing its value. The same happened with goal weights, which might indicate that 1.01% (31/3074) of the users reassessed their goal weight. In total, 19 of 31 users (62%) with more than one report reduced their initial goal weight, whereas 12 of 31 (38%) increased it.

User Online Activity

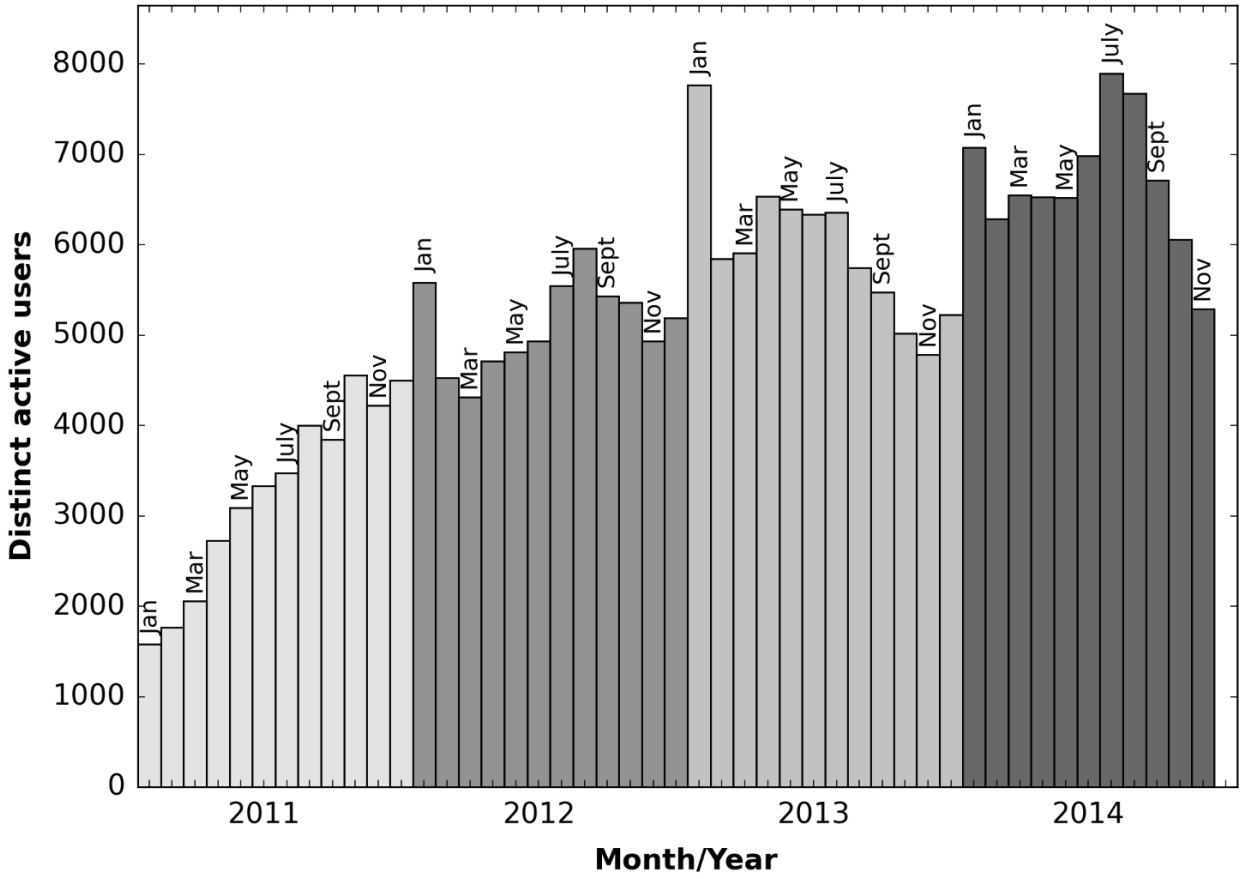
Figure 2 shows the distribution of the number of distinct active users in the community over the follow-up period. Overall, the number of unique active users increased over time, with high values in January (motivated by New Year's resolutions) and July to August (northern hemisphere summer).

Table 2 shows information about the user lifecycle. Considering the dates of the first and last activity, 50,705 of 107,886 (46.99%) users had a lifespan of one day, meaning they had a single activity in the network. Nevertheless, such short lifespans do not necessarily mean they left the community because they may have been simply acting as lurkers (ie, readers only). In contrast, 10,874 of 107,886 (10.08%) users had a lifespan longer than 1 year (449 days), and 543 of 107,886 (0.50%) reached 2 years (682 days). The longest life span was 1566 days (223 weeks). Disregarding the users who were active only once, for the 57,181 remaining users, the activity peak of 37,802 (66.10%) users was in week 1. Further, 45,403 of 57,181 (79.40%) users in the dataset reached their peak before week 10. In contrast, the peak for 3.54% (2024/57,181) of users was after week 40.

Table 2. Statistics about users' lifecycles on LoseIt.

Lifecycle	Median (IQR)	Mean (SD)
Life span (days)	2 (132.0)	124.60 (238.64)
Percentage of days online	3.81 (9.54)	11.11 (17.97)
Weeks with activities	1 (2.0)	3.05 (5.09)
Peak of activity (week)	1 (0.0)	5.35 (15.88)

Figure 2. Number of distinct active users on LoseIt per month. Different colors correspond to different years.



Semantics Extracted From Text

Table 3 shows the 10 topics most frequently found in posts and messages, which are representations of the semantics of the posts. Note that by simply looking at the words describing topic 1, for instance, one might say they do not necessarily refer to healthy food, but the qualitative analysis together with the messages used allow us to state that. Also, notice that we may have more than one topic with the same label. This happens because the method used to extract the topics (LDA) does not guarantee they are unique. Examples of topics include information about workouts (topics 4 and 8) and the best ways to control calorie intake (topics 3 and 5). The topics in the comments are not that different from those in posts, although a strong presence of user support is frequently found in comments. The following comment illustrates the type of message we were dealing with:

> *Good work dude, I am in the same boat you are...I recently started strong lifts as well as the low-carb high-protein diet it's awesome and I rarely feel hungry. Keep it up dude and when you feel comfortable post some pics. When I hit my first milestone of 50 lbs I will be posting some...hopefully soon down to go.*

Table 3. Most frequently discussed topics in the LoseIt community for users' (N=38,981) posts (n=67,387) and users' (N=101,003) comments (n=771,146).

Given label	Top descriptive words	Posts, n (%)
Posts		
1. Healthy food	Chicken, lunch, diner, breakfast, salad	3489 (5.18)
2. Clothing	Size, fit, clothes, shirt, pant	2873 (4.26)
3. Calories count	Calorie, day, counting, per, intake	2550 (3.78)
4. Workout	Run, running, mile, minute, walk	2305 (3.42)
5. Calories count	Using, use, mfp, track, myfitnesspal	1976 (2.93)
6. Looks	Fat, body, muscle, stomach, skin	1952 (2.89)
7. Habits	Water, drink, soda, drinking, cut	1933 (2.87)
8. Workout	Cardio, workout, minute, training, lifting	1875 (2.78)
9. Support	Loseit, thank, everyone, post, thanks	1831 (2.72)
10. Unhealthy foods	Food, eat, pizza, one, ate	1803 (2.67)
Comments		
1. Support	Great, look, awesome, job, amazing	44,829 (5.81)
2. Food	Chicken, cheese, salad, vegies, cup	38,960 (5.05)
3. Clothing	Size, fit, skin, clothes, loose	34,155 (4.43)
4. Calories count	Calorie, day, counting, eat, deficit	21,458 (2.78)
5. Calories count	Use, scale, track, using, mfp	21,081 (2.73)
6. Weight control	Week, pound, month, lost, two	20,610 (2.67)
7. Self-esteem	See, look, picture, progress, difference	20,588 (2.67)
8. Workout	Run, running, minute, mile, walking	20,450 (2.65)
9. Support	Feel, like, better, feeling, much	19,249 (2.49)
10. Testimony	Self, not, problem, control, issue	19,232 (2.49)

Understanding Weight Change

As showed in Figure 1, data on real-world characteristics were only available for 754 users; hence, the investigation of the factors associated with weight change is limited to this subsample. In this sample, 56.5% (426/754) of users were female and the mean age was 26 (SD 6) years. The mean difference between the start and goal weights was 35.6 (SD 24.8) kg; 3.7% (28/754) of users gained weight (mean 3.88%, SD 4.04), 3.5% (25/754) maintained weight, and 92.9% (701/754) lost weight. Overall, 514 of 754 users (68.2%) moved to a healthier category while participating in the LoseIt community as depicted in Table 4.

Table 4. User distribution according to initial and final obesity categories.

Initial category	Final category, n					
	Normal	Overweight	Obese I	Obese II	Obese III	Total
Total						
Normal	25	2				27
Overweight	70	58	1			129
Obese I	37	105	46	1		189
Obese II	10	52	76	32	1	171
Obese III	4	36	61	63	74	238
Female						
Normal	23	1				24
Overweight	60	39	1			100
Obese I	21	65	23	1		110
Obese II	8	23	35	11	1	78
Obese III	2	14	30	27	41	114
Male						
Normal	2	1				3
Overweight	10	19				29
Obese I	16	40	23			79
Obese II	2	29	41	21		93
Obese III	2	22	31	36	33	124

Among weight losers, 350 lost up to 14.2% of their start weight and the top 10.0% (70/701) of weight losers lost between 29.4% and 57.7% of their start weight. Median weight loss was 41.6 (IQR 41.4) kg. In general, weight losers were active users; on average, they contributed mean 3.55 (SD 6.11) posts, made mean 59.21 (SD 164.01) comments, and received mean 50.26 (SD 106.05) comments.

Table 5 shows the regression coefficients found in the models for different variables along with their standard errors (SE) and *P* values. A positive coefficient indicates the variable is correlated to an increase in weight loss, whereas a negative coefficient indicates the variable is related to a decrease in weight loss. The *P* value for each term tests the null hypothesis that the coefficient is equal to zero (no effect). A low *P* value (<.05) indicates that you can reject the null hypothesis (ie, the predictor is likely to be a meaningful addition to the model because changes in its value are related to changes in the response variable).

Table 5. Variable coefficients (and their standard errors) found by three linear models accounting for different factors associated with percentage weight loss.

Variable	Model 1		Model 2		Model 3	
	Coefficient (SE)	*P* value	Coefficient (SE)	*P* value	Coefficient (SE)	*P* value
Real world						
BMI	0.517 (0.090)	<.001	0.415 (0.090)	<.001	0.371 (0.044)	<.001
Gender	–1.357 (0.140)	<.001	–1.979 (1.570)	<.001	–1.471 (0.781)	<.001
Age	0.235 (1.630)	.88	0.126 (0.140)	.36	0.118 (0.069)	.09
Online behavior						
Activity			–0.008 (0.005)	.11	–0.006 (0.001)	.01
Comments received			0.120 (0.007)	<.001	0.005 (0.003)	.12
Upvotes received			0.002 (0.001)	.04	0.002 (0.000)	<.001
Number of weights			0.270 (0.120)	.02	0.288 (0.058)	<.001
Weeks active			0.008 (0.070)	.90	0.089 (0.033)	<.001
Off days			–0.004 (0.002)	.04	–0.004 (0.001)	<.001
Post topics						
Weight control apps					–57.26 (26.68)	.03
Self-esteem (1)[a]					118.50 (24.49)	<.001
Self-esteem (2)[a]					48.03 (27.47)	.08
Workout					37.22 (20.05)	.06
Friendship					83.72 (28.31)	.003
Health information					44.84 (31.49)	.15
Weight goals					77.90 (26.99)	.004
Feelings					–125.00 (37.61)	<.001
Asking for advice					68.97 (44.70)	.12
Motivation					68.51 (52.50)	.009
Weight check-ins					42.02 (26.25)	.10
Family					–47.16 (30.94)	.12
Comment topics						
Body transformations					112.60 (59.71)	.06
Asking for help					235.70 (96.420)	.01
Body measures					–290.90 (108.20)	.007
Changing lifestyle					–219.20 (141.40)	.12
Counting calories					187.40 (71.55)	<.001
Asking for support					–134.20 (63.51)	.03
Friendship					223.40 (105.20)	.03
Workout					295.30 (72.43)	<.001
Motivation (1)[a]					304.80 (149.60)	.04
Weight goals					243.00 (66.50)	<.001
Motivation (2)[a]					251.80 (100.50)	.01
Healthy foods					173.70 (91.41)	.05
Gratitude					160.20 (72.06)	.02
Starting again					–231.40 (106.10)	.02

Variable	Model 1		Model 2		Model 3	
	Coefficient (SE)	*P* value	Coefficient (SE)	*P* value	Coefficient (SE)	*P* value
Lifestyle change					221.00 (99.84)	.03

[a] Topics generated by latent Dirichlet allocation may overlap. The posts and comments for both self-esteem and motivation appear in two different topics, here indicated by (1) and (2) after their names.

Regarding the association between weight change and real-world characteristics, online activity behavior, and the semantics from text, we found that a higher initial BMI, higher number of weight check-ins and upvotes, the amount of time spent in the community, and the topics of comments and posts (self-esteem, friendship, motivation, asking for help, counting calories, workout, gratitude) were directly and independently associated with weight loss. Conversely, some topics (weight control apps, feelings, body measures, asking for support) were inversely associated with weight loss.

The addition to variables related to online activity behavior and topics to the model led to an improvement on its ability to explain weight loss (from R^2=.18 in model 1 to R^2=.26 in model 2 and from R^2=.26 in model 2 to R^2=.39 in model 3, respectively). The adjusted R^2 did not change for models 1 and 2, and decreased from .39 to .36 in model 3. As assessed by the cross-validation procedure, our final model showed generalization power and robustness with an R^2 mean of 0.39 (SD 0.01) and a weight loss correlation of 0.83 (SD 0.01).

Discussion

Knowing about characteristics, experiences, and interests of users might be of great value for improving weight-loss strategies in online communities. Our analyses have shown that the LoseIt users' activities are usually concentrated in their first 10 weeks in the community, when they are probably most motivated with the weight-loss process. Most of the active users reported that they lost weight, with approximately 70% moving to a lower obesity category. In addition, we found that users who reported weight change within a 30-day minimum interval were predominantly women, who declared themselves as overweight or obese. Female gender, BMI at baseline, high levels of online activity and of support (as measured by upvotes), and specific topics discussed within the community independently determined weight loss.

The predominance of women in comparison to men in our study may reflect both the higher prevalence of overweight and obesity among women in the general population [29] and a greater awareness of excessive weight among women in comparison to men [30]. Moreover, it may reflect the fact that women are more likely to pursue weight control [30,31] and to use the Internet to search for health information than men [32]. However, male sex was associated with greater weight loss. In real-world interventions, gender differences in success rates following short-term weight-loss programs are controversial [33], despite males' higher metabolic and lipolytic rates [34]. In practice, these differences in gender composition of online communities might suggest that several dimensions of weight history that are known to be different between men and women should be considered for customizing apps for weight loss. For instance, the online community can be programmed to approach emotional eating (in response to mood) and social eating (eating in social situations) differently according to the gender of the user because emotional eating has been reported to be more common in women and social eating more common in men [33].

In this study, BMI was positively associated with weight loss. Because weight and BMI were self-reported, we might imply that the higher the baseline BMI, the greater the perception of excessive weight and/or dissatisfaction with weight status. Weight perception accuracy and dissatisfaction with weight status have been consistently associated with trying to lose weight and better weight control among obese and overweight adults in population-based studies [35]. However, due to the cross-sectional nature of our study, it is not possible to establish causality between self-declaration of high BMI and successful weight loss.

The number of weight reports, which may be a proxy of regular weight automonitoring, was directly associated with weight loss. Regular self-weighing has been reported as a useful tool for weight loss because it might provide feedback on energy balance status and consequent improvement in self-regulation [36]. It is not possible to establish a causal link between more frequent reporting and losing weight, but because individuals with greater weight loss might be more motivated to report their weight, it has been reported that self-reports of weight are more accurate among those who lose weight than among those who do not [37].

Various measures of online activity were independent predictors of weight loss. Higher participation levels in the online social network might unveil higher levels of self-motivation, which has been associated with better weight-loss outcomes following real-world interventions as well [38]. Therefore, developing strategies that improve self-motivation and maintain users active in the online community should be a cornerstone of Web-based weight-loss apps. These strategies might involve a more personalized approach with a deeper understanding of the uniqueness of the situation and needs of each user. In contrast with real-world situations, it has been reported that, among patients who seek health care for weight loss, the perception of the individual's needs by health professionals was associated with higher rates of weight loss and adoption of healthy lifestyle habits [39]. Understanding that users have different demands in regard to the various types of social support [40], and developing computational algorithms to recognize these differences, might be key points to offer personalized assistance and enhance users' activity in online social network.

Patients report that nonjudgmental and empathic interactions with health professionals are key points to achieve success in

weight-loss programs in the real world [41]. Upvotes in online communities might lead to a sense of social belonging and improve perceived empathy of the user within the community [40]. This probably explains the positive association we found between the number of upvotes and weight loss. A satisfactory interaction between users can be accomplished in an online social network by moderation of posts and comments that might be stigmatizing or demotivating and implementation of rating systems that allow users to rate the usefulness of posts and comments.

The finding that adding topics discussed in posts and comments to the model that explains weight change led to a great improvement in the coefficient of determination of the model suggests that an online community should provide different types of social support to users to be effective because most topics reflect some kind of support. Social support in health communities has been shown to be associated with maintenance of health behavior change [42] and better weight-loss outcomes in real-world interventions [42,43]. Most of the topics that were significant determinants of weight loss can be associated with three of the four types of social support. Emotional (ie, provision of empathy) and/or appraisal (ie, provision of information that is useful for self-evaluation purposes) support might have been provided to users in posts and comments that discussed self-esteem, motivation, and friendship, for example. Informational (ie, provision of advice, suggestions, and information that may be used to solve problems) and appraisal support might have been provided by discussions regarding counting calories, body transformations, workout, healthy food, lifestyle changes, asking for help, and gratitude. Implementing computational strategies to recognize the topics discussed by users and making active efforts to maximize the engagement of users in forums that address these topics might be effective tools in online weight-loss programs.

A few topics we expected to show positive association with weight loss, such as weight control apps, body measures, feelings, and asking for support, showed a negative association to it. Regarding weight control apps, we can infer that users who talked about them in LoseIt might not have followed the interventions of the app appropriately because they may not have decided yet which weight control app to use. Concerning body measures, users talking about it might have been frustrated by their results or might have set unrealistic weight goals. Both conditions might be associated with less successful weight loss. Users who talked about feelings or asked for support probably did not feel appropriately supported, which might be related to unsuccessful weight loss.

We acknowledge some limitations of our study. The exclusion of less-engaged LoseIt users might have introduced a selection bias, which limits the generalization of the findings to active users of a closed online social network. Although it is not possible to exclude the possibility that unique users have multiple system log-ins, this issue probably did not influence our weight loss analyses due to the large sample size. Additionally, as in other studies with online communities, we relied on self-reports of weight, which may have reduced accuracy. The use of regular expressions for obtaining weight check-ins and real-world variables limited our data extraction and precluded us from having these data from the complete dataset. Furthermore, it was not possible to evaluate the influence of other factors that might impact LoseIt users' weight change, such as dieting and exercise planning. Due to the cross-sectional nature of the study, it is not possible to infer causality between the investigated factors and weight loss.

As major strengths, we must highlight the use of a quantitative methodology, which automatically looks at our measures of interest and allows for an analysis of a big sample, the long-term follow-up of the social network, and the investigation of the influence of real-world, online behaviors and semantics of online discussions on weight change reported by users of the online social network. We focus on a content-centered community instead of a user-centered one (ie, users in Reddit do not have connections to people but to posts), where the role of semantics may be even more accentuated. The semantics, analyzed with LDA, is a good way to summarize the topics being discussed as well as represent the interests of individual users.

In conclusion, our findings show that users who are more active and engage in discussions that provide emotional, informational, and appraisal social support are the ones with more successful weight loss in the online social network LoseIt. With increasing access worldwide to computers, apps, and the Internet, as well as the substantial amount of health care resources demanded by the high prevalence of obesity—particularly at young ages—online communities might be important public health strategies for obesity treatment and prevention. To potentialize the benefit of these communities, specific features that increase online activity should be investigated and incorporated to the online social network. Furthermore, activities that stimulate social support among users might be key points in the planning of online weight-loss interventions.

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Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface
BMI: body mass index
LDA: latent Dirichlet allocation
WHO: World Health Organization

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Original Paper

Ecological Assessment of Clinicians' Antipsychotic Prescription Habits in Psychiatric Inpatients: A Novel Web- and Mobile Phone–Based Prototype for a Dynamic Clinical Decision Support System

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Abstract

Background: Electronic prescribing devices with clinical decision support systems (CDSSs) hold the potential to significantly improve pharmacological treatment management.

Objective: The aim of our study was to develop a novel Web- and mobile phone–based application to provide a dynamic CDSS by monitoring and analyzing practitioners' antipsychotic prescription habits and simultaneously linking these data to inpatients' symptom changes.

Methods: We recruited 353 psychiatric inpatients whose symptom levels and prescribed medications were inputted into the MEmind application. We standardized all medications in the MEmind database using the Anatomical Therapeutic Chemical (ATC) classification system and the defined daily dose (DDD). For each patient, MEmind calculated an average for the daily dose prescribed for antipsychotics (using the N05A ATC code), prescribed daily dose (PDD), and the PDD to DDD ratio.

Results: MEmind results found that antipsychotics were used by 61.5% (217/353) of inpatients, with the largest proportion being patients with schizophrenia spectrum disorders (33.4%, 118/353). Of the 217 patients, 137 (63.2%, 137/217) were administered pharmacological monotherapy and 80 (36.8%, 80/217) were administered polytherapy. Antipsychotics were used mostly in schizophrenia spectrum and related psychotic disorders, but they were also prescribed in other nonpsychotic diagnoses. Notably, we observed polypharmacy going against current antipsychotics guidelines.

Conclusions: MEmind data indicated that antipsychotic polypharmacy and off-label use in inpatient units is commonly practiced. MEmind holds the potential to create a dynamic CDSS that provides real-time tracking of prescription practices and symptom change. Such feedback can help practitioners determine a maximally therapeutic drug treatment while avoiding unproductive overprescription and off-label use.

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KEYWORDS

clinical decision-making; antipsychotic agents; software; mobile applications; off-label use; prescriptions

Introduction

From Electronic Health Records to mHealth Applications

Over the last decade, management of patients in hospitalization units has been supported by the emergence of electronic health records (EHRs) [1]. This software facilitates portability and processing of pertinent health and pharmacological treatment information [2]. These systems can support prescription practice and help practitioners determine maximally therapeutic pharmacological treatments while avoiding pitfalls such as off-label use, polypharmacy, and overly high dosages. Moreover, the emergence of electronic prescribing or e-prescribing devices with clinical decision support systems (CDSSs) has significantly reduced diagnosis and prescription error rates [3]. However, it remains difficult to extract clinically relevant information from current CDSS tools, as these data are often not tailored to the exact needs of the patient and clinician [4]. The availability of mobile phones and other handheld computers provides the opportunity to improve prescription practices in institutions where e-prescribing systems are not yet available. For example, Web-based and mobile phone–based programs permit the gathering of naturalistic data that can be processed immediately and provide instantaneous decision-making assistance to clinicians [5,6]. Overall, the appearance of these devices in medical practice has heralded the mobile health (mHealth) era, which in turn falls under the umbrella of electronic health (eHealth), where mobile devices are used to advance public health [7]. The combination of high levels of mental illness and high levels of mobile phone usage worldwide highlights the potential for mH^2 interventions (ie, mHealth mental health interventions) [8].

Wirelessly connected technologies have also increased communication and data transfer between clinicians and their patients, which further helps achieve these mHealth goals [9]. The processing of naturalistic data is especially critical given the enormous complexity of individual conditions [10]. Data mining techniques can also allow for automatic extraction of meaningful data from large clinical databases, which can help answer important treatment and outcome questions and refine best practices. Moreover, this data mining can help develop algorithms and guidelines to help care providers who require assistance [11]. These algorithms may be of particular interest to prescribers and can be used to improve the incorporation of prescription guidelines into clinical practice [12].

Challenges in Managing Psychopharmacological Treatments

However, despite these technological advances, the management of psychopharmacological treatment still grapples with many challenges. Antipsychotics are widely prescribed in psychiatric inpatient units and, as a result, off-label use is common. Although they are mostly prescribed in schizophrenia spectrum and related disorders, antipsychotics are also used off-label in a range of chronic diseases and they have been utilized as augmentation for depressive disorder [13], autism spectrum disorders [14], or off-label use, which is controversial but not uncommon [15]. For example, one study conducted across 7 provinces within Spain showed that antipsychotics were not only used in schizophrenia (22.8%) but also in other psychiatric disorders such as bipolar disorder (14.4%), depressive disorders (12.5%), personality disorders (9%), substance use disorders (1.3%), and dementia (4.5%), with 32.8% considered off-label uses [16]. Antipsychotic polypharmacy (APP) is also controversial yet quite common. APP is the use of 2 or more antipsychotics concurrently by a single patient. APP is commonly used against general clinical guideline recommendations [17]. A recent systematic review of APP prevalence between 1970 and 2009 found in a sample of 1,418,163 patients with mental disorder (82.9% with a diagnosis of schizophrenia) a median APP prevalence of 19.6% across different geographical regions, ranging from 6% to 90%, with higher median prevalence in Asia (32%) and Europe (23%) compared with North America (16%) and Oceania (16.4%) [18]. APP differs according to treatment setting, requiring more extended use in greater illness severity, such as that in inpatient settings [19,20]. In Spanish inpatient settings, APP is common with 47.1% of patients in a psychiatric hospital [21] and figures between 40% and 50% in psychiatric brief hospitalization units [22]. These studies highlight the discrepancy between guidelines and the real-world treatment. We can observe a paradigm shift in APP from discouraging all uses of polypharmacy to determining patient profiles that could benefit from polypharmacy [23]. In a naturalistic observational study, Gaviria et al [24] analyzed existing EHRs to collect data on prescription habits in a sample of 1765 patients with schizophrenia. Out of the sample of 1765 patients, 505 (28.6%) were receiving treatment with antipsychotic monotherapy, whereas 1229 (69.6%) were receiving 2 or more antipsychotics. Another concern regarding antipsychotic prescription is the use of antipsychotics above their recommended doses. Overly high dosage can increase risk for adverse reactions and increases treatment cost without clear evidence of added therapeutic benefit [24]. This practice, although prevalent in clinical settings, is discouraged in clinical guidelines [25]. These challenges

highlight the importance of exploring innovative prescription monitoring methods for the field of mental health.

Toward a Mobile Clinical Decision Support System

Given the many proven benefits of EHRs for clinical practice, EHRs may also provide a possible solution to the issues that exist with antipsychotic prescription habits. Specifically, EHRs are a major source of structured data that can provide useful and ecologically valid insights into how antipsychotics are prescribed. These EHR systems, however, presented many limitations that are related to the methodology of such studies. First, conducting clinical research using data produced by EHRs can be challenging, as the timing, quality, and comprehensiveness of the clinical data often do not meet the rigorous standards of clinical research. Furthermore, owing to the architecture of traditional EHRs, data cannot be processed instantaneously to deliver a CDSS. Before delivering a CDSS, data must be deidentified as well as statistically analyzed, which has not yet been automated by software into an instantaneous process. Notably, most studies that use EHRs to describe antipsychotic habits implement retrospective methods [26]. As a result, researchers and clinicians miss the opportunity to process gathered data in the moment and use these data for clinical decision making. Finally, EHRs are usually only accessible as expensive commercial software packages, which precludes assessment of inpatients treated by institutions outside of large, mainstream health care institutions.

Web-based and mobile phone–based prescription management tools exhibit numerous advantages over these expensive, mainstream EHR software packages. Specifically, the low development cost and increasing popularity of mHealth apps (ie, health-related software applications) have made them particularly accessible across both large and small psychiatric care settings. In addition, mHealth apps often feature simple interfaces, can be used wirelessly from any location with a cell signal, and provide adequate computing power to provide CDSS capability. For the most part, these mHealth apps in mental health have been directly marketed to either consumers or small clinical practice settings. A review of mobile phone apps for schizophrenia found only 5 studies of mobile phone apps for patients with schizophrenia. All examined feasibility, and one assessed the preliminary efficacy [27]. For example, Nicholas et al [7] showed that the contents of currently available apps for bipolar disorder are not in line with practice guidelines or established self-management principles.

Taking into consideration the strengths and pitfalls of each of these strategies, our aim was to develop a Web application that could monitor prescription habits in psychiatric inpatient units. This study presents the preliminary step in the development of a CDSS. Our hypothesis was that a Web application developed for this study may be able to describe clinicians' prescriptions in a sample of inpatients. The objective of this study was to describe via the MEmind Web application the prescription habits of antipsychotics in a naturalistic inpatient setting focusing on off-label uses and APP.

The ultimate goal of this MEmind prototype is to allow physicians to provide more effective care while better adhering to clinical guidelines.

Methods

Study Design

This pilot study was a 5-month, multicenter, nonrandomized, and observational feasibility study. Participants were adults admitted in 2 brief psychiatric inpatient units (Fundación Jiménez Díaz Moncloa Hospital and Pontones Hospital, Madrid, Spain).

Setting

The 2 brief psychiatric inpatient units are part of the Department of Psychiatry of the Fundación Jiménez Díaz Hospital, which belongs to the National Health Services and provides medical coverage financed by taxes to a catchment area of ~800,000 people. A total of 4 psychiatrists are in charge of the 20 beds in each of these units. Roughly 14 nurses cover 3 work shifts in both units. Patients admitted were treated as usual. The psychiatrist in charge of the patient proposed participation in the study after verification of the inclusion criteria.

Inclusion and Exclusion Criteria

Inclusion criteria were either males or females, aged 18 years or older, who were admitted to a psychiatric inpatient unit, and who gave written informed consent. Participants were excluded from the study if they were younger than 18 years, incarcerated, under guardianship, were enrolled in other trials, or were in emergency situations where their state of health did not allow for obtaining written informed consent.

Study Procedure

During their hospitalization in the psychiatric unit (PU), all patients were assessed with the MEmind Web application after giving written informed consent. The MEmind application was developed for the study by an industrial partner and is available online for download via a secure link provided to the participant via email. The application was designed to gather observational data and to perform ecological momentary assessment (EMA). It has 2 distinct views: the clinician view and the patient view. The "clinician" view is designed to be used by doctors and nurses during their clinical rounds and during their medical or nursing visits (see Figure 1, which displays the MEmind Web application). MEmind was also designed to capture all the data typically gathered during a standard medical evaluation, including sociodemographic, diagnostic, and pharmacological treatment information. MEmind's design is based on commonly stored information in mental health management. To this end, the care providers can customize the software to add a number of large relevant scales to suit their individual needs (eg, the specific needs of research vs clinical settings). At the time of discharge, we collected patients' sex, age, diagnosis, and treatment types during their stay in the psychiatric unit. As the study was performed in Spanish mental health centers, the Spanish version of the tutorials for mental health professionals was used. In addition to the clinician view, the MEmind program features a patient view that allows patients to track their symptoms using EMA techniques. This feature was not assessed in our study. Medication compliance was not assessed in this study. For the purposes of this study, we monitored patients' diagnoses and clinicians' prescriptions. The only users who

accessed the app were the clinicians who recorded their prescriptions directly into MEmind's clinician interface. Clinicians could access the Web application either from a computer or their personal mobile phone.

Clinical diagnoses and treatment prescription were conducted during hospital admission as part to routine psychiatric evaluations that incorporated data from medical records, other research assessments, and clinical interviews. All diagnoses recorded into the MEmind app were coded according to the *International Classification of Diseases, Tenth Revision*, for mental disorders alongside the data from these aforementioned psychiatric evaluations.

Figure 1. View of the MEmind Web application.

Outcome Measures

Antipsychotic medication treatments were recorded into the MEmind app and then classified according to the Anatomical Therapeutic Chemical (ATC) classification system and the defined daily dose (DDD). For each patient, the treatment management function of the Web application calculated the average of daily dose prescribed for antipsychotics (N05A ATC code), prescribed daily dose (PDD), PDD 95% CI, and the mean PDD to DDD ratio. Although ATC classification includes lithium and antipsychotics under the N05A code, we chose to include only antipsychotics for the purposes of this study. To compare dosages of various antipsychotics, we used a fixed unit of measurement calculated by dividing the PDD by the DDD. A PDD/DDD ratio greater than 1.5 was defined as excessive dosing [28]. All analyses were conducted using SPSS version 22.0 (IBM Corporation).

Ethical Considerations

The research was in compliance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) and the standards established by the institutional review board and granting agency. All the participants provided written informed consent after the complete description of the study. Previously, the research protocol was approved by the Ethics Committee of Fundación Jiménez Díaz, Madrid.

Results

Sample Characteristics

A total of 359 patients received brief psychiatric care in the 2 psychiatric inpatient units from June 2014 to October 2014. Among them, 353 patients were evaluated with the MEmind application. Of the 6 patients who did not participate in the study, 1 patient refused to participate and 5 patients did not receive the proposal to participate. The distribution of the main psychiatric disorders according to age and sex is presented in Table 1.

Out of our total sample, 243 patients had 1 psychiatric diagnosis, with schizophrenia spectrum and related disorders being the most frequent diagnoses. Other diagnoses were comorbid diagnoses and were considered secondary to their psychotic disorder diagnoses. Antipsychotics, alone or in combination with other psychotropic drugs, were used in 217 of the 353 patients (61.5%). Of the 217 patients, 137 (63.2%) were administered pharmacological monotherapy and 80 (36.8%) were administered polytherapy (for details, see Table 2).

Table 1. Age and sex distribution of psychiatric disorders.

Psychiatric disorder	Patients with diagnosis, n (%)	Age, %					Sex, %		
		18-35 years	35-50 years	50-65 years	>65 years	*P* value[a]	Female	Male	*P* value[a]
Substance use disorders	79 (22.4)	19.3	47.4	33.3	0	.02	51.8	48.2	.41
Schizophrenia and other psychoses	134 (38)	28.4	37.9	24.2	9.5	.83	42.5	57.5	.79
Mood disorders	100 (28.3)	25.7	23.0	35.1	16.2	.009	54.0	46.0	.238
Personality disorders	70 (19.8)	35.4	47.9	16.3	0	.007	52.9	47.1	.505
Total (N=353)		27.3	35.5	27.3	9.8		48.7	51.3	

[a]The *P* value was calculated using the chi-square test.

Table 2. Antipsychotic medication use according to diagnosis.

Diagnosis	Patients with diagnosis, n (%)	Antipsychotic use	Antipsychotic monotherapy	Antipsychotic polytherapy
One diagnosis (n=243)				
Substance use disorders	16 (4.5)	8	6	2
Schizophrenia and other psychosis	101 (28.6)	101	62	39
Mood disorders	69 (19.5)	51	33	18
Anxiety-related disorders	24 (6.8)	5	4	1
Personality disorders	21 (5.9)	12	10	2
Rest of the diagnoses	12 (3.4)	0	0	0
Comorbidity (n=110)				
Organic disorders + mood disorders	5 (1.4)	2	1	1
Substance use disorders + schizophrenia and other psychosis	10 (2.8)	9	4	5
Substance use disorders + mood disorders	6 (1.7)	6	4	2
Substance use disorders + personality disorders	7 (2.0)	9	4	5
Schizophrenia and other psychosis + personality disorders	7 (2.0)	6	3	3
Mood disorders + personality disorders	6 (1.70)	4	2	2
Anxiety-related disorders + personality disorders	9 (2.5)	4	4	0
Other combinations	60 (17)	0	0	0
Total	353	217	137	80

Antipsychotic Medication Use Pattern

The frequencies of prescription according to diagnoses, as a unique or comorbid condition, were as follows: Of the 353 patients, 118 (33.4%, 118/353) patients had a diagnosis of schizophrenia and other psychosis (F20-F29), 86 (24.3%, 86/353) had a diagnosis of mood disorders (F30-F39), 50 (14.1%, 50/353) had a diagnosis of personality disorders (F60-F69), and 33 (9.3%, 33/353) had a diagnosis of anxiety-related disorders (F40-F49; see Table 2).

Antipsychotics were prescribed to 217 patients corresponding to a total of 365 antipsychotics prescriptions. In 62 (29.2%) patients, antipsychotics were the only psychotropic drug prescribed; in 40 (18.9%) patients 1 antipsychotic was prescribed and in 22 (10.4%) patients 2 antipsychotics were prescribed. For the remaining 155 patients, antipsychotics were used in combination with other psychotropic drugs. Thus, only 18.9% of our sample were patients in a pure monotherapy antipsychotic regimen. Table 3 presents the different antipsychotics prescribed, ATC/DDD classification, and doses used in our clinical practice. The antipsychotics used in excessive doses were amisulpride, olanzapine, risperidone, and paliperidone (both their oral and long-acting injectable forms). On the other hand, levomepromazine was used in the lowest dose followed by clotiapine and quetiapine.

The antipsychotics used more frequently in APP were clozapine (81.8%), clotiapine (81.8%), and amisulpride (70.6%) through oral administration and fluphenazine (100%), zuclopenthixol acufase (100%), and zuclopenthixol depot (83.3%) through

long-acting injectable forms (for details, see Multimedia Appendices 1 and 2).

Table 3. Anatomical Therapeutic Chemical classification with defined daily dose, prescribed daily dose values, and prescribed daily dose to defined daily dose ratio of antipsychotics prescribed.

No. of prescriptions (N=365)	Drug	ATC[a] code	DDD[b] (mg)	Median PDD[c] (mg)	Mean PDD (mg)	PDD (mg) 95% CI	Mean PDD/DDD[d]
17	Amisulpride[e]	N05AL05	400	800	811.76	652.4-971.1	2.03
37	Aripiprazole[e]	N05AX12	15	15	20.54	16.7-24.4	1.37
25	Asenapine[e]	N05AH05	20	10	14.4	11.3-17.5	0.72
11	Clotiapine[e]	N05AH06	80	40	35.45	24.4-46.5	0.44
11	Clozapine[e]	N05AH02	300	350	345.45	284.2-406.7	1.15
3	Fluphenazine[f]	N05AB02	1	0.89	1.19	0.61-1.78	1.19
7	Haloperidol[f]	N05AD01	8	5	7.63	2.4-12.9	0.95
3	Levomepromazine[f]	N05AA01	300	50	58.33	42.0-74.7	0.19
36	Olanzapine[e]	N05AH03	10	10	15.76	12.5-19.1	1.58
22	Paliperidone[f]	N05AX13	6	10.5	11.59	9.5-13.7	1.93
63	Long-acting paliperidone[f]	N05AX13	2.5	3.57	4.79	4.34-5.24	1.92
38	Quetiapine[f]	N05AH04	400	150	228.29	153.5-303.1	0.57
66	Risperidone[f]	N05AX08	5	6	7.61	6.5-8.7	1.52
1	Long-acting risperidone[e]	N05AX08	2.7	7.14	7.14	7.14-7.14	2.64
10	Tiapride[e,f]	N05AL03	400	300	290	244.3-335.7	0.73
1	Ziprasidone[f]	N05AE04	80	120	120	120.0-120.0	1.50
2	Zuclopenthixol acufase[f]	N05AF05	30	25	25	25-25	0.83
12	Zuclopenthixol depot[f]	N05AF05	15	9.5	10.3	8.8-11.9	0.69

[a]ATC: Anatomical Therapeutic Chemical.

[b]DDD: defined daily dose.

[c]PDD: prescribed daily dose.

[d]Mean PDD to DDD ratio.

[e]Oral administration.

[f]Injectable administration.

Discussion

Principal Findings

This study described a reproducible method for performing naturalistic prospective prescription analysis via a Web- and mobile phone–based application prototype, MEmind. This observational study was the first step in the development of a CDSS that may help care providers better monitor their prescriptions and make decisions regarding pharmacological treatment. In this study, we were able to identify polypharmacy, overly high dosage, and off-label use in a psychiatric inpatient setting. We found that APP was used in 35.8% of the patients in our 2 brief psychiatric inpatient units, with clozapine as the oral drug most used in APP and fluphenazine as the long-acting injection drug most used in APP. Antipsychotics were used mostly in schizophrenia spectrum and related psychotic disorders, but they were also prescribed in other nonpsychotic diagnoses. Risperidone and paliperidone, in both their oral and long-acting presentation, were the most prescribed antipsychotics. With respect to dosing, with the exception of only one prescription of long-acting risperidone, amisulpride was the antipsychotic prescribed at highest doses, whereas levomepromazine was the antipsychotic prescribed at lowest doses.

In our sample, the oral antipsychotics most used in APP regimen were clozapine, clotiapine, and amisulpride. One likely explanation for these findings regarding clotiapine in APP is that clotiapine is not principally used for its antipsychotic properties but rather for its hypnotic properties; this interpretation is supported by clotiapine's PDD/DDD ratio of 0.44. Clozapine was used in APP in 81.8% of cases. Out of 11

patients who were administered clozapine, 9 patients received pharmacological polytherapy and only 2 patients received monotherapy with a PDD/DDD ratio of 1.15. Amisulpride was used in APP in 70.6% (12/17) of cases. Our use of these antipsychotics is consistent with their pervasive clinical use in our country [21] and worldwide [29].

Clinical guidelines recommend the use of clozapine in APP only for ultraresistant patients with schizophrenia [22]. This will reduce clozapine dose, minimize adverse effects and allow for the use of amisulpride APP to be the rule rather than the exception [29]. Moreover, a very common antipsychotic combination is the clozapine augmentation with amisulpride in patients with ultraresistant schizophrenia.

Long-acting antipsychotics were rarely used with first-generation antipsychotics but were used most frequently in APP. Second-generation antipsychotics, however, were used in pharmacological monotherapy and polytherapy in the same proportion. In our sample, long-acting paliperidone has replaced long-acting risperidone (used in only 1 patient) and is used in APP in almost 50% of cases. The use of paliperidone in this inpatient setting probably represents a fluctuation period during the hospitalization.

When observing the range of doses used in our sample, we noticed that the drugs used in higher doses were amisulpride (PDD/DDD = 2.03) as well as paliperidone in its long-acting presentation (PDD/DDD = 1.92) and oral presentation (PDD/DDD = 1.93). Both of these drugs are antipsychotics with a high affinity for dopamine D_2 receptor blockade. As a D_2 receptor binding of 70% is necessary for therapeutic benefits [30], high doses of these antipsychotics are commonly used to better reach this level of binding. Given that many patients arrive at inpatient settings with severe psychopathology, clinicians may attempt to use pharmacotherapies at higher dosages to stabilize patients in shorter amounts of time. On the other hand, levomepromazine, clotiapine, and quetiapine were the antipsychotics used at the lowest doses. Specifically, their PDD/DDD ratios were less than 0.5, which likely reflects levomepromazine and clotiapine being prescribed for nonpsychotic symptoms (such as insomnia or anxiety) and low doses of quetiapine being prescribed for bipolar depression [30].

Limitations

To improve acceptance among care providers, diagnoses were provided by psychiatrists rather than being obtained as the result of a structured clinical interview, such as the Structured Clinical Interview for DSM-5 (SCID-5). As shown in other studies, the implementation of EHRs or CDSSs may increase clinician workload [26]. In order to ease the burden and improve acceptance of the study procedure among clinicians, we did not include in the baseline assessment a structured interview of participants. This “as usual” approach of conducting is also consistent with the noninterventional setting of our study. However, to further assess the effect of implementation of the CDSS on patients’ clinical outcomes, a standard assessment will be performed in a forthcoming study.

In this study, we did not report the effect of MEmind on prescription habits. Changes in prescription behaviors have been reported by other studies describing the implementation of an e-prescribing tool [31]. It could have been of interest to report the effect of having instantaneous feedback from MEmind concerning off-label use. This, however, would have required a distinct methodology relying on a randomized controlled trial and a larger sample, which does not fit with a feasibility study.

Perspectives

This Web- and mobile phone–based application allows data gathering by both care providers and patients. The second phase of the project would be to combine clinical assessment with pharmacological insight. It may be especially relevant for patient monitoring after discharge, given that mHealth EMA is a promising method for reporting the clinical effects of pharmacological management. It will provide momentary assessment of the effects of a drug, including subjective perception of patients’ quality of life and health outcomes [7]. We will also be able to assess these features in the near future. These systems are able to explain how clinical practice is sometimes ahead of available evidence and may help develop better practices and security. At this point, we were able to provide information about drug management under real conditions and highlight points of conflict between ideal and real practice using the Web application. Our project may support the integration of mHealth techniques in prescription management systems and the development of future CDSSs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Proportion of antipsychotic polypharmacy compared with monotherapy.

[PDF File (Adobe PDF File), 30KB - jmir_v19i1e25_app1.pdf]

Multimedia Appendix 2

Antipsychotic defined daily dose (DDD) when use in monotherapy versus polytherapy.

[PDF File (Adobe PDF File), 33KB - jmir_v19i1e25_app2.pdf]

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Abbreviations

APP: antipsychotic polypharmacy
ATC: Anatomical Therapeutic Chemical
CDSS: clinical decision support system
DDD: defined daily dose
EHR: electronic health record
EMA: ecological momentary assessment
mHealth: mobile health
PDD: prescribed daily dose

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Original Paper

Patient Information Websites About Medically Induced Second-Trimester Abortions: A Descriptive Study of Quality, Suitability, and Issues

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Abstract

Background: Patients undergoing medically induced second-trimester abortions feel insufficiently informed and use the Web for supplemental information. However, it is still unclear how people who have experience with pregnancy termination appraise the quality of patient information websites about medically induced second-trimester abortions, whether they consider the websites suitable for patients, and what issues they experience with the websites.

Objective: Our objective was to investigate the quality of, suitability of, and issues with patient information websites about medically induced second-trimester abortions and potential differences between websites affiliated with the health care system and private organizations.

Methods: We set out to answer the objective by using 4 laypeople who had experience with pregnancy termination as quality assessors. The first 50 hits of 26 systematic searches were screened (N=1300 hits) using search terms reported by the assessors. Of these hits, 48% (628/1300) were irrelevant and 51% (667/1300) led to websites about medically induced second-trimester abortions. After correcting for duplicate hits, 42 patient information websites were included, 18 of which were affiliated with the health care system and 24 with private organizations. The 4 assessors systematically assessed the websites with the DISCERN instrument (total score range 16-80), the Ensuring Quality Information for Patients (EQIP) tool (total score range 0-100), as well as questions concerning website suitability and perceived issues.

Results: The interrater reliability was 0.8 for DISCERN and EQIP, indicating substantial agreement between the assessors. The total mean score was 36 for DISCERN and 40 for EQIP, indicating poor overall quality. Websites from the health care system had greater total EQIP (45 vs 37, $P>.05$) and reliability scores (22 vs 20, $P>.05$). Only 1 website was recommended by all assessors and 57% (24/42) were rated as very unsuitable by at least one assessor. The most reported issues with the websites involved lack of information (76%, 32/42), and poor design (36%, 15/42).

Conclusions: The high number of irrelevant hits and poor quality of patient information websites are considerable issues that must be addressed and considered when consulting patients awaiting medically induced second-trimester abortions. In clinical encounters, health professionals should initiate discussions concerning websites about medically induced second-trimester abortions and inform patients about the issues and quality deficits associated with these websites.

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KEYWORDS

consumer health information; induced abortion; information literacy; Internet; popular works; second pregnancy trimester

Introduction

Patients often use the Web to read about health-related information [1,2], particularly young [1,3] and pregnant women [4]. The Web is a potential source of highly accessible and tailored information that transcends traditional informational processes. Moreover, it has the potential to promote equity and patient empowerment by improving knowledge [5-8]. Many view the Web as an important source of health-related information [1], and patients use it before and after consultations with health professionals. Before a consultation, they use it to manage their situation and to decide for themselves whether or not they need professional help. After a consultation, they use it to feel reassured by reading supplemental information or due to dissatisfaction with the information offered during the clinical encounter with health professionals [9]. However, the considerable plethora of available and uncontrolled information on the Web results in disorganization, which can lead to difficulties navigating and finding relevant information [5,10]. Studies investigating techniques for information retrieval among lay consumers have observed suboptimal search methods when they try to find health-related information on the Web, suggesting a need for efforts to help patients identify high-quality information [11,12]. Moreover, the lack of peer reviews or other regulating systematic activities as methods to control the quality of the information available on the Web increases the risk of patients to come in contact with low-quality information [5], and the lack of easy access to high-quality, relevant information is an identified barrier for patients [10]. Consequently, poor quality of patient information websites is a concern [5,13,14]. Considering these problems and risks, research is needed to investigate the quality of patient information websites.

Individuals who undergo medically induced second-trimester abortions experience both emotional distress and physical pain before, during, and after the abortion [15-19]. To deal with their difficult situation, they have a great need for information and support [15-18]. Preparatory information is an indicator of quality abortion care, and the literature suggests that women should always be offered sufficient information before the procedure [20]. However, people who undergo the procedure describe that they feel insufficiently informed about it, resulting in unanswered questions and unpreparedness [15-18]. To feel adequately prepared and well-informed, they search the Web for supplemental information about pregnancy terminations [17,18,21]. However, inductive qualitative research indicates issues with searching difficulties and poor website quality [18], calling attention to the need for systematic investigations that draw more generalizable conclusions. Previous investigations on websites about abortions have shown that some of these websites include medical inaccuracies and misleading information [22-24], for example, erroneous claims about associations between abortion and mental health risks, preterm births, breast cancer, and infertility [22,24]. However, the quality of patient information websites about medically induced second-trimester abortions remains unclear.

Studies that investigate the quality of patient information on the Web typically use health professionals or researchers as assessors. However, previous research has illustrated a mismatch between patients' perspectives and those of researchers [25] as well as health professionals [26], thereby raising questions concerning patient perspectives and preferences regarding patient information on the Web. In other words, it is possible that the perspectives and preferences regarding information websites differ among those consuming the information and those typically developing or investigating it. To accomplish high-quality patient information materials, research suggests a need for information developers to produce materials based on the needs of the intended consumers and to actively involve them in the development process [27]. It is still unclear how people who have experience with pregnancy termination appraise the quality of information websites about medically induced second-trimester abortions, whether they consider the websites suitable for patients, and what issues they experience when reading the information. Moreover, the mismatched perspectives call attention to the importance of surveying the landscape on the Web with regard to website affiliation in order to gain knowledge about the potential differences in quality between websites affiliated with the health care system and private organizations.

With this study, we set out to provide descriptive data on currently available patient information websites about medically induced second-trimester abortions, grounded in the perspectives and preferences of laypeople with personal experience. Thus, the aim was to investigate the quality of, suitability of, and issues with patient information websites about medically induced second-trimester abortions, and investigate possible differences between websites affiliated with the health care system and private organizations.

Methods

Study Context

In Sweden, all pregnant women are offered a second-trimester routine obstetric ultrasound examination, usually performed at 18 weeks of gestation. Swedish law states that pregnant women have the right to decide on termination of pregnancy up to 18 completed weeks of gestation. At later gestations, approval must be granted for from the National Board of Health and Welfare, and in practice, few pregnancies are terminated after 22 weeks. The majority of second-trimester abortions performed in Sweden are medically induced labors with vaginal deliveries of the fetus [28].

Search Procedure

Thirteen search terms reported by 4 individuals who have experience with medically induced second-trimester abortion were used to find Swedish websites about medically induced second-trimester abortions. Bing and Google, currently the 2 most used search engines on the Web [29], were used to perform the searches. The searches were conducted in October 2015 and yielded a total of 4,578,500 hits (Table 1).

Table 1. Search terms and number of hits.

Search terms	Bing	Google
Abortion due to a heart defect	16,900	11,500
Angel mum	36,600	44,100
Grieving work after losing a baby	45,800	56,800
How a late abortion is done	1,770,000	212,000
How great is the risk that a fetal heart defect is repeated	16,900	6490
How to manage a late abortion	19,400	123,000
Late abortion	81,700	454,000
Late abortion after discovery in routine ultrasound	63,300	132,000
Late termination of pregnancy	12,800	8610
Miscarriage after late abortion	13,100	119,000
Pregnant after late abortion	174,000	193,000
Termination	194,000	618,000
Termination in week 20	72,100	83,400
Total hits (all search terms)	2,516,600	2,061,900

Figure 1. Sampling procedure.

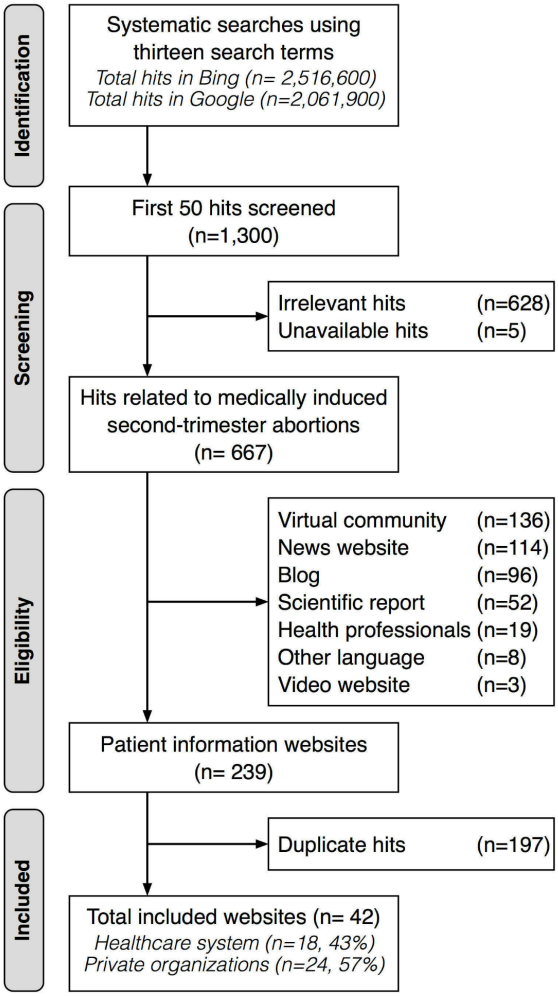
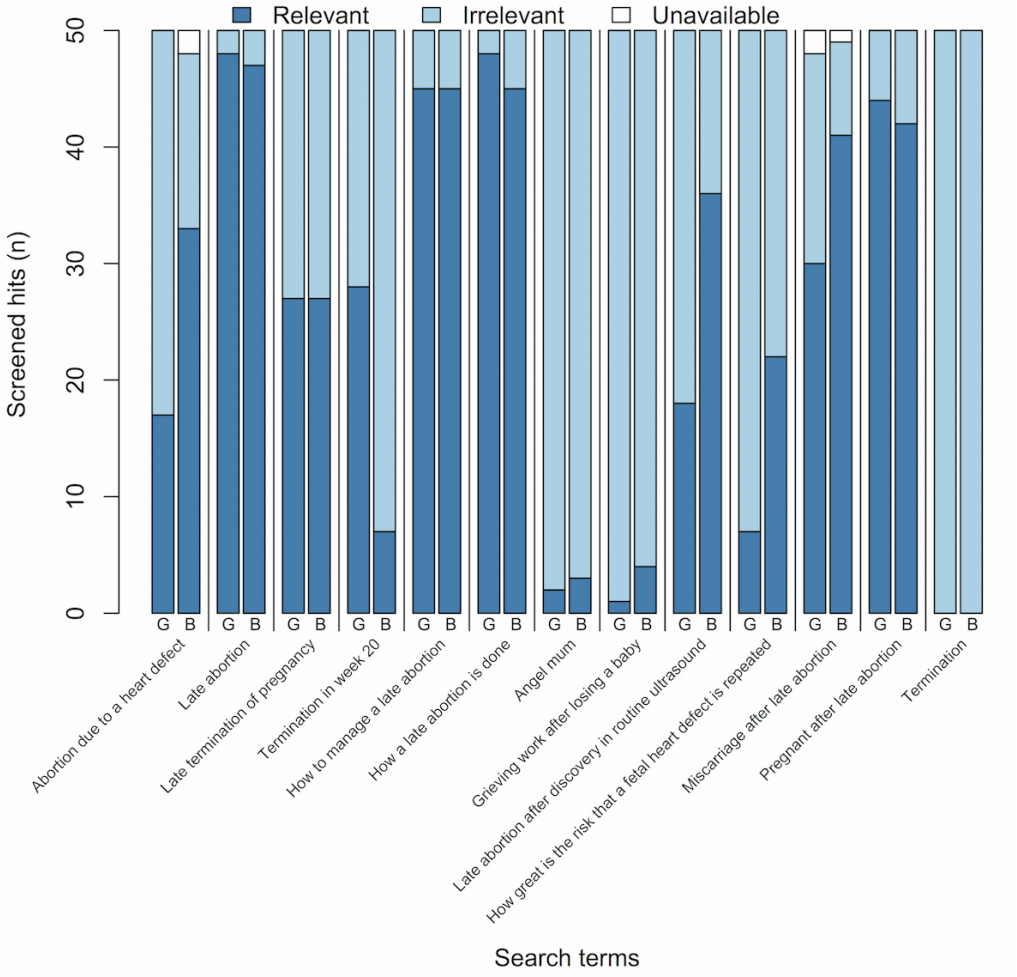


Figure 1 presents the sampling procedure. The first 50 hits of each search (N=1300 hits screened in total) were screened for inclusion by the first author. The 4 individuals who have experience with medically induced second-trimester abortions were not involved in the process of site selection. To be included, the websites needed to provide patient information

about medically induced second-trimester abortions and be written in Swedish. In total, 48% (628/1300) of the hits were irrelevant, 5 hits were unavailable and 51% (667/1300) led to websites about medically induced second-trimester abortions. Figure 2 presents the number of relevant and irrelevant hits among the first 50 hits in Google and Bing.

Of the relevant hits, 64% (428/667) were excluded because they led to (1) virtual communities (136/667), (2) news websites (114/667), (3) blogs (96/667), (4) scientific reports (52/667), (5) websites intended for health professionals (19/667), (6) websites in other languages (8/667), or (7) video websites (3/667). This resulted in 18% (239/1300) of the total hits leading to patient information websites about medically induced second-trimester abortions. Of these, 82% (197/239) were duplicate hits. Consequently, 42 websites were included: 43% (18/42) of which were affiliated with the health care system, and 57% (24/42) with private organizations. More than half of the included websites were identified through searches in both Google and Bing (69%, 29/42). Seven of the included websites were only identified through searches in Google, and 6 were only identified through searches in Bing.

Figure 2. Number of relevant and irrelevant hits among the first 50 hits in Google (G) and Bing (B).



Data Collection

The same 4 individuals who reported the search terms were also used as assessors of the included websites. These assessors with personal experience with medically induced second-trimester abortion were recruited from a consecutively recruited sample of women and partners participating in an interview study at 2 tertiary fetal medicine centers in central Sweden. From this original sample, 4 assessors were purposefully invited to participate in the assessments, with the aim of selecting a representation of males and females with different ages. Two assessors were females and 2 were male partners, all native Swedes between the ages of 23 and 42 years. Two of the assessors were a couple and the other 2 were not associated with one another. The assessors individually accessed and rated each of the included websites at their homes between November 2015 and January 2016, resulting in 42 assessments from each of the assessors (168 assessments in total). Because we aimed to investigate the perspectives of laypeople, the assessors did not receive any particular training for performing the assessments. They were instructed to access, read, and assess any sections of the included websites that they considered relevant and related to the topic of medically induced second-trimester abortions. The couple was instructed to assess the websites independently.

Website Quality

The DISCERN instrument [30] and the Ensuring Quality Information for Patients (EQIP) tool [31] were used to assess website quality; both are validated and reliable instruments for systematically assessing the quality of patient information [32-34]. The DISCERN instrument was chosen because it has been used extensively in previous studies, and the EQIP tool was chosen because it includes dimensions not covered by DISCERN, such as design and language [34]. The 2 instruments were translated into Swedish by a native Swedish speaker and back-translated by a native English speaker to check for consistency.

DISCERN contains 16 questions rated on a Likert scale from 1 (serious shortcomings) to 5 (minimal shortcomings), resulting in a total score between 16 and 80. The 3 sections assess reliability (8 questions), information about treatment (7 questions), and overall quality (1 question) [30]. EQIP contains 20 questions rated as "yes" (1 point, quality criterion fulfilled), "partly" (0.5 point, quality criterion partly fulfilled), and "no" (0 point, quality criterion not fulfilled). The final score is calculated as a percentage of the maximum achievable score, resulting in a total score between 0 and 100 [31].

Suitability

The assessors were asked if they would recommend the website to others (yes or no) and to rate the suitability of the website as a source of information for individuals awaiting a medically induced second-trimester abortion, on a Likert scale from 1 (very unsuitable) to 5 (very suitable).

Issues

One open-ended question was asked regarding perceived issues with the websites, in which the assessors were free to write as much or as little as they wanted in free text.

Data Analysis

The data was analyzed using R version 3.2.2 (R Foundation for Statistical Computing). Intraclass correlation coefficients were calculated to determine interrater reliability. Independent *t* tests were used to compare the mean scores of websites from the health care system and private organizations; $P<.05$ was considered statistically significant.

The responses to the open-ended question were analyzed using manifest qualitative content analysis, a method that aims to systematically find patterns in written text [35]. Meaning units concerning issues with the websites were identified and defined as words, sentences, or paragraphs containing aspects related to each other through their content and context. These meaning units were organized into categories, that is, collections of meaning units that shared similar content.

Ethical Considerations

The study was approved by the regional ethics committee in Uppsala, Sweden (Reference number 2014/504, approval date: 14/01/2015). Informed consent was collected before enrolment and the assessors received SEK 3000 (approximately US $350) for their work.

Results

Website Quality

The total mean score was 36 (SD 10) of a maximum achievable score of 80 for DISCERN and 40 (SD 14) of a maximum achievable score of 100 for EQIP. The interrater reliability for all 4 assessors ranged from 0.77 to 0.83 and was somewhat lower for the 2 assessors who were a couple (for the couple: total DISCERN=0.77, reliability=0.67, information about treatment=0.75, overall quality=0.83, total EQIP=0.55). Compared with websites from the health care system, websites from private organizations had significantly lower reliability and EQIP total scores (Table 2).

Table 2. Interrater reliability, assessment means, and standard deviations for the websites from the health care system (n=18) and private organizations (n=24).

Instrument or tool (maximum achievable score)	Interrater reliability	Health care system (n=18)	Private organizations (n=24)	Total (n=42)
		Mean (SD)	Mean (SD)	Mean (SD)
DISCERN				
Reliability (40)	0.79	22.4[a] (5.3)	19.6[a] (5.8)	20.8 (5.7)
Information about treatment (35)	0.77	11.9 (4.1)	14.0 (5.4)	13.1 (5.0)
Overall quality (5)	0.83	2.2 (1.2)	2.1 (1.1)	2.2 (1.1)
Total score (80)	0.80	36.5 (8.9)	35.7 (10.7)	36.0 (10.0)
EQIP[b]				
Total score (100)	0.78	44.6[a] (11.5)	36.6[a] (15.3)	40.0 (14.3)

[a]$P<.05$.

[b]EQIP: Ensuring Quality Information for Patients.

Mean scores and 95% CIs for each question in the DISCERN instrument are presented in Figure 3. Websites from both the health care system and private organizations had mean scores below 3.0 for 12 of the 16 questions, representing below

moderate quality. Compared with websites from the health care system, websites from private organizations had significantly lower scores (P<.01) for the questions "explicit aims," "aims achieved," and "balanced and unbiased information." Conversely, websites from private organizations had significantly higher scores (P<.05) for the questions "areas of uncertainty," "benefits of treatment," and "risks of treatment."

Mean scores and 95% CIs for each question in the EQIP tool are presented in Figure 4. Websites from both the health care system and private organizations had mean scores below 0.5 for 10 of the 20 questions, representing below moderate quality. Compared with websites from the health care system, websites from private organizations had significantly lower scores (P<.01) for the questions "address the reader," "respectful tone," "satisfactory design," "logical order," "contact information," and "name of producer." Conversely, websites from private organizations had significantly higher scores (P<.05) for the questions "advantages of induced abortion" and "risks or side effects of induced abortion."

Figure 3. Mean scores and 95% CIs for each question in the DISCERN instrument. Comparisons are presented between websites from the health care system and private organizations (* P<.05, ** P<.01).

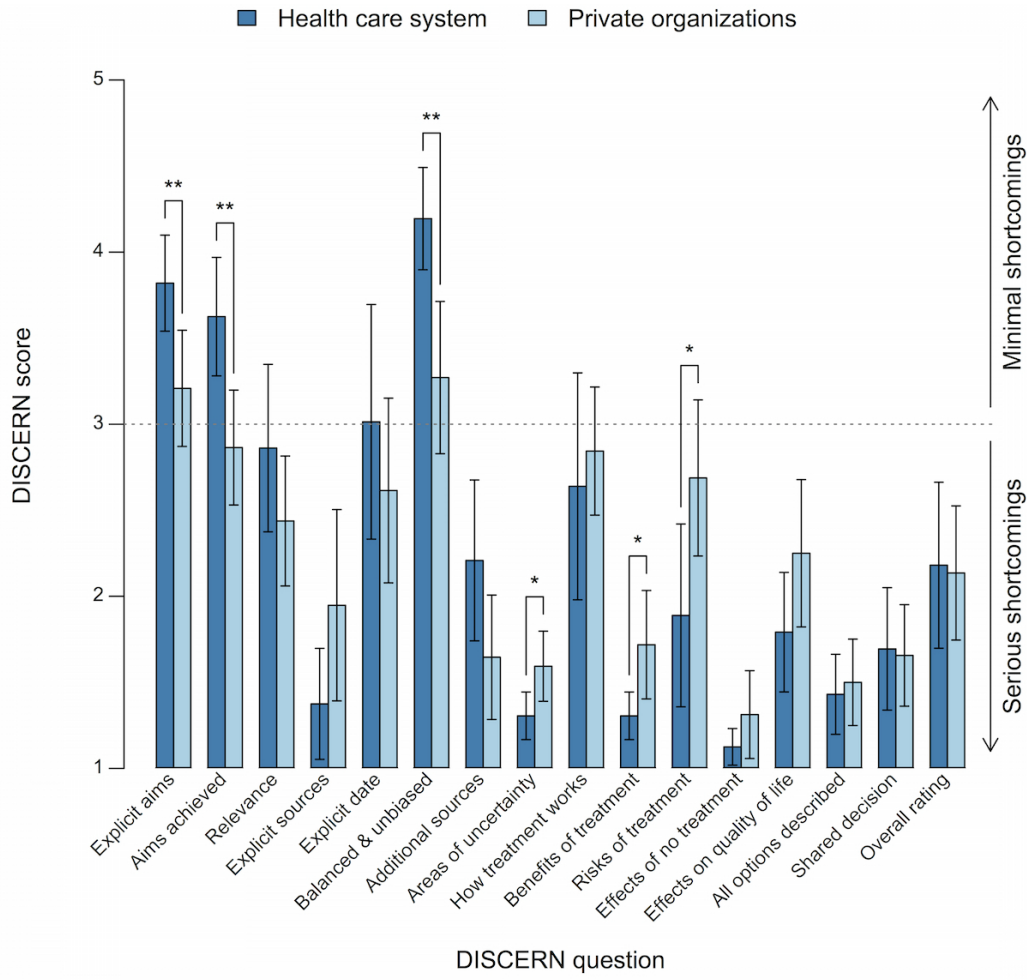
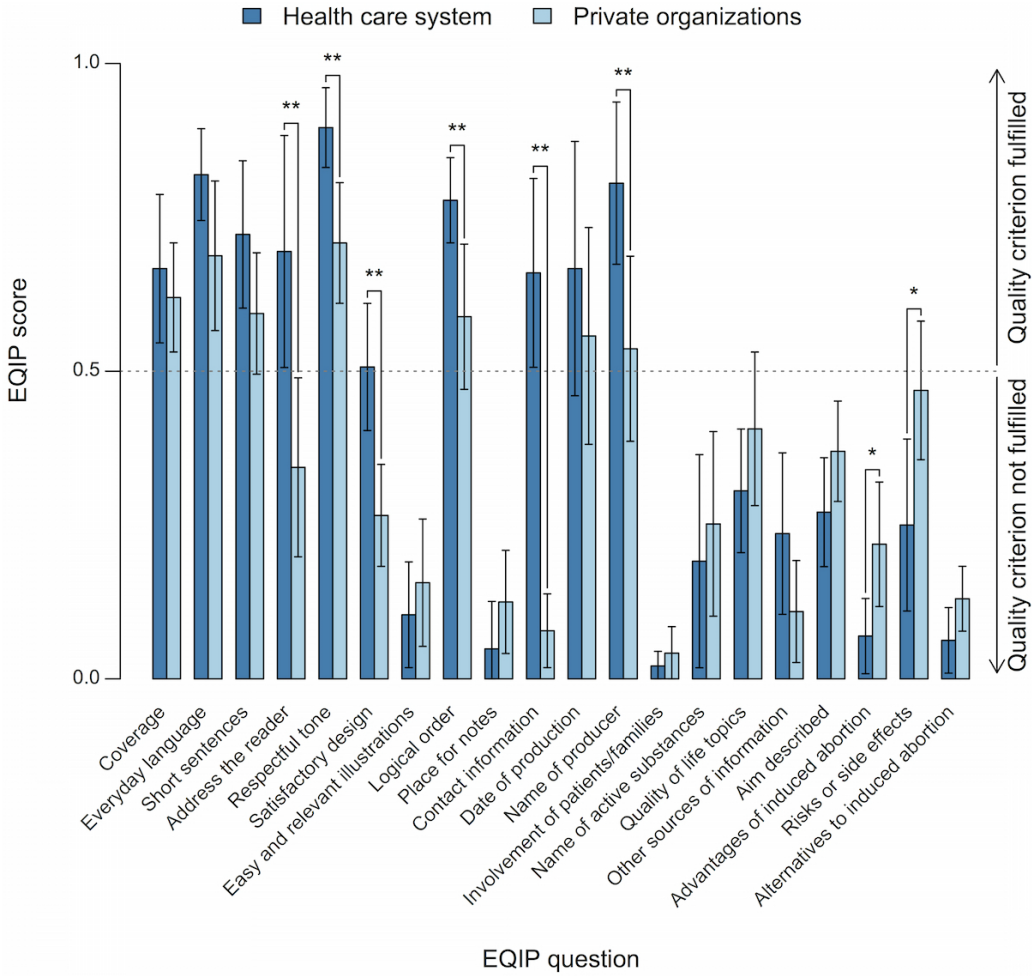


Figure 4. Mean scores and 95% CIs for each question in the Ensuring Quality Information for Patients (EQIP) tool. Comparisons are presented between websites from the health care system and private organizations (* *P*<.05, ** *P*<.01).



Suitability

The mean score for suitability was 2.6 (SD 1.2) of a total score of 5.0, indicating below moderate suitability (corresponding to a score of 3.0). More than half of the websites (57%, 24/42) were rated as very unsuitable by at least one assessor. No significant differences in suitability scores were observed between websites from the health care system (mean 2.8/5.0, SD 1.1) and private organizations (mean 2.3/5.0, SD 1.2). Few websites were recommended by more than 1 assessor (31%, 13/42), and only 1 website was recommended by all 4 assessors (Table 3).

Issues

Nine categories of issues were identified in total (Table 4). The most reported issues with the websites, reported by at least one assessor, were lack of information (76%, 32/42) and poor design (36%, 15/42). All websites from the health care system (n=18) had at least one assessor who reported lack of information, compared with 58% (14/24) from private organizations.

Table 3. Websites that were recommended by 1, 2, 3 or all assessors from the health care system (n=18) and private organizations (n=24).

Recommended by number of assessors (n=4)	Health care system (n=18)	Private organizations (n=24)	Total (n=42)
	n (%)	n (%)	n (%)
1 assessor	2 (11)	7 (29)	9 (21)
2 assessors	4 (22)	2 (8)	6 (14)
3 assessors	3 (17)	3 (13)	6 (14)
4 assessors	1 (6)	0 (0)	1 (2)

Table 4. Issues reported by at least one assessor, for websites from the health care system (n=18) and private organizations (n=24), identified in the open-ended question.

Reported issue	Health care system (n=18)	Private organizations (n=24)	Total (N=42)	Illustrative quote
	n (%)	n (%)	n (%)	
Lack of information	18 (100)	14 (58)	32 (76)	Hardly any information on the website
The abortion procedure	10 (56)	5 (21)	15 (36)	Does not address the procedure
Emotional difficulties	5 (28)	3 (13)	8 (19)	Scanty information on the emotional side of things
Reasons for abortion	2 (11)	3 (13)	5 (12)	No info on reasons for late abortion
Professional support	2 (11)	2 (8)	4 (10)	No info on what help is available
The fetus	3 (17)	1 (4)	4 (10)	No mention at all of what happens to the fetus
Medications	1 (6)	1 (4)	2 (5)	No info on how Mifepristone impacts the fetus
Follow-up care	0 (0)	1 (4)	1 (2)	Nothing on aftercare
No contact information for health care services	1 (6)	0 (0)	1 (2)	Does not say who to contact
Poor design	4 (22)	11 (46)	15 (36)	Disastrous interface
Disrespectful and belittling tone	4 (22)	5 (21)	9 (21)	It is like a sermon, and has a negative and arrogant tone
Poor language	1 (6)	8 (33)	9 (21)	Very difficult to understand what it says, as the words hardly form sentences
Biased against abortions	0 (0)	8 (33)	8 (19)	Biased website, clearly against abortion
Inaccurate information	0 (0)	5 (21)	5 (12)	Description of late abortion is completely wrong
Irrelevant information	2 (11)	3 (13)	5 (12)	No relevant information at all
Untrustworthy or unclear source of the information	0 (0)	3 (13)	3 (7)	No info on who produced the site

Discussion

Principal Findings

The included websites had poor quality and suitability, and the majority had issues with lack of information. Although the difference was small, websites from the health care system had higher reliability and overall EQIP quality scores. The Web contains an immense number of websites, resulting in an overwhelming amount of information and searching difficulties [14,36,37]. Moreover, it has been shown that consumers of health information use suboptimal search strategies [11] and are unsuccessful at finding satisfactory information on the Web [38]. The findings of this study confirm this, as the search terms reported by laypeople resulted in a high number of irrelevant hits and few hits leading to relevant patient information websites. Considering the small number of relevant patient information websites identified with these search terms, the findings indicate a need for health professionals to involve themselves by initiating discussions about search strategies and information on the Web. Health professionals should inform patients about the potential difficulties of identifying relevant high-quality patient information websites. One potential strategy to encourage patients to come in contact with high-quality sources could be to offer a list of appropriate search terms and recommended websites. However, most professionals lack the time needed to familiarize themselves with the Web and the quality of its various available sources [10,39], and articulate a number of difficulties when consulting Web-informed patients [39,40]. Consequently, individual professionals cannot be expected to have the knowledge, technical skills, and time to identify and stay updated about appropriate Web-based sources. Thus, it is possible that a need exists for overarching institutions responsible for stipulating updated lists of recommendations for high-quality patient information available on the Web. Most appropriately, such efforts should be made in collaboration with laypeople that have personal experience with pregnancy termination.

The results concerning low website quality echo previous studies in other health contexts [13,14]. It seems that, in addition to containing inaccurate and misleading information [22,24], websites about abortions are also of poor quality and lack information. It has previously been shown that health information seekers place greater trust in sources from official authorities [11]. In contrast with this, our results indicate that websites from both the health care system and private organizations have low reliability and poor-quality information about medically induced second-trimester abortions. A particular issue with the included websites was the lack of comprehensiveness. Most of the websites were reported to lack information about topics the assessors considered important, and both quality instruments indicated very poor quality concerning information about quality of life and risks of treatment. The results indicate that health professionals must make critical appraisals before referring patients to websites

about medically induced second-trimester abortions, irrespective of website affiliation. Overall, there is a great need for systematic efforts to improve the quality of patient information websites about medically induced second-trimester abortions. Website developers must take steps to ensure sources that correspond with the preferences and needs of laypeople awaiting pregnancy termination. One such step could be to involve patients in the production of the information [27]. The included websites had low scores for the EQIP questions concerning involvement of patients, indicating a need for improvement.

The assessors recommended few of the included websites, the majority of the websites were considered unsuitable, and one-fifth were considered to have a disrespectful or belittling tone, including 4 from the health care system. Moreover, websites from private organizations had significantly lower scores for the EQIP question concerning whether the information was written in a respectful tone, suggesting that some of these websites may be particularly disrespectful. In accordance with our findings, previous research has highlighted that patients who read printed patient information criticize these materials by calling attention to the use of patronizing language, including a conveyed attitude that the doctor knows best [27]. Nonjudgmental and respectful attitudes are indicators of quality abortion care [20], and are highly desired by women who seek abortions [17,41]. Many women who terminate a pregnancy regard the decision as emotionally painful [16,17,42] and are at risk of significant psychological consequences [43]. Contact with unsuitable and disrespectful information could potentially increase these difficulties and aggravate psychological morbidity. Moreover, many of the included websites were criticized for use of poor language, which made it difficult to understand the information. Website and information developers should take note of these findings, and work toward the use of respectful and easy-to-read language about abortions.

Strengths and Limitations

One strength of this study is that it used assessments by individuals with experience with medically induced second-trimester abortions. To our knowledge, no other study has included laypeople with personal experience to assess the quality of websites offering information about medically induced second-trimester abortions. Thus, this study investigated patient perspectives on information websites, leading to a more patient-focused approach. For example, the reported lack of information illustrates a mismatch between what information individuals want when awaiting a medically induced second-trimester abortion and the information produced by website developers. Moreover, the reported disrespectful or belittling tone highlights the strength of using laypeople as assessors. These findings call attention to the importance of consumer-focused perspectives in studies investigating website quality.

Only Swedish websites were included, which could implicate limited generalizability to other countries with different contexts. However, Swedish websites are probably similar to those of many other countries. To identify websites accessed by laypeople, search terms from individuals with personal experience were used. For each search term, the first 50 hits were screened for inclusion, resulting in 1300 screened hits in total. Previous research has shown that individuals rarely go beyond the first 10 hits [11]. Moreover, many of the screened hits that led to relevant patient information websites were duplicate hits, indicating that we achieved saturation. Google and Bing are the 2 most used search engines in Sweden, Google being the most used, with over 90% of usage [44]. The majority of the included websites were identified through searches in both Google and Bing. Considering these aspects, we argue that the patient information websites identified represent those that women and their partners come in contact with when searching the Web for patient information about medically induced second-trimester abortions.

Two validated instruments [32-34] developed by patient information experts and laypeople were used to assess the quality of the included websites. The DISCERN instrument has been used extensively in previous studies to assess the quality of information on the Web about many different health issues, such as congenital heart defects [14] and caesarean section [45]. The EQIP tool was chosen since it includes dimensions not covered by DISCERN, such as design and language [34], and has previously been used to assess, for example, the quality of websites offering information on breast augmentation [46]. Thus, the 2 instruments complemented one another and showed similar results concerning poor website quality. The instruments were originally developed to systematically judge the quality of patient information [32,33] and the interrater reliabilities among the assessors were approximately 0.8 across the different subscales, indicating substantial agreement [47]. A separate analysis of the ratings of the 2 assessors who were a couple did not reveal higher interrater reliability compared with the overall interrater reliability. Consequently, we argue that the couple rated the websites individually and that the inclusion of a couple as assessors did not introduce bias into the study.

Suggestions for Future Research

This was a descriptive study with the overarching aim to investigate the quality of, suitability of, and issues with existing patient information websites about medically induced second-trimester abortions. The findings highlight a number of different problems that exist with these sources, calling attention to further studies needed within this field of research. Steps need to be taken to raise the overall quality of patient information websites about medically induced second-trimester abortions.

First, the confronted searching difficulties highlight the need to investigate which counseling strategies are appropriate to guide consumers to the highest quality Web-based sources. Second, more research is needed that investigates the potential effects that publicly available patient information websites have on the psychological health of individuals awaiting medically induced second-trimester abortions. Finally, the findings call attention to the mismatch between the preferences of laypeople and existing websites, indicating a need for research that investigates how websites should be developed to meet the requirements of the intended consumers. For example, the next step could be to develop guidelines for website development for this specific patient population. We encourage researchers

to initiate intervention studies with the aim of raising the quality standard of the available sources on the Web about medically induced second-trimester abortions.

Conclusions

The high number of irrelevant hits and poor quality of patient information websites are issues that must be considered when consulting patients awaiting medically induced second-trimester abortions. Poor quality of the information and low reliability were found in websites affiliated with the health care system as well as private organizations, indicating problems irrespective of website affiliation. Although the difference was small, websites from the health care system had higher reliability and overall quality.

When consulting women and partners who are awaiting medically induced second-trimester abortions, health professionals should initiate discussions concerning web-based patient information sources, and inform them about the issues and quality deficits associated with these websites. In clinical encounters, professionals should offer recommendations for appropriate search terms, search strategies, and patient information websites. There is a need for overarching systematic efforts to stipulate and continuously update lists with such recommendations.

The results indicate that website developers need to take steps to enhance the quality of websites about medically induced second-trimester abortions and ensure that websites meet the preferences and needs of the intended consumers. Developers should make sure that websites contain comprehensive, accurate, and easy-to-read information. The information must be written respectfully and without bias against induced abortions, and include details about how the information was produced. More research is needed to investigate how to help patients come in contact with the most appropriate web-based supplemental patient information about medically induced second-trimester abortions.

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Authors' Contributions

TC conceived and designed the study. TC collected the data. TC and OA analyzed and interpreted the data. TC drafted the manuscript. OA revised the manuscript critically for important intellectual content. TC and OA gave the final approval of the version to be published.

Conflicts of Interest

None declared.

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Abbreviations

EQIP: Ensuring Quality Information for Patients

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Original Paper

Rare Diseases on the Internet: An Assessment of the Quality of Online Information

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Abstract

Background: The importance of the Internet as a medium for publishing and sharing health and medical information has increased considerably during the last decade. Nonetheless, comprehensive knowledge and information are scarce and difficult to find, especially for rare diseases. Additionally, the quality of health or medical information about rare diseases is frequently difficult to assess for the patients and their family members.

Objective: The aim of this study is to assess the quality of information on the Internet about rare diseases. Additionally, the study aims to evaluate if the quality of information on rare diseases varies between different information supplier categories.

Methods: A total of 13 quality criteria for websites providing medical information about rare diseases were transferred to a self-disclosure questionnaire. Identified providers of information on the Internet about rare diseases were invited to fill out the questionnaire. The questionnaire contained questions about the information provider in general (eg, supplier category, information category, language, use of quality certificates, and target group) and about quality aspects that reflect the 13 quality criteria. Differences in subgroup analyses were performed using *t* tests.

Results: We identified 693 websites containing information about rare diseases. A total of 123 questionnaires (17.7%) were completely filled out by the information suppliers. For the remaining identified suppliers (570/693, 82.3%), the questionnaires were filled out by the authors based on the information available on their website. In many cases, the quality of websites was proportionally low. Furthermore, subgroup analysis showed no statistically significant differences between the quality of information provided by support group/patient organization compared to medical institution (P=.19). The quality of information by individuals (patient/relative) was significantly lower compared to information provided by support group/patient organization (P=.001), medical institution (P=.009), and other associations and sponsoring bodies (P=.001) as well.

Conclusions: Overall, the quality of information on the Internet about rare diseases is low. Quality certificates are rarely used and important quality criteria are often not fulfilled completely. Additionally, some information categories are underrepresented (eg, information about psychosocial counseling, social-legal advice, and family planning). Nevertheless, due to the high amount of information provided by support groups, this study shows that these are extremely valuable sources of information for patients suffering from a rare disease and their relatives.

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KEYWORDS

health literacy; rare disesases; quality indicators; health information exchange

Introduction

The quality of information provided on the World Wide Web has been highly discussed in the literature for the past few years (eg, [1-3]). In particular, regarding medical information, the provision of high-quality information is very important because misinformation can lead to serious health consequences for the affected patients. This is particularly relevant for information on the World Wide Web, where the information is used without the intervention of a medical professional, even though the related websites clearly state that this information cannot replace a medical professional's consultation [4-9].

In the field of rare diseases, information is scarce; it is difficult to find the right information as well as to assess the quality of the provided information in detail [10-12]. Additionally, only a few medical experts for specific rare diseases have comprehensive knowledge about the diseases. This limits the ability of patients to get access to high-quality information [13,14]. The definitions of rare diseases vary from 12:100,000 in Australia to 75:100,000 in the United States [15]. This study is set in Germany; therefore, it is based on the European Union definition that considers diseases to be rare when the prevalence is less than 50:100,000 [16]. It is estimated that there are between 5000 and 8000 different rare diseases affecting nearly 30 million people in the European Union and 4 million people in Germany alone [15,17,18].

A detailed description of the framework of this study can be found in the literature [19]. In brief, the aim of the project is to conceptualize and implement a central information portal about rare diseases in Germany, which refers to existing quality-assured information sources [20]. The distribution of information and knowledge about rare diseases is an important factor to improve the overall situation of people affected by a rare disease [17,21]. In this context, the Internet as a worldwide open-access medium has become more important during the last decade [22,23]. The Internet can improve the distribution of information about rare diseases to the general public and, in particular, to medical professionals, patients, and relatives of patients [22]. For the latter group, the Internet is one of the most frequently used information resources and often the primary source to search for information after getting a diagnosis [24]. Nevertheless, patients reported that they are often overstrained with the information they find on the Internet [25]. Information is often disordered and refers to different stages of the disease. Moreover, it is not possible to assess the quality of the information and to find the right information, such as social-legal advice [1]. For medical professionals, it is important to have access to the latest innovative research results and evidence-based therapeutic options as well as actual contact details of support groups [26].

The aim of this study is to assess the quality of information on the Internet about rare diseases. Additionally, the study aims to evaluate if information about rare diseases (eg, information provided by support groups) is as reliable as information provided by medical institutions by performing subgroup analyses. The assessment is based on 13 quality criteria for websites providing medical information about rare diseases [19].

Methods

We divided the methodological framework into several steps. First, as mentioned previously, 13 quality criteria for websites providing medical information were included to a self-disclosure questionnaire. The questionnaire contained questions about the information provider in general (eg, supplier category, information categories, language, use of quality certificates, and target group) and questions about quality aspects reflecting the 13 quality criteria (Textbox 1). The disclosure was not anonymous because the answers need to be checked by the authors. The questionnaire was verified and pretested by the patient organization Alliance of Rare Chronic Diseases Germany (ACHSE eV) and Orphanet Germany. Additionally, the verified version of the questionnaire was tested by selected rare disease information providers, which were randomly identified by an Internet search.

Second, information providers on the Internet were identified by an Internet search; all 8000 rare diseases, as listed in the Orphanet list of rare diseases and synonyms [27], were entered into the Google search engine by a number of research assistants from May 2015 to January 2016. This list included all registered rare diseases and their synonyms. For every disease, the first two hit lists, meaning the first 20 hits, were screened to identify information websites in the German language. A random check with 30 diseases showed that we could assume that a screening of the first two hit lists of each rare disease was sufficient to identify all relevant information websites. Websites that provided information about rare diseases were included in the database, whereas those that just presented contact data, for example, with no further information were excluded. Furthermore, websites providing information about several rare diseases were included into the database as a singular information provider. Third, all information providers were invited by email to fill out the self-disclosure questionnaire (September 2015 to March 2016). Then, these datasets were double-checked using the information available on the website. Data were checked for correctness (eg, does the website provide information about the stated information category?) and plausibility (eg, is the description of the process of systematic or literature research comprehensible?). For all information providers who did not fill out the questionnaire, the questions were answered by the authors based on the information available on the website. For that, authors checked the content and the characteristics of each identified website carefully. However, just 10 of 13 quality criteria could be answered by publicly available information. The remaining three quality criteria, representing the authoring information, evaluation of information, and review of information, were not reviewable by the authors. Consequently, for the main evaluation, these quality criteria were excluded. In the end, all datasets were evaluated. Microsoft Access was used for data storage. For data analysis, both Microsoft Excel and Microsoft Access (versions 2007) were used. Differences in subgroup analyses were performed using *t* tests.

Textbox 1. Quality criteria for websites about rare diseases.

Authoring information

- Do you perform a systematic (literature) search prior to providing information for your home page? If yes, then please describe this process.
- Are experts involved in providing information? If yes, then which field do they belong to?
- Do you document the process of providing information? If yes, then please describe the documentation process.
- Do you inform users about the process of developing information? If yes, please describe the process and provide the respective URL.

Authors

- Is general information about the authors mentioned?
- Are other persons who contributed to developing information mentioned?
- Is user-generated content distinguishable and labeled with a username?

Sources

- Does the information concern primary sources of information?
- If no, then do you quote external sources?

Creation or update date

- Is the creation date of information mentioned?
- Is the update date of information mentioned?

Privacy statement

- Is a privacy policy used to inform the user about the usage, storage, and disclosure of personal data?
- Do you inform the user in a prominent position about the storage of personal data for internal usage (eg, research) with an analysis tool and does the user has the opportunity to disagree?
- Does the user has to agree actively to the disclosure of personal data to third parties?

Declaration of evidence

- Is all medical information evidence-based and it is discernible on what basis points are made (eg, studies, expert statements)?
- Do you provide references to the limitations of the evidence and set out further evidence needs?

Marking of conflicts of interests

- Are advertisements marked as such plainly?
- Are sponsors named?
- Are targets and purposes of the home page published (eg, commercial interest)?
- Is the funding (except from self-financing) published?
- Are conflicts of interests mentioned?

Consideration of target group

- Is information presented target group-specific?
- Is it discernible to whom the information is addressed (eg, patients, doctors)?

Evaluation of information

- Does an archive with former or changed contents exist?
- Is all information checked consistently regarding correctness and accuracy?

Review of information

- Does an internal review process (content quality assessment) for the evaluation of contents exist? If yes, then please describe the process.

Characteristics of the website (accessibility)

- Did you check the website for accessibility through a BITV-Test? (The BITV-Test is a comprehensive accessibility evaluation instrument.) If yes, how many points has the website scored in this test?

- Is the font size of the website adjustable?
- Do you consider persons with color vision deficiency in the website coloration?
- Is the main menu selectable without a mouse?
- Information is available in a simple language (eg, according to the rules of the network Simple Language).
- Is the website's content readable by a software tool?
- Is it possible to subscribe to a newsletter?
- Is information available in a printed version?
- Are the contents shown in multimedia (eg, in terms of videos and photos)?

Imprint

- Is the imprint created according to § 5 TMG/§ 55 RStV following German law?

Contact facility

- Do users have the facility to provide feedback or to get in touch with the operator?
- Is a contact sheet easy to access?

Results

Overall, we identified 693 information suppliers on the Internet providing information about rare diseases in the German language or from German-speaking countries. A total of 123 questionnaires (17.7%) were completely filled out by the information suppliers. For the remaining identified suppliers (570/693, 82.3%), the questionnaires were filled out by the authors, omitting the questions referring to quality criteria representing the authoring information, evaluation of information, and review of information. A list of the identified information supplier is available from the corresponding author on reasonable request.

Most of the websites were located in Germany (632/693, 91.2%), Austria (21/693, 3.0%), or Switzerland (40/693, 5.8%); therefore, most of the sites were available in the German language (682/693, 98.4%). However, some were available only, or additionally, in the English language (108/693, 15.6%). The fact that websites can be available in more than one language has to be taken into account. The majority of websites were those of patient organizations or support groups (269/693, 38.8%). Other important providers were medical institutions (186/693, 26.8%), other associations and sponsoring bodies (65/693, 9.4%), and individuals (eg, patient/relative; 52/693, 7.5%). The three most frequent information categories of all information suppliers were information about disease patterns/symptoms (633/693, 91.3%), information about diagnostics (517/693, 74.6%), and information about medication, curative means, and aids (359/693, 51.8%). Little information was available about psychosocial counseling (49/693, 7.1%), in particular. As a target group, adults were most frequently addressed (662/693, 95.5%). All characteristics are shown in detail in Table 1.

Tables 2 and 3 show the comparison and distribution between supplier and information categories. For instance, it can be seen that information provided by individuals mostly focused on disease patterns/symptoms, wherby information provided by medical institutions additionally focused on diagnostics. Furthermore, information exchange with other patients and information about psychological counseling were mostly provided by support groups/patient organizations.

Table 1. Characteristics of information providers (N=693).

Item	n (%)
Supplier category	
Support group/patient organization	269 (38.8)
Medical institution	186 (26.8)
Other associations and sponsoring bodies	65 (9.4)
Individual (patient/relative)	52 (7.5)
Expert association	40 (5.8)
Individual (medical expert)	29 (4.2)
Pharmaceutical or medical technology company	26 (3.8)
Publishing or media company	21 (3.0)
Other	5 (0.7)
Information category (multiple answers possible)	
Disease pattern/symptoms	633 (91.3)
Diagnostics	517 (74.6)
Medication, curative means, and aids	359 (51.8)
Assistance for self-help	347 (50.1)
Information exchange with other patients	320 (46.2)
Other therapy options	317 (45.7)
Research	254 (36.7)
Personal advice	164 (23.7)
Training and continued education	128 (18.5)
Advice from doctors	116 (16.7)
Therapeutic guidelines	101 (14.6)
Desire to have children/family planning	93 (13.4)
Social-legal advice	86 (12.4)
Psychosocial counseling	49 (7.1)
Language (multiple answers possible)	
German	682 (98.4)
English	108 (15.6)
Country	
Germany	632 (91.2)
Switzerland	40 (5.8)
Austria	21 (3.0)
Target group (multiple answers possible)	
Adults	662 (95.5)
Children	235 (33.9)
Medical professionals	221 (31.9)
Self-disclosure	
Accomplished by the supplier	123 (17.7)
Accomplished by authors	570 (82.3)

Table 2. Comparison and distribution between supplier (individual-medical expert, individual-patient/relative, expert association, medical institution, and pharmacetuical or medical technology company) and information categories.

Category	Supplier									
	Individual (medical expert)		Individual (patient/relative)		Expert association		Medical institution		Pharmaceutical or medical technology company	
	n (%)	Supplier %	n (%)	Supplier %	n (%)	Supplier %	n (%)	Supplier %	n (%)	Supplier %
Medication, curative means, and aids	12 (3.3)	41.4	26 (7.2)	50.0	18 (5.0)	45.0	79 (22.0)	42.5	22 (6.1)	84.6
Information exchange with other patients	8 (2.5)	27.6	41 (12.8)	78.9	6 (1.9)	15.0	8 (2.5)	4.3	3 (0.9)	11.5
Diagnostics	22 (4.3)	75.9	27 (5.2)	51.9	30 (5.8)	75.0	158 (30.6)	85.0	21 (4.1)	80.8
Research	11 (4.3)	37.9	11 (4.3)	21.2	20 (7.8)	50.0	92 (36.2)	49.5	5 (2.0)	19.2
Training and continued education	6 (4.7)	20.7	3 (2.3)	5.8	13 (10.2)	32.5	46 (35.9)	24.7	0 (0.0)	0.0
Assistance for self-help	9 (2.6)	31.0	21 (6.1)	40.4	17 (4.9)	42.5	32 (9.2)	17.2	11 (3.2)	42.3
Desire to have children/family planning	5 (5.4)	17.2	6 (6.5)	11.5	1 (1.1)	2.5	14 (15.1)	7.5	5 (5.4)	19.2
Disease pattern/symptoms	28 (4.4)	96.6	47 (7.4)	90.4	32 (5.1)	80.0	165 (26.1)	88.7	23 (3.6)	88.5
Personal advice	6 (3.7)	20.7	2 (1.2)	3.9	7 (4.3)	17.5	41 (25.0)	22.0	5 (3.0)	19.2
Psychosocialcounseling	0 (0.0)	0.0	0 (0.0)	0.0	2 (4.1)	5.0	10 (20.4)	5.4	0 (0.0)	0.0
Other therapy options	16 (5.0)	55.2	27 (8.5)	51.9	15 (4.7)	37.5	98 (30.9)	52.7	11 (3.5)	42.3
Social-legal advice	1 (1.2)	3.5	2 (2.3)	3.9	3 (3.5)	7.5	13 (15.1)	7.0	4 (4.7)	15.4
Therapeutic guidelines	6 (5.9)	20.7	3 (3.0)	5.8	10 (9.9)	25.0	26 (25.7)	14.0	2 (2.0)	7.7
Advice from doctors	4 (3.4)	13.8	0 (0.0)	0.0	18 (15.5)	45.0	62 (53.5)	33.3	5 (4.3)	19.2

Table 3. Comparison and distribution between supplier (support group/patient organization, publishing or media company, other associations and sponsoring bodies, and other) and information categories.

Category	Supplier							
	Support group/patient organization		Publishing or media company		Other associations and sponsoring bodies		Other	
	n (%)	Supplier %	n (%)	Supplier %	n (%)	Supplier %	n (%)	Supplier %
Medication, curative means, and aids	148 (41.2)	55.0	15 (4.2)	71.4	36 (10.0)	55.4	3 (0.8)	60.0
Information exchange with other patients	227 (70.9)	84.4	3 (0.9)	14.3	24 (7.5)	36.9	0 (0.0)	0.0
Diagnostics	193 (37.3)	71.8	20 (3.9)	95.2	42 (8.1)	64.6	4 (0.8)	80.0
Research	76 (29.9)	28.3	4 (1.6)	19.1	33 (13.0)	50.8	2 (0.8)	40.0
Training and continuededucation	41 (32.0)	15.2	3 (2.3)	14.3	16 (12.5)	24.6	0 (0.0)	0.0
Assistance for self-help	223 (64.3)	82.9	4 (1.2)	19.1	29 (8.4)	44.6	1 (0.3)	20.0
Desire to have children/family planning	51 (54.8)	19.0	5 (5.4)	23.8	6 (6.5)	9.2	0 (0.0)	0.0
Disease pattern/symptoms	259 (40.9)	96.3	21 (3.3)	100.0	53 (8.4)	81.5	5 (0.8)	100.0
Personal advice	91 (55.5)	33.8	0 (0.0)	0.0	12 (7.3)	18.5	0 (0.0)	0.0
Psychosocial counseling	33 (67.4)	12.3	0 (0.0)	0.0	4 (8.2)	6.2	0 (0.0)	0.0
Other therapy options	108 (34.1)	40.2	14 (4.4)	66.7	24 (7.6)	36.9	4 (1.3)	80.0
Social-legal advice	54 (62.8)	20.1	0 (0.0)	0.0	9 (10.5)	13.9	0 (0.0)	0.0
Therapeutic guidelines	37 (36.6)	13.8	7 (6.9)	33.3	10 (9.9)	15.4	0 (0.0)	0.0
Advice from doctors	9 (7.8)	3.4	3 (2.6)	14.3	14 (12.1)	21.5	1 (0.9)	20.0

As a first investigation, all identified websites about rare diseases were analyzed for the use of quality certificates. The majority of websites about rare diseases did not use certifications or quality seals. Of the 693 websites analyzed, only 28 (4.0%) were certified by the international Health on the Net Foundation Code of Conduct (HONcode) [28]. Additionally, some were certified by the German certification programs German Action Forum Health Information System (afgis) [29] (7/693, 1.0%) or Medisuch [30] (8/693, 1.2%).

Table 4 shows the results for the evaluation of the quality of information on the Internet about rare diseases. The quality criteria authoring information, evaluation of information, and review of information were based on the datasets from the 123 questionnaires that were filled out by the information supplier. All other quality criteria were based on the datasets of all information providers. It was examined whether the information of websites satisfied the defined quality categories. For some categories, it was not necessary to meet every corresponding item; it was sufficient to fulfill a part of the corresponding items (eg, to fulfill the category sources, the website must contain either primary information or mention external sources, not necessarily both of them). None of the websites fulfilled all the quality criteria and the corresponding categories completely.

Table 4. Quality of information websites (N=693).

Item	n (%)
Quality criteria	
Authoring information[a]	102 (82.9)
Authors	376 (54.3)
Sources	229 (33.0)
Creation or update date	467 (67.4)
Privacy statement	474 (68.4)
Declaration of evidence	360 (51.9)
Marking of conflicts of interests	211 (30.4)
Consideration of target group	643 (92.8)
Evaluation of information[a]	99 (80.5)
Review of information[a]	47 (38.2)
Characteristics of the website (accessibility)	
BITV-Test (barrier-free information technology regulation)	0 (0.0)
Font size adjustable	692 (99.9)
Consideration of persons with color vision deficiency in coloration	396 (57.1)
User can have read out website's content	692 (99.9)
Main menu selectable without a mouse	689 (99.4)
Information in simple language	0 (0.0)
Newsletter	120 (17.3)
Printed version	218 (31.5)
Multimedia	299 (43.1)
Imprint	638 (92.1)
Contact facility	687 (99.1)
Use of quality certificates	
HONcode	28 (4.0)
Medisuch	8 (1.2)
Afgis	7 (1.0)
Stiftung Gesundheit	0 (0.0)

[a] Based on the datasets from the 123 questionnaires that were filled out by the information supplier.

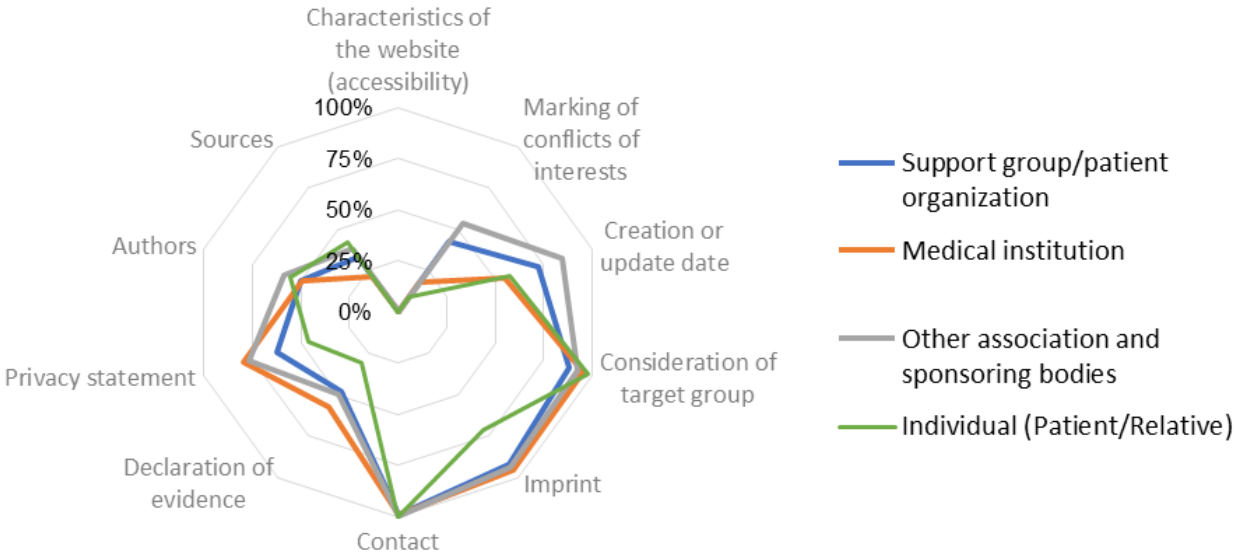
More than 90% of the information suppliers fulfilled the quality criteria of providing contact facility (687/693, 99.1%), imprint (638/693, 92.1%), and consideration of target group (643/693, 92.8%). Although important quality criteria for websites providing information about rare diseases, the criteria declaration of creation or updating date (467/693, 67.4%) and

privacy statement (474/693, 68.4%) were met by only approximately 70% of the identified information suppliers.

The information criteria about characteristics of the website (accessibility) can be divided into several aspects for more detailed analyses. For instance, 43.1% (299/693) of the websites provided the information with the support of multimedia, 31.5% (218/693) also provided printed information, and 17.3% (120/693) provided an email newsletter service. Moreover, 57.1% (396/693) considered persons with color vision deficiency in designing their websites. Detailed results are shown in Table 4.

Subgroup analyses were performed for the four most frequent information supplier categories: support group/patient organization, medical institution, other associations and sponsoring bodies, and individuals (patient/relative). Under the assumption that the fulfillment of every single quality criterion has equal weight, the quality of information of various information supplier categories were compared. On the basis of the 10 quality categories which could be evaluated for all information providers, statistically significant differences could be observed for the supplier category individuals (patient/relative) using a *t* test analysis. The quality of information by these suppliers was significantly lower compared to information provided by support group/patient organization (*P*=.001), medical institution (*P*=.009), and other associations and sponsoring bodies (*P*=.001) as well. No statistically significant differences were observed for the quality of information provided by support group/patient organization compared to medical institution (*P*=.19). Additionally, information provided by other associations and sponsoring bodies showed statistically significant differences compared to that provided by support group/patient organization (*P*=.007) and by medical institution (*P*=.001). The quality of information provided by other associations and sponsoring bodies was significantly higher. Figure 1 shows the distribution of fulfillment of quality criteria by information and supplier categories.

Figure 1. Fulfilment of quality criteria by information provider.



Discussion

Principal Findings

Information about rare diseases is scarce. In the German-speaking setting, 693 websites containing information about rare diseases were identified. In many cases, the quality of these websites, based on the defined quality criteria for websites containing information about rare diseases, can be assessed as insufficient. In addition, quality certificates are rarely used by information providers of rare diseases.

Particularly, the accessibility of the websites needs to be improved, although because of browser configuration, the adjustment of the font size, the selection of the main menu without a mouse, and the readout of website's content seems to be working for most of the websites without any problems. However, providing information by other means, such as email, newsletters, and printed versions, is offered only by some information providers. Support group/patient organizations and other associations and sponsoring bodies are more commonly among those who provide access to their information in various ways. None of the information suppliers provide information in simple language according to the official rules of the network of simple language [31]. Additionally, mentioning of sources of information and disclosing conflicts of interests are seldom stated, although these are important aspects for assessing medical or health information. Furthermore, because of rapid advantages in the development of information and to demonstrate the latest research findings, the documentation of the creation or updating date and the declaration of evidence should be stated more often. On the positive side, an opportunity to contact the website operator is provided in most cases.

Not all information suppliers provide an adequate imprint and privacy statement, even though this is required by German law. In particular, support groups/patient organizations and individuals (patient/relative) do not provide these kinds of

information, although their implementation should be rather straightforward. It can be hypothesized that ignorance and limited experience prevent these supplier categories presenting themselves as professionally as other information providers online. A guidance document for support groups/patient organizations and individuals could help to improve the website's quality.

By far, support groups and patient organizations provide most of the information websites for rare diseases. This reflects the importance of support groups for patients suffering from rare diseases and their relatives [32]. Due to limited knowledge about the diseases, the insufficient experiences of most of the medical professionals, and often limited therapeutic approaches, as well as the low number of affected patients, support groups for patients with rare diseases are important possibilities to share knowledge, experiences, and advice with other affected patients. Support groups and patient organizations for rare diseases constitute very important sources of information about rare diseases and contain high potential to solve upcoming research questions [32]. Moreover, the significant number of identified websites by individuals providing information about specific rare diseases shows that these persons feel isolated with the disease and that they want to make information about themselves public to get in touch with other people affected by the disorder.

Information about psychosocial counseling and the desire to have children and/or family planning are rarely presented on the websites containing information about rare diseases. Nevertheless, both are important information categories for patients suffering from a rare disease [26,33] and their relatives because 80% of all rare diseases have genetic causes [18]. Genetic questions are in line with questions about family planning and genetic theory. Moreover, because of the low number of affected persons and the feeling of being overstrained with the situation of being the only person suffering from this specific disease, psychosocial counseling constitutes an important role for all patients. For this, support groups and patient organizations already provide most of the available information in the categories of information exchange with other patients, assistance for self-help, family planning, personal advice, psychosocial counseling, and social-legal advice. Nevertheless, information and knowledge about psychosocial counseling and family planning in the field of rare diseases need to be extended.

Interestingly, there were no statistically significant differences identified between the quality of information provided by support groups/patient organizations and medical institutions. Only the quality of information provided by other associations and sponsoring bodies showed statistically better results than information provided by self-help group/patient organizations and medical institutions. Overall, cooperation and information transfer between all supplier categories can help to improve information quality and information access for patients suffering from rare diseases, their relatives, and medical professionals. Especially for rare diseases, cooperation activities can improve evidence-based clinical and health care research.

Future research on the quality of information about rare diseases must be considered in a more international context. Especially for ultrarare diseases, for which limited information is available and only a few people worldwide are affected, an international and intercontinental research context is indispensable.

Limitations

This evaluation of quality of information on the Internet about rare diseases is based on information websites available in the German language and/or hosted in Germany, Austria, and Switzerland. Information available on social media accounts were not included in the analysis [34]. The quality criteria cannot verify the actual medical content of health information. These criteria simply verify the factors influencing good thematic content, as well as the quality of the website itself. An evaluation of the quality of information about specific disease groups (eg, rare skin diseases) is not feasible due to the ambiguous classification of rare diseases provided by Orphanet.

Conclusions

The quality of information on the Internet about rare diseases was assessed based on 13 quality criteria for websites providing medical information about rare diseases. Overall, the quality of information on the Internet about rare diseases is insufficient, quality certificates are rarely used, and important quality criteria are often not fulfilled. Subgroup analyses have shown that information provided by support groups and patient organizations are as reliable as information provided by medical institutions. Additionally, there are some information categories that are underrepresented (eg, information about psychosocial counseling, social-legal advice, and family planning). These information categories need to be strongly addressed in future research on information on websites. Nevertheless, this study has shown that support groups are extremely important for patients suffering from a rare disease and their relatives.

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Conflicts of Interest

None declared.

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Abbreviations

ACHSE eV: German Alliance of Chronic Rare Diseases
afgis: German Action Forum Health Information System
HONcode: Health On the Net Foundation Code of Conduct

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Original Paper

Trust Me, I'm a Doctor: Examining Changes in How Privacy Concerns Affect Patient Withholding Behavior

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Abstract

Background: As electronic health records (EHRs) become ubiquitous in the health care industry, privacy breaches are increasing and being made public. These breaches may make consumers wary of the technology, undermining its potential to improve care coordination and research.

Objective: Given the developing concerns around privacy of personal health information stored in digital format, it is important for providers to understand how views on privacy and security may be associated with patient disclosure of health information. This study aimed to understand how privacy concerns may be shifting patient behavior.

Methods: Using a pooled cross-section of data from the 2011 and 2014 cycles of the Health Information and National Trends Survey (HINTS), we tested whether privacy and security concerns, as well as quality perceptions, are associated with the likelihood of withholding personal health information from a provider. A fully interacted multivariate model was used to compare associations between the 2 years, and interaction terms were used to evaluate trends in the factors that are associated with withholding behavior.

Results: No difference was found regarding the effect of privacy and security concerns on withholding behavior between 2011 and 2014. Similarly, whereas perceived high quality of care was found to reduce the likelihood of withholding information from a provider in both 2011 (odds ratio [OR] 0.73, 95% confidence interval [CI] 0.56-0.94) and 2014 (OR 0.61, 95% CI 0.48-0.76), no difference was observed between years.

Conclusions: These findings suggest that consumers' beliefs about EHR privacy and security, the relationship between technology use and quality, and intentions to share information with their health care provider have not changed. These findings are counter to the ongoing discussions about the implications of security failures in other domains. Our results suggest that providers could ameliorate privacy and security by focusing on the care quality benefits EHRs provide.

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KEYWORDS

privacy; electronic health records; disclosure; trust; electronic medical records; personal health information

Introduction

Electronic health records (EHRs) are now an omnipresent feature throughout the health care system, having been adopted by the majority of hospitals and physicians [1-4]. Moreover, new technologies such as health information exchange enable sharing of health records with other health care entities, and personal health records (PHRs) enable patient access to their health records [3]. As a result of this digitization, patients are more likely than ever to have their personal health information

(PHI)—demographic information, medical history, and test and laboratory results—stored in an electronic format. In addition, a great deal of financial and other demographic data are collected and stored in a digital format for reimbursement purposes.

The growth in health information technology (HIT) use throughout the health care industry has aimed to improve care quality, as well as the efficiency of the health care system [5,6]. Health information technology can provide clinicians with more complete patient records at the point of care, enabling better clinical decision making, facilitating improved care coordination, and insuring patient safety as people move throughout the health care system [7]. HIT can also serve as a tool to enable better patient-provider communication, for example through secure messaging, leading to more patient-centered care [8,9]. Despite these potential benefits, recent high-profile, EHR security breaches reported in the media [10,11] make patients wary of this shift to the digital format [12,13]. Patients are concerned about the privacy of their information and its security as it is stored and transferred across the health care system [14-16]. These concerns can manifest themselves in a range of behaviors that can undermine the potential of the technology to facilitate improved care. In particular, Agaku et al found that patients deliberately withheld PHI from their provider due to concerns over the security of their EHR systems [17]. However, it is possible that quality perceptions can mediate this relationship. Campos-Castillo et al found that patients reporting higher quality of care experiences had a lower likelihood of withholding PHI out of privacy and security concerns [18]. However, due to limitations of the specific iteration of the dataset used by both authors, the study by Campos-Castillo et al did not include privacy and security concern items, and the study by Agaku et al did not include quality perceptions. Thus, while these 2 studies provide a foundation for understanding how patient concerns can manifest themselves in adverse behaviors, they examined different factors that taken together might result in different PHI withholding behaviors.

The purpose of this study was to build on the aforementioned 2 studies and advance the understanding of the factors that contribute to PHI withholding behavior. Moreover, this study examined changes in the influence of privacy and security concerns on PHI withholding behavior between 2 time points. As more new technologies facilitate data sharing across the health care system, it is essential to understand the factors that lead to patient mistrust of the health care system and to observe changes in this dynamic over time. Looking at an expanded set of factors that contribute to PHI withholding behaviors can help practitioners understand the relative strength of these factors in consumers' minds. Such information can help providers and health care professionals respond to and mitigate patient privacy and security concerns in a manner that preserves the trust necessary to allow for high-fidelity PHI disclosure.

Methods

Sample

We created a pooled cross-section using data from both the 2011 and 2014 Health Information National Trends Survey (HINTS). The survey is administered as repeat cross-sections by the National Cancer Institute to a national sample of noninstitutionalized adults and gathers information regarding attitudes and perceptions about health information access and use [19]. HINTS maintains a core set of questions asked in each wave of the survey, but specific topic modules are included in separate cycles. Such is the case at-hand. The questions of interest were included only in the 2011 and 2014 surveys, restricting our research to these 2 cross-sections.

Both years of the survey were mail based. HINTS employed a stratified probability sample of the US adult, civilian, noninstitutionalized population. Addresses were randomly selected from the US Postal Service's list of residential addresses, and then an adult within a selected household was chosen to respond to the survey using the next birthday method. The next birthday method asked for the adult in the household who would next have a birthday to complete the survey and was used to eliminate bias associated with the household member most likely to receive mail. A prepaid incentive was sent at the first mailing, and multiple follow-ups were sent to recipients in order to maximize the response rate. For household with a Hispanic last name, a Spanish version of the questionnaire was delivered in addition to the English version. The total number of respondents in the 2011 and 2014 surveys were 3959 and 3677, respectively. Taking into account survey design and weighting issues, the HINTS response rates were 36.67% (3959/10796) in 2011 and 34.44% (3677/10676) in 2014. Both survey iterations yielded samples that allowed for population-level inferences after adjustment. All respondents with complete responses for all variables of interest were included in the analytic sample.

Measures

For the dependent variable, the HINTS survey asked whether the respondent had "ever kept information from (their) health care provider because (they) were concerned about the privacy and security of (their) medical record" (yes, no). This variable was used as the outcome variable for all analyses.

For our independent variables of interest, we closely followed the variable construction of related research [17,18]. Using data from the 2011 HINTS, Agaku et al evaluated the relationship between 4 indicators of privacy and security concerns and withholding behavior [17]. These 4 questions were also asked in the 2014 HINTS, making comparability possible between years. The 4 related questions about privacy and security concerns were as follows: do respondents have concerns about unauthorized access to their medical information when it is transferred electronically between providers; do respondents have concerns about unauthorized access to their medical information when it is faxed between health care providers; do they feel confident that safeguards are in place to protect their medical information from unauthorized access; and do they feel confident that they had a say in the collection, use, and sharing

of their medical information. Respondents could answer each of these 4 questions in 3 levels: not at all concerned or confident, somewhat concerned or confident, or very concerned or confident. We tested differences in our model using all 3 levels and compared the results to using only 2 levels (not at all vs at least somewhat) and found no differences. Thus, for the purposes of simplicity, we dichotomized these variables.

Using the 2011 and 2012 HINTS surveys, Campos-Castillo et al identified a suppressor relationship between the perception that a provider had an EHR ("As far as you know, do any of your doctors or other health care providers maintain your medical information in a computerized system?") and perceived global quality of care rating on withholding behavior [18]. This suppressor relationship occurred when 1 variable, the suppressor (eg, global quality of care rating), had a positive association with a covariate of interest (eg, perception of EHR use), but a negative relationship with the outcome variable (eg, withholding behavior). Accounting for the suppressor could reveal associations between the covariate and the outcome that might not have been detectable without controlling for the suppressor. Thus, we also included the perception that a provider had an EHR (yes, no) and perceived global quality of care rating as key independent variables of interest. The HINTS asked respondents who had a nonemergency department visit in the last 12 months to rate their perception of the quality of care they received using a Likert scale (poor, fair, good, very good, excellent). For comparability to the study by Campos-Castillo et al, the quality of care variable was left as a continuous variable and coded so that higher values indicated better care.

For comparability to the study by Campos-Castillo et al, our control variables aligned with their model [18]. The control variables captured respondents' sociodemographic characteristics, health status, and health care utilization and preferences. Sociodemographic characteristics included race or ethnicity (white, black, Latino, other), gender (male, female), categorical age in years (18-35, 35-49, 50-64, 65-74, 75 or older), education level (less than high school, high-school, some college, college, graduate), annual category of household income (<US $20,000, US $20,000-$34,999, US $35,000-$49,999, US $50,000-$74,999, >US $75,000), an indicator for living in a rural area (defined as a nonmetro county), home-ownership status (homeowner, not homeowner), marital status (married, not married), any health insurance coverage (yes, no), immigration status (born in United States, immigrant), and employment status (employed, not employed). Items about patient health status included a self-rated general health measure (poor, fair, good, very good, excellent), an anxiety and depression index (none, mild, moderate, severe), and self-care self-efficacy (not confident, a little confident, somewhat confident, very confident, completely confident). Health care utilization and preferences included the number of nonemergency room visits in the year prior to the survey (1, 2-4, 5-9, 10 or more), regular health care provider (yes, no), perceived importance of personal health record access (not at all important, somewhat important, very important), and perceived importance that providers share data electronically (not at all important, somewhat important, very important).

Analyses

Weighted, but unadjusted *t* tests or chi-squares were used to compare sample characteristics across the 2 years. Our analytic approach was designed to test the association of the independent variables of interest with withholding behavior in each year independently, as well as to test whether the relationship of the variables on withholding behavior changed between 2011 and 2014. To accomplish these tests, the 2 cross-sections were pooled together and a single fully interacted multivariate logit model, with each independent variable interacting with year, was estimated. This interacted model was solved to determine the adjusted odds ratios (OR) and confidence intervals (CI) within each year. The significance of the interaction term was used to evaluate the relative differences between years for each parameter. All results were weighted to yield US population-level inferences using a standard weighting approach developed for the HINTS dataset [20]. All analyses were conducted using Stata 14 (StataCorp LP) [21].

Results

Overall, 2217 respondents from 2011 had complete information and were included in the analytic sample, and 2176 respondents from 2014 were included. Demographic characteristics in each year are displayed in Table 1, along with the results from a chi-square test to show any differences between years.

The dependent variable of interest for this study was whether the respondent had ever withheld any PHI from a medical provider out of privacy or security concerns. No difference in the level of this behavior was observed between years: in 2011, 14.79% (328/2217) of respondents reported this behavior, whereas in 2014, 14.93% (325/2176) of respondents reported withholding information from their provider out of privacy concerns (Table 2). Comparison of the rates of additional variables of interest between 2011 and 2014, including attitudes concerning privacy and security, quality perceptions, and health care utilization, are presented in Table 2.

To test the hypothesis that the relationship between the withholding behavior and the attitudinal variables and quality perceptions was unchanged between years, the 2 cross-sections of data were pooled and a fully interacted multivariate model predicting withholding behavior was estimated and solved for each different level of year. The interaction terms allowed for testing the relative differences of each parameter between the 2 years (see Table 3 for adjusted ORs; see Multimedia Appendix 1 for average marginal effects). This analysis revealed no changes between 2011 and 2014 in the association of privacy and security attitudes on withholding behavior. No effect of concerns regarding unauthorized access to electronic medical information on withholding behavior in either year was observed, and no difference in this effect between years was found. While concerns about unauthorized access to faxed medical information on withholding behavior was found to be significant in both 2011 and 2014, no difference in this effect was found between years. Respondent confidence that safeguards were in place to protect their medical information was not related to withholding behavior in either year, and again no difference was found between years. Lastly, there was no

effect on respondent confidence that they had some control over their medical information on withholding behavior in either year, and no difference was found between the 2 years.

The perception of greater quality of care was found to significantly lower the odds of withholding behavior in both 2011 and 2014, but no difference was observed between years. Provider having an EHR was not found to be related to withholding behavior in either 2011 or 2014, and no difference was observed between years.

Table 1. Demographic characteristics of the analytic sample in 2011 and 2014. Frequencies and test statistics were adjusted for survey weights.

Variable	2011 (n=2217), n (%)	2014 (n=2176), n (%)	*P* value
Sex			.30
Female	1550 (53.94)	1407 (55.48)	
Male	1024 (46.06)	834 (44.52)	
Race			.57
White	1736 (69.76)	1403 (71.51)	
Black	370 (10.28)	355 (10.02)	
Latino	272 (12.93)	321 (12.51)	
Other	176 (7.02)	154 (5.96)	
Education			<.001
Less than high school	191 (10.48)	159 (9.14)	
High school	455 (18.79)	353 (15.63)	
Some college	796 (33.88)	698 (31.11)	
College	666 (21.61)	613 (26.49)	
Graduate	466 (15.24)	418 (17.62)	
Age (years)			.59
18-35	408 (30.70)	309 (29.52)	
35-49	629 (27.05)	500 (28.55)	
50-64	912 (26.55)	810 (25.62)	
65-74	379 (9.09)	388 (9.48)	
75+	246 (6.63)	235 (6.88)	
Employed	1380 (58.25)	1175 (62.16)	.08
Income			<.001
<US $20,000	482 (19.71)	441 (16.58)	
US $20,000-$34,999	416 (16.37)	290 (10.35)	
US $35,000- $49,999	378 (13.07)	339 (15.08)	
US $50,000-$74,999	453 (17.46)	405 (18.20)	
>US $75,000	845 (33.40)	766 (39.79)	
Married	1436 (53.93)	1114 (54.97)	.49
Rural	409 (16.33)	300 (16.54)	.91
US Immigrant	318 (11.90)	298 (11.60)	.82
Homeowner	1805 (61.35)	15.2 (62.59)	.82
Health insurance	2415 (87.92)	2039 (90.80)	.04

Table 2. Withholding behavior, privacy and security concerns, health and quality perceptions, and health care utilization compared between 2011 and 2014. Frequencies and test statistics were adjusted for survey weights.

Variable	2011 (n=2217), n (%)	2014 (n=2176), n (%)	*P* value
Withheld information	328 (14.80)	325 (14.90)	.22
Electronic information safe			.17
Not at all	824 (37.95)	711 (34.64)	
At least somewhat concerned	1472 (62.05)	1529 (65.36)	
Faxed information safe			.07
Not at all	781 (34.39)	633 (30.47)	
At least somewhat concerned	1538 (65.61)	1601 (69.53)	
Confident safeguards exist			.01
Not at all confident	560 (25.85)	487 (19.72)	
At least somewhat confident	1758 (74.15)	1747 (80.28)	
Control over use of information			.37
Not at all confident	677 (29.45)	623 (27.38)	
At least somewhat confident	1644 (70.55)	1614 (72.62)	
Quality of care (mean+SE)	4.01 (0.03)	4.03 (0.04)	.87
Important that providers share electronic health record data			.71
Not at all	128 (4.94)	102 (5.83)	
Somewhat	704 (29.25)	615 (28.22)	
Very	1742 (65.81)	1524 (65.94)	
Important to have access to personal health record			.18
Not at all	192 (7.96)	147 (5.80)	
Somewhat	589 (21.62)	512 (22.05)	
Very	1793 (70.42)	1582 (72.15)	
Perceived provider electronic health record use	2303 (88.31)	2134 (94.54)	<.001
General health			.14
Poor	79 (2.39)	85 (2.10)	
Fair	315 (11.96)	297 (10.16)	
Good	909 (33.85)	845 (39.12)	
Very good	959 (38.09)	773 (34.57)	
Excellent	312 (13.71)	241 (14.05)	
Depression			.24
None	1725 (66.84)	1584 (71.37)	
Mild	503 (19.67)	404 (17.86)	
Moderate	197 (7.15)	144 (6.11)	
Severe	149 (6.34)	109 (4.65)	
Nonemergency room visits in past year			.18
1	451 (21.54)	375 (19.30)	
2-4	1398 (53.25)	1269 (58.40)	
5-9	460 (15.87)	362 (13.13)	
≥10	265 (9.34)	235 (9.17)	
Have a regular provider	2054 (73.42)	1736 (73.24)	.93
Self-care efficacy, mean (SE)	3.87 (0.03)	3.85 (0.03)	.80

Table 3. Comparison of patient attitudes and demographic variables that are associated with withholding behavior in 2011 and 2014 based on a fully interacted model with a pooled cross-section (N=4393; model adjusted for survey weights).

Variable	2011 Odds ratio (95% CI)	2014 Odds ratio (95% CI)	Significance of interaction
Electronic information safe			
Not at all	Ref[a]	Ref	
At least somewhat concerned	1.63 (0.74-3.62)	1.82 (0.78-4.22)	.85
Faxed information safe			
Not at all	Ref	Ref	
At least somewhat concerned	7.09 (2.56-19.66)[b]	3.27 (1.37-7.83)[c]	.25
Confident information safe			
Not at all confident	Ref	Ref	
At least somewhat confident	0.73 (0.34-1.57)	1.54 (0.66-3.60)	.20
Control information			
Not at all confident	Ref	Ref	
At least somewhat confident	1.71 (0.91-3.21)	1.10 (0.55-2.20)	.35
Quality of care	0.72 (0.56-0.94)[c]	0.61 (0.48-0.76)[b]	.30
Important that providers share electronic health record data			
Not at all	Ref	Ref	
Somewhat	0.77 (0.26-2.34)	0.56 (0.10-3.02)	.74
Very	0.58 (0.21-1.62)	0.72 (0.14-3.61)	.83
Important that you have access to personal health record			
Not at all	Ref	Ref	
Somewhat	0.31 (0.08-1.19)	1.31 (0.26-6.52)	.17
Very	0.47 (0.13-1.69)	1.81 (0.45-7.30)	.16
Provider has an electronic health record	1.47 (0.79-2.74)	0.70 (0.30-1.66)	.17
Sex			
Female	Ref	Ref	
Male	0.84 (0.58-1.24)	1.10 (0.67-1.80)	.40
Race			
White	Ref	Ref	
Black	1.63 (0.75-3.55)	0.98 (0.43-2.24)	.37
Latino	1.21 (0.53-2.78)	1.37 (0.53-3.57)	.84
Other	2.28 (0.89-5.84)	1.97 (0.81-4.81)	.82
Education			
Less than high school	Ref	Ref	
High school	0.56 (0.19-1.68)	1.16 (0.40-3.36)	.35
Some college	1.14 (0.40-3.24)	0.90 (0.37-2.19)	.73
College	0.80 (0.27-2.40)	0.86 (0.33-2.24)	.92
Graduate	1.18 (0.38-3.69)	1.43 (0.57-3.63)	.79
Age (years)			
18-35	Ref	Ref	
35-49	1.60 (0.83-3.09)	1.03 (0.49-2.20)	.39
50-64	1.11 (0.54-2.26)	0.63 (0.31-1.30)	.27

Variable	2011 Odds ratio (95% CI)	2014 Odds ratio (95% CI)	Significance of interaction
65-74	0.87 (0.38-1.98)	0.59 (0.24-1.48)	.54
75+	0.67 (0.18-2.50)	0.26 (0.07-0.94)[c]	.32
Employed	1.79 (0.96-3.35)	1.53 (0.83-2.84)	.83
Income			
<US $20,000	Ref	Ref	
US $20,000- $ 34,999	0.76 (0.30-1.93)	0.97 (0.43-2.21)	.70
US $35,000- $49,999	0.57 (0.23-1.42)	0.99 (0.39-2.54)	.40
US $50,000- $74,999	0.77 (0.35-1.69)	0.84 (0.38-1.85)	.87
>US $75,000	0.55 (0.24-1.25)	0.68 (0.29-1.60)	.72
Married	0.79 (0.50-1.24)	0.72 (0.41-1.26)	.85
Rural	1.00 (0.54-1.86)	1.18 (0.47-2.92)	.77
US immigrant	1.01 (0.55-1.88)	0.73 (0.37-1.41)	.46
Homeowner	1.21 (0.67-2.21)	0.71 (0.41-1.23)	.19
Health insurance	1.35 (0.47-3.88)	0.95 (0.41-2.21)	.61
General health			
Poor	Ref	Ref	
Fair	1.26 (0.27-5.92)	0.41 (0.12-1.39)	.25
Good	1.50 (0.33-6.72)	0.28 (0.08-1.03)	.10
Very good	2.13 (0.46-9.77)	0.41 (0.11-1.50)	.11
Excellent	2.16 (0.44-10.67)	0.49 (0.10-2.31)	.19
Depression			
None	Ref	Ref	
Mild	1.14 (0.61-2.13)	0.87 (0.42-1.81)	.57
Moderate	2.71 (1.14-6.42)[c]	1.85 (0.59-5.79)	.59
Severe	1.13 (0.39-3.26)	1.13 (0.42-3.01)	.99
Nonemergency room visits in past year			
1	Ref	Ref	
2-4	0.91 (0.52-1.60)	1.06 (0.49-2.29)	.75
5-9	1.08 (0.50-2.32)	1.02 (0.39-2.65)	.92
≥10	1.10 (0.45-2.73)	1.66 (0.66-4.18)	.53
Have a regular provider	0.98 (0.56-1.72)	1.75 (0.95-3.23)	.17
Mean self-care efficacy	0.97 (0.69-1.38)	0.97 (0.65-1.44)	.97

[a]Ref: reference category.

[b]*P*<.001.

[c]*P*<.05.

Discussion

Principal Findings

Public perception of the safety of their medical records is critical to not only encouraging full disclosure to their health care provider, but also supporting adoption and use of electronic modes of health communication made available by new technologies. Distrust can lead to withholding of information from providers and undermine the delivery of high-quality, efficient care. The aim of our analysis was to determine the factors that contribute to this withholding behavior, and how the effect of these factors may be shifting over time. In short, we found that the association between patient concerns and withholding information from a provider remained unchanged between 2011 and 2014.

Earlier work using 2011 HINTS data found that respondents with concerns about both faxed and electronic data, and lack of confidence that safeguards were in place to protect medical

information, were more likely to withhold information from their provider [17]. Our model included a more extensive set of control variables, as well as indicators of quality and provider EHR use, and found no such relationships to exist in either 2011 or 2014. This discordance between the 2 analyses suggests that patient concerns over the safety of their medical information may not be adversely related to their disclosure of PHI to their providers. Alternatively, other factors beyond general privacy and security concerns may lead to withholding behaviors, such as lack of trust, stigma, or concerns about insurance rates [22-24].

In contrast to the lack of replicability of the earlier findings regarding the relationship between security and privacy concerns, and withholding behavior, our analysis did observe findings similar to those of Campos-Castillo et al regarding the association between quality and withholding behavior [18]. The original work did not include the privacy and security questions used in this analysis, but did include an identical set of covariates. Nonetheless, Campos-Castillo et al found that perceptions of greater quality of care reduced the odds of PHI withholding behavior [18]. This relationship was observed in our study in both 2011 and 2014, effectively reinforcing the earlier work of Campos-Castillo et al [18]. Interestingly, no difference was observed in the correlation between quality and withholding behavior between years. This latter finding suggests that despite the rise in ubiquity of EHRs alongside more public privacy breaches, high perceived quality of care may still trump any concerns that contribute to withholding behavior.

Related to this issue, our study did observe an increase in perceived EHR use between 2011 and 2014. Despite similar findings regarding quality perceptions between our study and the study by Campos-Castillo et al, our work found no relationship between perceived provider EHR use and withholding behavior, while their study did find the presence of such relationship [18]. To be specific, the study by Campos-Castillo et al found that quality acted as a suppressor variable that moderated the relationship between perceived EHR use and patient withholding behavior [18]. The variables regarding attitudes about EHR and privacy and security may be acting as confounders in the relationship, which would explain the significance in the earlier study but not this one.

Overall, our analysis suggests that in spite of the existence of security and privacy concerns, focusing resources on the delivery of high-quality care may be an effective strategy to foster patient trust. Patients may perceive quality as an indicator of a provider's carefulness with their medical information. Quality may also help to build the patient-provider relationship [25,26]. Alternatively, the notion of privacy is evolving as more and more personal information is held on the Internet [27,28]. It may be possible that given the increasing digitization of personal information, the US population is willing to accept greater amounts of privacy risks of their personal data as a trade-off for greater convenience or better quality of care. This is a ripe area for future research, as the field of health services research should consider the role that changes in collective ideas of privacy may be playing in how patients relate to the health care system.

Limitations

Our analysis faced 3 important limitations. First, the administration of HINTS combined with the weighting technique allowed for the survey to be nationally representative. However, selection bias might have remained that limited the generalizability of the sample. Furthermore, our dependent variable (withholding behavior) could be related to survey response, and respondents with complete answers to all questions might systematically differ from nonrespondents. Related to this issue, because the HINTS survey was administered to only noninstitutionalized individuals, the findings regarding withholding behavior might be biased toward the outpatient environment. Continued monitoring of the factors that contribute to patient withholding with future iterations of HINTS can help to assess the impact of this bias and evaluate the true relationship between the variables of interest and the outcome.

Second, all information in HINTS was self-reported, potentially resulting in unreliable responses. This concern was particularly relevant to the withholding behavior question that was subject to social desirability bias [29]. Third, while our analysis did compare data from 2 different years, the cross-sectional nature of HINTS made the determination of causal inference challenging. Specifically, HINTS asked whether a person had *ever* withheld information from their provider, leaving open the possibility that withholding behavior preceded concerns about privacy and security, or quality perceptions. This issue was further complicated by the ordering of the questions in both cycles of the HINTS survey used in this study, where the question about perception of quality of care preceded the questions about perceived EHR use and withholding behavior. Furthermore, the frame of reference for the quality of care question was "…in the past 12 months," while for EHR use or withholding behavior question, the frame of reference was undefined or "ever." As a result, the responses to these questions might have drawn on different experiences, and might not necessarily reference the same encounter with the health care system. Thus, our findings regarding quality of care might be biased away from the null, and our study results should be interpreted with these measurement limitations in mind. However, despite the inability to detect causality, the national representativeness of HINTS makes it useful to identify macro trends at the individual variable level. Future studies that examine the effect of privacy and security concerns on patient withholding behavior may take a more micro approach, potentially using in-depth interviews to better understand how these concerns may manifest themselves and to identify specific omitted factors.

Conclusions

Monitoring and assessing how technological advances may be related to patient behavior is critical to insure high-quality care and patient safety. In contrast to previous findings, the analysis presented in this study suggested minimal effects of privacy and security concerns on PHI withholding behavior, and that this relationship was constant over time. Similarly, the relationship between quality perceptions and withholding behavior was also constant over time, yet negatively correlated

at both time points. Thus, our findings suggested that improving quality can buffer privacy and security concerns. While technological safeguards to protect patient health information remains important, health professionals should not forget that individual relationships remain the foundation of the patient's experience with the health care system.

Authors' Contributions

TJ and DW conducted the data analysis. DW drafted and edited the manuscript. DW, EW, and TH conceived of and oversaw all stages of this study. All authors approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Average marginal effects of patient attitudes and demographic variables that are associated with withholding behavior, in 2011 and 2014, based on a fully interacted model with a pooled cross-section (n=4393).

[PDF File (Adobe PDF File), 54KB - jmir_v19i1e2_app1.pdf]

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Abbreviations

EHR: electronic health record
HINTS: Health Information and National Trends Survey
HIT: health information technology
PHI: personal health information
PHR: personal health record

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Original Paper

The Associations Among Individual Factors, eHealth Literacy, and Health-Promoting Lifestyles Among College Students

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Abstract

Background: eHealth literacy is gaining importance for maintaining and promoting health. Studies have found that individuals with high eHealth literacy are more likely to adopt healthy eating, exercise, and sleep behaviors. In addition, previous studies have shown that various individual factors (eg, frequency of seeking information on health issues, degree of health concern, frequency of eating organic food, and students' college major) are associated with eHealth literacy and health-promoting lifestyles. Nevertheless, few studies have explored the associations among individual factors, eHealth literacy, and health-promoting lifestyles among college students. Moreover, there is a lack of studies that focus on eHealth literacy as a predictor of psychological health behaviors.

Objective: To examine the associations among various individual factors, eHealth literacy, and health-promoting lifestyles.

Methods: The eHealth Literacy Scale is a 12-item instrument designed to measure college students' functional, interactive, and critical eHealth literacy. The Health-promoting Lifestyle Scale is a 23-item instrument developed to measure college students' self-actualization, health responsibility, interpersonal support, exercise, nutrition, and stress management. A nationally representative sample of 556 valid college students in Taiwan was surveyed. A questionnaire was administered to gather the respondents' background information, including the frequency of seeking information on health issues, the frequency of eating organic food, the degree of health concern, and the students' major. We then conducted a multiple regression analysis to examine the associations among individual factors, eHealth literacy, and health-promoting lifestyles.

Results: The study found that factors such as medical majors (t_{550}=2.47-7.55, P<.05) and greater concern with health (t_{550}=2.15-9.01, P<.05) predicted college students' 4-6 health-promoting lifestyle dimensions and the 3 dimensions of eHealth literacy. Moreover, critical eHealth literacy positively predicted all 6 health-promoting lifestyle dimensions (t_{547}=2.66-7.28, P<.01), functional literacy positively predicted 2 dimensions (t_{547}=2.32-2.98, P<.05), and interactive literacy predicted only the self-actualization dimension (t_{547}=2.81, P<.01).

Conclusions: This study found that participants who majored in medical fields had greater concern with their health and frequently sought health information, exhibited better eHealth literacy, and had a positive health-promoting lifestyle. Moreover, this study showed that college students with a higher critical eHealth literacy engaged better in health-promoting activities than those with functional and interactive literacy.

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KEYWORDS

individual factors; health-promoting lifestyle; eHealth literacy

Introduction

Global health challenges have gained increasing attention in recent years. Improving national health is an international goal. Developing countries strive to promote longevity and a good quality of life for their people and regard this goal as a national competition. The US Department of Health and Human Services found that unhealthy behaviors and lifestyles were 2 important factors that lead to the 10 major causes of death and greatly affect people's health in their daily lives [1].

A health-promoting lifestyle is an important strategy to achieve public health. A health-promoting lifestyle, including self-actualization, health responsibility, exercise, nutrition, interpersonal support, and stress management, can be viewed as positive actions or perceptions directed toward maintaining or enhancing health and well-being [1]. A health-promoting lifestyle can help individuals attain positive health outcomes [2]. Therefore, understanding individuals' health-promoting lifestyles can help us identify health problems and develop interventions to promote health.

Gillis reviewed the literature and found that health-promoting lifestyles are affected by individuals' self-efficacy, social support, perceived benefits, and self-concepts as well as marital status, education, and knowledge about healthy lifestyles [3]. As health knowledge is based on health literacy, health literacy has been identified as a public health goal for the 21st century. The advent of the Internet has dramatically changed the landscape of health information; therefore, it is important to examine how eHealth literacy affects health-promoting lifestyles.

eHealth literacy is defined as the ability to seek, find, understand, and appraise health information from electronic sources and to apply the knowledge gained to address or solve health problems [4,5]. According to Nutbeam, health literacy can be divided into 3 levels: functional, interactive, and critical literacy. At the most basic level, functional literacy refers to basic reading and writing skills and the ability to apply basic literacy skills to health-related materials, such as reading the label on a pill bottle. Next is interactive literacy, which is predicated on functional health literacy and requires more advanced cognitive skills along with social skills that can be used to abstract information and derive meaning from different forms of communication. The highest level of critical literacy builds on functional and interactive literacy and involves the most advanced cognitive skills that can be applied to critically analyze information, discern the quality of health websites, and use quality information to make informed decisions about health. Together, interactive and critical health literacy involves complex skills that individuals use to extract, apply, evaluate, and analyze health-related information [6].

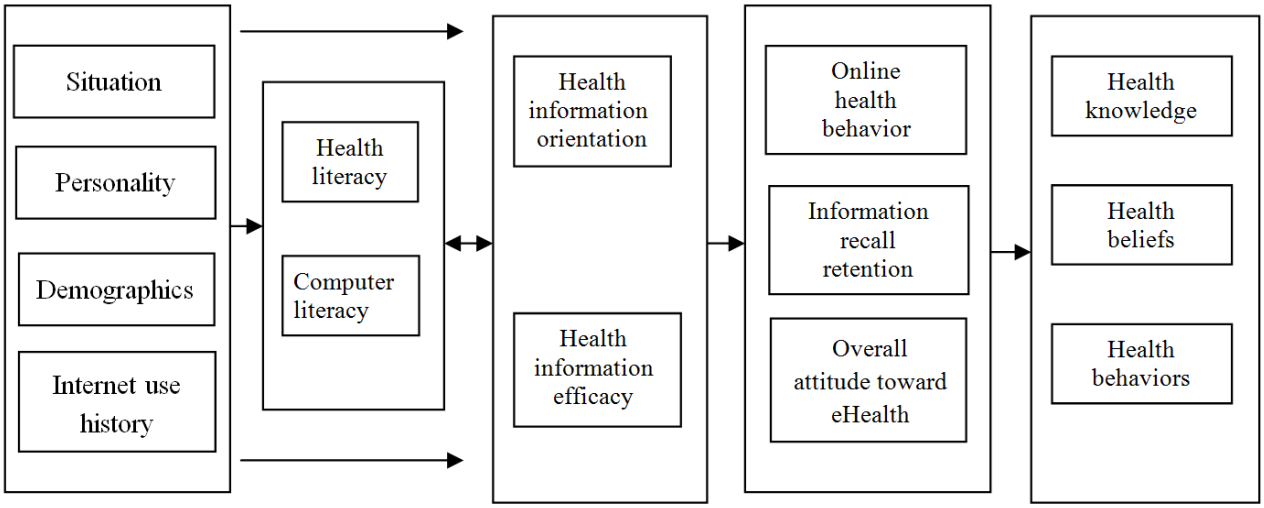
eHealth literacy is becoming important in maintaining and promoting health. According to Pender's health promotion model (HPM), each person has unique personal characteristics and experiences that affect subsequent health-promoting behaviors [7]. People who have better-developed health literacy will thus have skills and capabilities that enable them to engage in a range of health-enhancing actions [6]. The integrative model of eHealth use (IMeHU) suggests that people with high eHealth literacy are not only more inclined to use the Internet to find answers to health-related questions, but are also able to understand the information that they find, verify the veracity of the information, and use this information to promote health behaviors (Figure 1) [8].

Studies have found that the use of health information on the Internet affects personal exercise habits and eating or food consumption habits [9]. Similarly, studies have found that individuals with high eHealth literacy are more likely to adopt healthy eating, exercise, and sleep behaviors [5,10]. From the above study, it is clear that eHealth literacy affects physical health behaviors. A complete health-promoting lifestyle is composed of multiple dimensions, including psychological health behaviors (eg, self-actualization, health responsibility, interpersonal support, and stress management) [1,11,12]. However, few studies have examined the effect of individuals' eHealth literacy on their psychological health behaviors. Thus, we adopt Pender's HPM and IMeHU to explore the association between eHealth literacy and multiple types of health behaviors. A number of studies have found a positive relationship between health literacy and health-promoting behaviors [13-15]. For example, studies have found a significant association between health knowledge and health-promoting lifestyles among women of childbearing age [16]. In addition, eHealth literacy is actively promoted via health education. The eHealth intervention, which incorporates the functions and strategies of the eHealth interactive technology, encourages the adoption of physical and psychological behaviors among school health educators [17]. Accordingly, we propose the following hypothesis:

H1: College students who possess better eHealth literacy will engage in more positive health-promoting lifestyle behaviors.

Individuals' health literacy and health behavior may be affected by their background such as education and situational characteristics related to health [18]. According to Pender's HPM, an individual's health concern is the factor that prompts the individual to adopt a health-promoting lifestyle. Previous studies have shown that individuals who prioritize their health or have numerous sources of health information tend to adopt more health-promoting lifestyles [19-21]. Some studies have also found that nurse training is significantly associated with health-promoting lifestyle behaviors [22]. Individuals who reported higher medical knowledge had better interpersonal relationships and lower levels of stress [23,24]. In addition, studies have found a positive link between organic food and an active lifestyle [25]. Accordingly, we propose the second hypothesis that is as follows:

Figure 1. The integrative model of eHealth use.



H2: The individual factors of college students (eg, frequency of seeking information on health issues, degree of health concern, frequency of eating organic food, and students' major) can predict their health-promoting lifestyles.

The IMeHU suggests that individual factors may affect an individual's level of health and computer literacy as well as the individual's perceived ability to use the Internet for health purposes [8]. Studies have found that college students who major in medical fields and who seek health information more frequently and have greater concern for their own health are more likely to have better eHealth literacy [5,26]. Organic foods are marketed as being healthier than conventional foods because organic food contains more antioxidants and lower levels of toxic metals and pesticide residues, and organic food consumers are more health conscious than other consumers are. Thus, it is inferred that individuals who consume organic food have better eHealth literacy. Accordingly, we propose the third hypothesis that is as follows:

H3: The individual factors of college students (eg, frequency of seeking information on health issues, degree of health concern, frequency of eating organic food, and students' major) can predict eHealth literacy.

As a result, this study aimed to analyze whether the backgrounds of college students in Taiwan predict their eHealth literacy and health-promoting lifestyles and whether students' eHealth literacy predicts a health-promoting lifestyle. These findings may have implications for health education for college students' care and the popularization of national health policies for college students.

Methods

Participants

Sample for the Pretesting

It is important to test survey instruments before using them to collect data. Pretesting can help authors identify questions that do not make sense to participants, as well as problems with questionnaires that might lead to biased answers. Thus, pretesting was conducted to develop and test the adequacy of the research instrument designed by the authors. Exploratory factor analysis was used to assess the reliability of the survey instrument. For the pretest sample, a purposive sample of 250 college students was drawn from 3 schools in Taiwan. Each participant was mailed a questionnaire, and 207 usable (completed) questionnaires were returned, resulting in an effective response rate of 82.8%.

Sample for the Formal Study

This study was a cross-sectional study in Taiwan. We recruited 700 college students from 14 schools to participate in the survey in December 2015. The participants completed the questionnaire in their schools. After eliminating the respondents who had not completed the entire survey or who gave invalid responses, 556 valid surveys (79.4%) were retained. Among these 556 valid respondents, 207 (37.2%) studied in the northern region of Taiwan, 154 (27.7%) studied in the central region of Taiwan, 170 (30.6%) studied in the southern region of Taiwan, and 25 (4.5%) studied in the eastern region of Taiwan.

The Survey Instrument

Individual Factors

We gathered the respondents' individual factors, including the information about the frequency of seeking information on health issues, the frequency of eating organic food, the degree of health concern, and the students' major. The frequency of seeking information on health issues and eating organic food was measured by asking how often the students sought general health-related information and ate organic food and was rated based on the responses on a scale from 1 (never) to 5 (always).

The students' degree of health concern was measured by 1 item asking about their perception of health concerns ("Are you concerned about your health?") and was rated on a scale from 1 (strongly unconcerned) to 5 (strongly concerned).

The major dimension was divided into the participants who were majoring in medical fields and the participants who were

not. In a subsequent analysis, the 2 groups were transformed into dummy variables. We used the nonmedical group as the reference group.

eHealth Literacy Scale

eHealth Literacy was assessed by Chiang et al's eHealth Literacy Scale (EHLS), which has been validated for Taiwan college students. The 3 subscales can be distinguished and show good internal consistency [10]. The individual item reliability of the 12-item EHLS ranged from 0.36 to 0.74. The standardized factor loadings ranged from 0.60 to 0.86 (P<.001). Composite reliability ranged from 0.75 to 0.84, and the average variance extracted for each dimension ranged from 0.50 to 0.52.

The EHLS is a reliable and valid measure of functional eHealth literacy (3 items), interactive eHealth literacy (4 items), and critical eHealth literacy (5 items). Answers were given on a 5-point Likert scale ranging from 5 (total agreement) to 1 (total disagreement). Mean scores for eHealth literacy scale were calculated by summing the item scores divided by the total number of items, resulting in a score ranging from 1 (lower eHealth literacy) to 5 (higher eHealth literacy).

Health-Promoting Lifestyle Scale

The Health-Promoting Lifestyle Scale (HPLS) was developed following a thorough review of the literature [1,11,12]. It contains 6 dimensions, which are as follows:

1. Self-actualization: attitudes toward and expectations of life (5 items, eg, willingness to try new things and challenges).

2. Health responsibility: paying attention to and taking responsibility for one's own health (4 items, eg, discussions about health-related issues with health professionals).

3. Interpersonal support: a sense of intimacy and close relationships (4 items, eg, maintaining good relationships with others).

4. Exercise: regular exercise patterns (4 items, eg, exercise at least three times a week).

5. Nutrition: meal patterns and food choices (3 items, eg, intake of fiber-rich foods).

6. Stress management: ability to cope with stress (3 items, eg, a good balance between work and life). The items were answered using a 5-point Likert scale with scores ranging from 1 (never) to 5 (always).

An exploratory factor analysis (principal components extraction) revealed that the Kaiser-Meyer-Olkin test value was .89 (χ^2_{253} =2528.70, P<.05), Bartlett sphericity test was significant (P<.05), factor loadings ranged from 0.59 to 0.81, and the explained variance was 69.8%. The high Cronbach alpha coefficients (0.86 for self-actualization, 0.87 for health responsibility, 0.84 for interpersonal support, 0.87 for exercise, 0.75 for nutrition, 0.71 for stress management, and 0.92 for the total scale) demonstrated high internal consistency.

Data Analysis

First, a peer review was used to confirm the content validity of the HPLS. Second, exploratory factor analysis was used to assess the reliability of the HPLS. Third, 3 multiple regression analyses were used to examine the effects of individual factors on the 3 dimensions of eHealth literacy. Finally, 6 hierarchical multiple regression analyses were performed to examine the predictive variables on 6 dimensions of health-promoting behaviors. The researcher determined the order of the variables entered into a model based on logical or theoretical considerations. In step 1, individual factors were entered. In step 2, 3 dimensions of eHealth literacy were entered.

Ethical Considerations

The study was reviewed and approved by the Institute of Education at the at the National Sun Yat-Sen University. The study adopted an anonymous questionnaire, in line with our government's institutional review board rules of exempt review. The questionnaire instructions informed the participants of the research purpose and confidentiality and that they had the right to refuse to participate in the study at any time. The participants received the questionnaire and gifts at the same time. Even if a participant decided to drop out of the investigation, he or she still received the gifts. This approach was intended to be fair to each participant, to avoid the impact of gift inducements on the participants, and to serve as a compensation for the participants.

Results

Participant Demographics and Characteristics

Table 1 presents the demographics and characteristics of the study participants. Of the 556 participants, 80.9% were female. In terms of the participants' majors, less than 20% of the participants majored in medical fields. Although a relative majority of the participants (43.5%) reported that their degree of health concern was average, an absolute majority of the participants (98.2%) reported that they had the experience of seeking health-related information. In terms of organic food, approximately 90% of the participants reported that they had experience eating organic foods.

Table 1. Sociodemographic and health information of the sample (N=556).

Variable and group	n (%)
Gender	
Male	106 (19.1)
Female	450 (80.9)
Degree of health concern	
Strongly unconcerned	4 (0.7)
Unconcerned	39 (7.0)
Average	242 (43.5)
Concerned	199 (35.8)
Strongly concerned	72 (12.9)
Major	
Major in medical field	106 (19.1)
Major in nonmedical field	450 (80.9)
Frequency of seeking information on health-related issues	
Never	10 (1.8)
Seldom	125 (22.5)
Sometimes	270 (48.6)
Often	116 (20.9)
Always	35 (6.3)
Frequency of eating organic food	
Never	60 (10.8)
Seldom	199 (35.8)
Sometimes	202 (36.3)
Often	71 (12.8)
Always	24 (4.3)

Hierarchical Multiple Regression Analysis of the Variables Predicting a Health-Promoting Lifestyle

The results of hierarchical multiple regression analysis are displayed in Multimedia Appendix 1 (Model 1) and Multimedia Appendix 2 (Model 2). Multimedia Appendix 1 indicates that the individual factors positively predicted 6 dimensions of a health-promoting lifestyle, with a moderate level of predictive explanatory power for health responsibility (30%), exercise (23%), and nutrition (22%) and a low level of predictive explanatory power for self-actualization (17%), interpersonal support (16%), and stress management (15%). Notably, health concern positively predicted all 6 health-promoting lifestyle dimensions, and students' major predicted the 4 health-promoting lifestyle dimensions. Both frequent health information seekers and organic food consumers emerged as predictors of health responsibility and exercise. Multimedia Appendix 2 shows that when controlling for the individual factors, critical eHealth literacy positively predicted all 6 health-promoting lifestyle dimensions. Functional eHealth literacy positively predicted the self-actualization and interpersonal support dimensions, whereas interactive eHealth literacy predicted only the self-actualization dimension. Among the 3 dimensions of eHealth literacy, critical eHealth literacy emerged as the best indicator.

Multiple Regression Analysis of Individual Factors Predicting eHealth Literacy

Multimedia Appendix 3 indicates that all the individual factors except organic food consumption positively predicted the 3 dimensions of eHealth literacy, yielding low (functional adjusted R^2=.14) and medium (Interactive: adjusted R^2=.22, critical: adjusted R^2=.20) predictive explanatory powers. In functional literacy, students' major emerged as a strong predictor, frequently seeking information on health issues emerged as the strongest predictor of interactive literacy, and both greater health concerns and frequently seeking information on health issues emerged as the strongest predictors of critical literacy.

Discussion

Principal Findings

This study found that the participants who majored in medical fields had a greater concern for their health and frequently sought health information, exhibited better eHealth literacy, and had a positive health-promoting lifestyle. Moreover,

participants who possessed better critical eHealth literacy engaged in more positive health-promoting lifestyle behaviors.

Lower Influence of Functional and Interactive Than Critical eHealth Literacy on Health-Promoting Lifestyles

Health literacy is a cognitive skill to empower individuals to take responsibility for their health and to adopt an appropriate lifestyle to keep themselves healthy resulting in personal benefit [6,27]. According to IMeHU, the promotion of individual eHealth literacy influences an individual's health decision making and subsequently influences future actions that may help achieve better health [8]. The findings of the study showed that individuals with adequate health literacy have the knowledge and ability to make healthy choices and adopt healthy lifestyles to engage in a range of physical and mental health-enhancing actions [28]. Thus, Hypothesis 1 was partly supported. However, the study found that individuals with higher critical eHealth literacy engage in more health-promoting activities than those with functional and interactive literacy. In particular, critical literacy affects all dimensions of health-promoting behaviors. Critical literacy allows individuals to evaluate health issues and recognize risks and benefits as well as to advocate for themselves [29], thus enabling college students to engage in health-enhancing actions.

Notably, the finding of a lower influence of functional and interactive than critical eHealth literacy on health-promoting lifestyles is quite reasonable. Functional and interactive literacy are basic levels and the processing involved in functional and interactive eHealth literacy does not engage as deeply with issues as critical eHealth literacy do. According to the involvement theory [30], critical literacy is a more advanced cognitive skill than functional and interactive literacy. It is not sufficient for individuals to obtain health information; they must further evaluate and use the information to make decisions about their health. This may explain why functional and interactive eHealth literacy are less influential than critical eHealth literacy.

Individuals With Medical Majors and Greater Health Concern Might Have More Positive Health-Promoting Lifestyles

Consistent with Pender's HPM and some other previous studies [19,21-24], this study found that participants with greater health concerns tended to adopt all 6 positive health-promoting lifestyles, with medical majors adopting 4 health behaviors (with the exception of exercise and nutrition). Individuals who frequently sought health information demonstrated better exercise and health responsibility. The findings largely supported the Hypothesis 2. The findings are also consistent with the social cognitive theory, suggesting that individuals' medical knowledge can prompt individuals to adopt health-promoting behaviors. As medical school students have better cognitive understanding and perceptions of health information than nonmedical majors do, they are more willing to engage in appropriate health behaviors.

Individuals Who Are Medical Majors, Have Greater Health Concern, and Frequently Seek Health Information Might Have Better eHealth Literacy Development

Consistent with previous studies [5,10,26], our findings revealed that participants with medical majors and greater health concerns and those who frequently sought health information tended to have better functional, interactive, and critical eHealth literacy than other students did. Therefore, Hypothesis 3 was largely supported. The findings verified Bodie and Dutta's IMeHU [8], indicating that eHealth literacy is influenced by a person's educational background, intrinsic interest in health, and Internet use history. Medical school students have more medical knowledge [31] and therefore possess greater eHealth literacy than nonmedical school students. Individuals who have greater health concern and frequently use Web-based health resources are likely to pay more attention to their health and thus are likely to increase their eHealth literacy.

Organic Food Consumption Predicts a Health-Promoting Lifestyle, But Not eHealth Literacy

This study found that college students who frequently consumed organic food demonstrated better exercise and health responsibility than other students. Previous studies have shown that insufficient information and knowledge about organic labeling affects the distinction between organic food and conventional food [32]. Customers who consume organic food may need to understand the attributes and standards of organic food through greater efforts such as involvement in related information and discussion with relevant professionals. Consequently, it is reasonable that college students who frequently consume organic food demonstrate better health responsibility. In addition, some studies indicate a strong link between organic food choices and perceived healthfulness, well-being, and quality of life [33]. Regular consumers of organic food may have a high internal locus of control and naturally pay more attention to the positive benefits of food to maintain a healthy lifestyle [25,34]. Therefore, these consumers are ready to adopt healthy actions such as regular exercise and are accountable for their own personal health. It is also likely that people who are physically active pay more attention to their health and therefore buy organic food.

The study found that the frequency of organic food consumption did not predict the nutritional dimension. Previous studies lack strong evidence that organic foods are significantly more nutritious than conventional foods, and a number of studies have revealed that consumers' choice of organic food depends on the perceived benefits of organic food [25,35,36]. Researchers have found that health is one of the most prominent motives for organic food consumption [25]. The perceived benefits of food safety, environmental protection, quality, and consumers' perceptions of and attitudes toward labeling systems, message framing, and local origin are also identified as motivating factors for the consumption of organic food. The Taiwan food scandal involved a series of food safety incidents that came to light in 2014. This situation may have further strengthened Taiwan college students' motivation to purchase organic food for food safety and reasons other than nutrition. Moreover, they could obtain appropriate nutrients via a balanced diet. Future studies might examine additional factors that

characterize college students' preferences and behavior toward organic food products.

The study found that the frequency of organic food consumption did not predict the nutrition dimension. According to previous studies, price is a factor that influences organic food consumption. Compared with conventional food, the overpricing of organic food can be considered an important barrier to the purchase desire of consumers [37,38]. Moreover, studies lack strong evidence that organic foods are significantly more nutritious than conventional foods [25]. Therefore, given the high price and uncertain benefits of organic food, students do not necessarily consume organic food to achieve the nutritional aspects of healthy living such as the intake of fiber-rich foods.

Notably, the frequency of organic food consumption did not predict any dimensions of eHealth literacy. This result may be caused by food safety awareness. Various food safety incidents worldwide have increased consumers' concern about the safety of foods and are considered primary reasons for the increasing demand for organic food, which is perceived as healthier and safer [32,39]. Regardless of their level of health literacy, customers who buy organic products may be affected by their perceptions of the safety of the food rather than by the knowledge of organic food. Furthermore, eHealth literacy involves a complex interplay of basic literacy skills, the ability to successfully navigate the dominant language framework (English) and culture utilized for Web-mediated communication, and sufficient levels of technology adoption and proficiency [40]. When consumers shop for organic food in Taiwan, they need to look for the "CAS Organic" label. However, the label does not provide knowledge about the food, food sources, and nutritional facts. If consumers want to understand the nutritional facts of organic food, they need to seek, identify, understand, and use information about organic food. However, more than 90% of Web-based content is in English and is developed from the cultural perspectives of English speakers [41]. It is difficult for speakers of English as a second language to understand, extract, and evaluate eHealth information about organic food.

College students may have a positive attitude toward organic foods and high eHealth literacy but may not consume natural foods due to the higher price of these foods or a lack of convenience. Most Taiwan college students live on campuses, where the accommodations are not suitable for cooking, and they often eat restaurant food. In addition, there are few organic food courts. Even if students cook for themselves, they may not be able to afford organic food, which is more expensive than other food.

Therefore, the relationships among eHealth literacy, health-promoting behaviors, and organic food consumption require further studies to identify other mediating variables.

Limitations

This study did not gather respondents' variables such as age, school type, parental marital status, socioeconomic status, and health status. The analysis would have been stronger if the relationship between eHealth literacy and health-promoting lifestyles were also investigated while controlling for these individual factors. Moreover, this study found that functional and interactive eHealth literacy positively predicted 1-2 health-promoting lifestyle dimensions. There may be other mediating or confounding variables that should be taken into consideration. In addition, given that the factors that influence health-promoting lifestyles are complex and interdependent, future studies should explore which factors are critical and how these factors influence one another. For example, self-efficacy has been found to be a significant predictor of health-promoting lifestyles [2,42]. Future studies could further examine whether the measurement of self-efficacy and other critical factors add value to our understanding of the pathway from eHealth literacy to perceptions of health-promoting lifestyles. Notably, this study found that organic food consumption does not predict health promotion and eHealth literacy as much as students' majors and health concerns do. Studies could consider other mediating or confounding variables such as food safety, organic food price, and attitude toward consumption. Further studies may utilize more integrative theories to study the factors involved in consumers' choice of organic food and how they relate to eHealth literacy and health-promoting lifestyles.

Conclusions

This study extends the previous research by identifying the associations among individual factors, eHealth literacy, and health-promoting lifestyles. The findings of our study corroborate the importance of individual factors in the occurrence of health-promoting behaviors and support the theoretical relationships among the concepts of the health-promotion model. In particular, greater health concern and medical majors affect eHealth literacy and health-promoting lifestyles. Given that greater health concern and medical majors are strong predictors of health-promoting behaviors and eHealth literacy, interventions to strengthen the importance and value of health and to enrich medical knowledge must be considered in programs for health improvement.

Previous studies have identified a positive change in health literacy and healthy lifestyle behaviors as the result of the education process [17,22]. Thus, by "learning health" to "live healthy," school and government authorities can design appropriate programs to provide a much-needed repertoire of proven strategies to help students promote their eHealth literacy and maintain healthy lifestyles.

Moreover, this study showed that college students with higher critical eHealth literacy engage better in health-promoting activities than students with functional and interactive eHealth literacy. Thus, health education should aim not only to enhance basic reading and writing in functional literacy, but should also empower students with critical literacy to develop the skills, knowledge, and efficacy to act on that knowledge and maintain good health via participatory and critical approaches.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Hierarchical multiple regression analysis of 6 dimensions of a health-promoting lifestyle (Model 1).

[PDF File (Adobe PDF File), 29KB - jmir_v19i1e15_app1.pdf]

Multimedia Appendix 2

Hierarchical multiple regression analysis of 6 dimensions of a health-promoting lifestyle (Model 2).

[PDF File (Adobe PDF File), 34KB - jmir_v19i1e15_app2.pdf]

Multimedia Appendix 3

Multiple regression analysis of individual factors predicting eHealth literacy.

[PDF File (Adobe PDF File), 24KB - jmir_v19i1e15_app3.pdf]

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Abbreviations

EHLS : eHealth Literacy Scale
HPLS : Health-Promoting Lifestyle Scale
HPM : health promotion model
IMeHU : integrative model of eHealth use

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Original Paper

Development of the Digital Health Literacy Instrument: Measuring a Broad Spectrum of Health 1.0 and Health 2.0 Skills

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Abstract

Background: With the digitization of health care and the wide availability of Web-based applications, a broad set of skills is essential to properly use such facilities; these skills are called digital health literacy or eHealth literacy. Current instruments to measure digital health literacy focus only on information gathering (Health 1.0 skills) and do not pay attention to interactivity on the Web (Health 2.0). To measure the complete spectrum of Health 1.0 and Health 2.0 skills, including actual competencies, we developed a new instrument. The Digital Health Literacy Instrument (DHLI) measures operational skills, navigation skills, information searching, evaluating reliability, determining relevance, adding self-generated content, and protecting privacy.

Objective: Our objective was to study the distributional properties, reliability, content validity, and construct validity of the DHLI's self-report scale (21 items) and to explore the feasibility of an additional set of performance-based items (7 items).

Methods: We used a paper-and-pencil survey among a sample of the general Dutch population, stratified by age, sex, and educational level (T1; N=200). The survey consisted of the DHLI, sociodemographics, Internet use, health status, health literacy and the eHealth Literacy Scale (eHEALS). After 2 weeks, we asked participants to complete the DHLI again (T2; n=67). Cronbach alpha and intraclass correlation analysis between T1 and T2 were used to investigate reliability. Principal component analysis was performed to determine content validity. Correlation analyses were used to determine the construct validity.

Results: Respondents (107 female and 93 male) ranged in age from 18 to 84 years (mean 46.4, SD 19.0); 23.0% (46/200) had a lower educational level. Internal consistencies of the total scale (alpha=.87) and the subscales (alpha range .70-.89) were satisfactory, except for protecting privacy (alpha=.57). Distributional properties showed an approximately normal distribution. Test-retest analysis was satisfactory overall (total scale intraclass correlation coefficient=.77; subscale intraclass correlation coefficient range .49-.81). The performance-based items did not together form a single construct (alpha=.47) and should be interpreted individually. Results showed that more complex skills were reflected in a lower number of correct responses. Principal component analysis confirmed the theoretical structure of the self-report scale (76% explained variance). Correlations were as expected, showing significant relations with age (ρ=–.41, P<.001), education (ρ=.14, P=.047), Internet use (ρ=.39, P<.001), health-related Internet use (ρ=.27, P<.001), health status (ρ range .17-.27, P<.001), health literacy (ρ=.31, P<.001), and the eHEALS (ρ=.51, P<.001).

Conclusions: This instrument can be accepted as a new self-report measure to assess digital health literacy, using multiple subscales. Its performance-based items provide an indication of actual skills but should be studied and adapted further. Future research should examine the acceptability of this instrument in other languages and among different populations.

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KEYWORDS

digital health literacy skills; eHealth literacy; measurement; validity; performance-based instrument

Introduction

Digitization in health care has changed rapidly over the last decades, and online information and (mobile) applications are playing a growing role in health care. Along with these changes, skills to search, select, appraise, and apply online health information and health care-related digital applications are becoming increasingly important for health care consumers. These skills are called digital health literacy [1], or eHealth literacy [2]. The relevance of this form of literacy is demonstrated in recent studies, showing that people's self-perceived skills to use online information actually affect their health and the quality of their health care, and that a lack of such skills may lead to adverse outcomes [3,4]. Hsu et al. [3] found that digital health literacy skills are associated with various types of health behavior, including healthy eating, exercise, and sleep behavior. Neter and Brainin [4] found relationships between digital health literacy and the presence of chronic illness, perceived self-management skills, and better self-perceived understanding of health status, symptoms, and optional treatments.

A valid measurement instrument on digital health literacy is essential to examine the effects of these skills, both on an individual level and on a population level. On an individual level—for example, in daily clinical practice—a measurement tool could support decisions about the extent to which a patient is able to benefit from particular eHealth tools and interventions [5,6]. Also, it could provide input to coach and train patients who need support in using Web-based health tools [7,8]. On a population level, a proper measurement instrument could provide insight into vulnerable subgroups that face additional challenges in using health care, due to its digitization. For example, previous studies have shown that digital health literacy is related to sociodemographics such as age, education, and income [4,9,10], and studies have shown that certain populations do not have the skills and knowledge to use Web-based health tools for their own benefit and might thereby even become underserved [5,10]. Better insight into populations at risk of low digital health literacy can lead to development and tailoring of health technologies for these specific groups [5,11].

In research, the focus regarding digital health literacy has mainly been on the use of health *information* that is available on the Internet (Health 1.0). Yet eHealth is a broad concept that extends beyond the use of information alone. More recent applications (so called Health 2.0 applications) offer all sorts of interactive technologies, which support people to communicate about their health (with peers and with health care professionals; eg, via forums or e-consults), to self-monitor their health (eg, via patient portals), and even to receive treatment via the Internet (eg, via Web-based cognitive behavioral therapy) [12]. To measure peoples' ability to use this broad spectrum of applications, an assessment of very diverging skills is essential, since using interactive Health 2.0 applications asks for a more diverse range of skills than retrieving health information alone does [6,13-15]. A study on the digital health literacy skills of patients with rheumatic diseases found that 6 types of competences are essential to properly use both Health 1.0 and Health 2.0 applications [16]. First, people need operational and navigation skills to use a computer and Internet browser; this involves, for example, using a keyboard, touch screen, and search engine and being able to find one's way around on the Internet. Second, they need information and evaluation skills to search, appraise, and apply online information; this involves, for example, formulating a correct search query, choosing a reliable search result, understanding the obtained search results, and being able to select the results that are reliable and applicable. To use Health 2.0 applications, people need additional skills related to interactivity on the Web. This encompasses adding self-generated content to the Internet (eg, being able to express oneself in written language) and considering both their own and others' privacy (eg, knowing who is able to read what one has posted on the Internet) [15,16]. Therefore, when measuring a person's digital health literacy skills, the ability to interact on the Internet should be taken into account as well.

Studies on digital health literacy up until now have used the 8-item eHealth Literacy Scale (eHEALS) [17], which has been the only validated instrument on these skills for a long time. It provides a reliable insight into the self-reported skills of health care consumers when searching and using online health information. Studies on its validation have shown that it measures 1 overall concept [17,18], or 2 separate concepts: seeking and appraising online information [19,20]. In order to extent the measurement of digital health literacy and to assess the broad spectrum of skills that are involved, we developed a new instrument. The Digital Health Literacy Instrument (DHLI) aims to incorporate the diversity of skills to use both Health 1.0 and Health 2.0 tools [14,16]. To promote the feasibility of assessment, this is done with self-reportage of health care consumers' perceived skills. Nevertheless, it its known that self-reportage can cause a bias, since people tend to over- or underestimate their own Internet skills [18,21,22]. A study on the predictive validity of the eHEALS has shown that the relationship between people's own perceived skills and their actual performance on Web-based health-related assignments is only small [18]. To overcome this bias in the DHLI instrument, we strive to measure digital literacy skills more objectively as well.

This study's objective was to determine the instrument's reliability and validity, and to explore the value of both the self-report items and the performance-based items. To this extent, we determined distributional properties, internal consistency, test-retest reliability, content validity, and construct validity. The construct validity was assessed by studying the correlation with several concepts that can be assumed to be related. First, we investigated the relation with traditional "digital divide" variables (sociodemographics, Internet use, and use of Web-based health apps). Based on previous studies on health literacy and eHealth literacy, we hypothesized small to moderate (.10-.30) negative correlations with age and positive correlations with education and (health-related) Internet use

[23-27]. Second, we studied the relation with health status, as digital health literacy can be assumed to have an important influence on health behavior and health-related choices that people make [3,4]. Due to the low number of studies on this subject, and heterogeneity in how health is measured, the expected correlation needs to be estimated. Taking the broadness of this concept into account and all the other variables that influence it, we expected a small correlation of .20. Third, we measured the relation with existing instruments that measure strongly related concepts, namely the Newest Vital Sign (NVS) [28] and the eHEALS [17]. The NVS aims to measure skills related to health literacy (reading ability, numeracy, and applying information). Since this only implies regular health information and does not include digital skills, we expected a moderate correlation (±.30). The eHEALS measures digital health literacy skills, but only on a Health 1.0 level. It does not assess interactive skills on the Internet; therefore, we expected a moderate to large correlation (±.50).

Methods

Development of the Digital Health Literacy Instrument

The DHLI operationalizes 7 separate skills. The types of skills are based on a study in which patients with rheumatic diseases were asked to perform a wide range of Health 1.0 and 2.0 eHealth assignments (to find and appraise online health information, to use interactive apps to communicate with peer patients, and to use a personal electronic medical record to retrieve disease-related information and monitor their health status). Since that study used a bottom-up method to determine all relevant skills in health-related use of the Internet, this provided a valid starting point for the instrument [16]. While participants were performing these assignments, we recorded a diverse range of problems, which we divided into 6 categories: (1) operational skills, to use the computer and Internet browser, (2) navigation skills, to navigate and orientate on the Web, (3) information searching skills, to use correct search strategies, (4) evaluating reliability and relevance of online information, (5) adding self-generated content to Web-based apps, and (6) protecting and respecting privacy while using the Internet. In designing the instrument, for each skill we formulated 3 items (in Dutch) to measure people's self-perceived abilities. In the operationalization process, we divided category 4 into 2 separate concepts—evaluating reliability of the information in general, and determining relevance of the information to oneself in a particular situation—resulting in a total of 7 skill categories measured by 21 self-report items. With these self-report items, people score how difficult they perceive certain tasks to be and how often they experience certain problems on the Internet. Each item was scored on a 4-point scale, with response options ranging from "very easy" to "very difficult" and from "never" to "often." Scores were reversed, so that a higher score represented a higher level of digital health literacy. The 3 items on the skill of protecting privacy were not obligatory to fill in: when respondents did not have any experience with posting messages on social media or other communication portals, they could leave the items blank.

The DHLI was translated into English, using forward and backward translation, according to World Health Organization guidelines [29]. The exact wording of the items can be found below. We calculated subscores for each skill by using the mean of the 3 items on every skill. We calculated a total score by using the total mean, for which answers on at least 18 items were necessary. Additionally, for each skill, we added a performance-based item, using questions that asked the participant to apply the particular skill in a fictional situation (see Multimedia Appendix 1). Typically, the skill items display a "print screen" of a search engine or website and ask the participant a skill-related question that can be answered that can be scored as correct (score=1) or false (score=0). Examples of performance-based questions are what button to press for a certain action, or what piece of information would be most valuable in a certain situation. Each item has 5 answer options: 4 different answers (of which 1 is correct) and an "I don't know" option (score=0). Each correct answer receives 1 point, adding up to a maximum total score of 7 points. To calculate a total score, at least 6 out of 7 items should be answered.

We tested face validity of this initial instrument among 11 people, using a 3-step test cognitive interview [30]. Participants were asked to think aloud while completing the items, in order to gain insight into their reasoning and decision-making process when answering the questions [31]. After completion, the research leader asked several follow-up probing questions related to the items that had seemed to cause problems in understanding or answering. In this way, we gained insight into the readability and clarity of the items and altered them accordingly. After these initial alterations, we conducted a second pilot test among 8 people. We made only a few minor alterations in wording in this last pilot round.

Design of the Survey Study

We studied the reliability and validity of the instrument in a paper-and-pencil survey study among the general Dutch population. We did not use a Web-based survey, in order not to exclude people with low digital health literacy skills beforehand.

Participants and Procedure

A total of 200 people participated in the study. Inclusion criteria were having Internet access, being fluent in Dutch, and being 18 years of age or older. We recruited participants through convenience sampling using stratification based on age, sex, and educational level to reach an equal distribution on these sociodemographics. Regarding age, the categories were (1) 18-34 years, (2) 35-49 years, (3) 50-64 years, and (4) 65 years or older. Regarding education, the categories were (1) low: no education, primary school only, or lowest level of high school, (2) middle: higher levels of high school or secondary vocational education, and (3) high: bachelor's degree or higher. On this variable, complete stratification was not feasible, resulting in an overrepresentation of more highly educated respondents.

People who were invited to participate received an invitation letter explaining the inclusion criteria, purpose of the study, its duration (30 minutes), and its voluntary nature. People who consented to take part in the study were contacted in person, by

telephone or email, to confirm their interest in the study and to schedule an appointment. The assessment was done at a quiet location (mostly the participant's home). At the start of the survey (T1) an informed consent form was signed. Participants were asked to fill out the questionnaire and, after that, the research leader assessed the NVS (see Measures section) in a face-to-face setting, which took approximately 4 minutes. We asked all participants 2 weeks later to fill out the DHLI again (T2). After completion of data collection, we raffled off 10 gift certificates of €25 each among the participants at T1.

The study was approved by the Psychology Ethics Committee of Leiden University, Leiden, the Netherlands.

Measures

Besides the DHLI, the survey assessed the participants' (1) sociodemographics: sex, age, and educational level; (2) Internet use: means of Internet access, frequency of Internet use, and self-rated Internet skills; (3) health-related Internet use; (4) health status; (5) health literacy; and (6) eHealth literacy.

We measured health-related Internet use by asking participants the number of occasions on which they had used several eHealth applications, divided into online information, health-related communication tools (such as a patient forum and e-consult), and treatment-related applications (monitoring, Web-based self-help, mobile phone app), with a total of 12 items. Answer options were "never" (score=0), "once" (score=1), "several times" (score=2), and "often" (score=3). We calculated the sum score by adding up the scores on each item.

We measured health status with 3 subscales of the Dutch version of the RAND 36-Item Health Survey (RAND-36), namely General Health Perceptions, Physical Functioning, and Emotional Well-being [32-34]. These scales contain, respectively, 5, 10, and 5 items on perceived general health and perceived health in relation to others (alpha=.81), experienced limitations due to physical health (alpha=.92), and states of emotional well-being (alpha=.85) [34].

We measured health literacy with the Dutch version of the NVS [28,35]. The instrument consists of 6 items based on a nutrition label from an ice cream container. The NVS measures reading skills, numeracy skills, and the ability to apply information. Each correctly answered item receives 1 point, which can be summed up as a total sum score (alpha=.78).

We measured eHealth literacy with the Dutch version of the eHEALS [17,18]. The eHEALS contains 8 items on self-perceived skills to use online health information, measured by a 5-point Likert scale with response options ranging from "strongly disagree" to "strongly agree." Total scores of the eHEALS are summed to range from 8-40, with higher scores representing higher self-perceived eHealth literacy (alpha=.93).

Data Analyses

Data were analyzed using IBM SPSS version 23.0 for Windows (IBM Corporation). Cronbach alpha served as a measure of internal consistency, reflecting the (weighted) average correlation of items within the scale [36]. In general, a Cronbach alpha of .7-.8 is regarded as satisfactory for scales to be used as research tools [37]. We calculated item-total correlations using Spearman rho correlations. Distributional properties of the DHLI and the possible subscales were inspected to examine their normality and to identify floor and ceiling effects. We used skewness and kurtosis values, as well as a Kolmogorov-Smirnov test, to assess the distribution of the scores at T1 and T2. Skewness and kurtosis scores between ±1 and significance on the Kolmogorov-Smirnov test indicate no or slight nonnormality [38]. We considered floor or ceiling effects to be present if >15% of the participants scored the worst or the best possible score on the subscales [39]. Paired samples *t* tests were performed to check for any differences between T1 and T2. To study the test-retest reliability, we calculated intraclass correlation coefficients (ICCs). We assumed a correlation of ≥.70 to be satisfactory [40]. Content validity was assessed with a principal component analysis and varimax rotation to examine the fit with the theoretical 7-factor structure of the instrument. We used expectation-maximization imputations for the missing data. The suitability of using factor analysis on the dataset was assessed using Bartlett test of sphericity (P<.05) and the Kaiser-Meyer-Olkin statistic (recommended value of .6) [38]. We considered factor loadings in excess of .71 to be excellent, .63 to be very good, and .55 to be good [37]. Evidence for construct validity was determined by studying Spearman rho correlations between total scores on the DHLI and sociodemographics, (health-related) Internet use, health status, the NVS, and the eHEALS.

Results

Participants

In total, 200 respondents completed the survey at T1. The response rate on the retest survey was 33.5%; 67 respondents completed the DHLI at T2. Table 1 shows the characteristics of the sample populations at T1 and T2. At T1, 53.5% (107/200) were female. Mean age was 46.4 (SD 19.0) years, and the distribution among the 4 age groups was rather equal, with participants between 18 and 34 years old making up 30.0% (60/200); between 35 and 49, 21.0% (42/200); between 50 and 65, 28.5% (57/200); and 65 and older, 20.5% (41/200). More highly educated people were overrepresented, at 41.5% (83/200) of the total sample.

Table 1. Sociodemographics of participants completing the survey at baseline (T1; N=200) and at 2 weeks (T2; n=67).

Characteristics	T1	T2
Sex, n (%)		
Male	93 (46.5)	31 (46)
Female	107 (53.5)	36 (54)
Age in years		
Mean (SD)	46.4 (19.0)	46.2 (16.3)
Range	18-84	18-78
Educational level, n (%)		
Low	46 (23.0)	13 (19)
Middle	71 (35.5)	27 (40)
High	83 (41.5)	27 (40)

The largest proportion of the respondents used the Internet frequently (see Table 2) and rated their Internet skills as excellent (n=59, 29.5%) or good (n=81, 40.5%). Most respondents accessed the Internet via a mobile phone (n=166, 83.0%), laptop (n=161, 80.5%), personal computer at home (n=115, 57.5%), or tablet (n=113, 56.5%). Of all respondents, 89.5% (n=179) had ever searched the Internet for health- or treatment-related information. Around half had ever read posts on a health-related peer support forum or social media website (n=103, 51.5%) or a health care review website (n=92, 46.0%). A third had ever used a health-related mobile phone app (n=65, 32.5%). Posting self-generated content on the Internet and using treatment-related apps was reported by a smaller proportion of the sample (between 5.5% and 18.0%, see Table 2). Respondents who filled out the survey at T2 did not differ from the total sample on any of the demographic variables, but did report using the Internet more often (t_{163}=1.30, P=.02). This suggests that nonresponse bias might have occurred.

Table 2. General and health-related Internet use among respondents at baseline (T1; N=200) and at 2 weeks (T2; n=67).

	T1, n (%)	T2, n (%)
Frequency of Internet use		
(Almost) every day	178 (89.0)	63 (94)
Several days a week	12 (6.0)	2 (3)
About 1 day a week	5 (2.5)	1 (2)
(Almost) never	3 (1.5)	1 (2)
Means of Internet access[a]		
Mobile phone	166 (83.0)	61 (91)
Laptop	161 (80.5)	57 (85)
Personal computer at home	115 (57.5)	33 (49)
Tablet	113 (56.5)	36 (54)
Computer at work	87 (43.5)	33 (49)
Public computer	26 (13.0)	10 (15)
Self-rated Internet skills		
Excellent	59 (29.5)	18 (27)
Good	81 (40.5)	30 (45)
Average	38 (19.0)	15 (22)
Reasonable	17 (8.5)	3 (5)
Poor	5 (2.5)	1 (2)
Number of respondents who have ever used the Internet to…		
Search for information on health or illness	179 (89.5)	57 (85)
Schedule an appointment with their health care provider	103 (51.5)	36 (54)
Read on a health-related forum or social media website	103 (51.5)	31 (46)
Read a health care review	92 (46.0)	35 (52)
Use a health-related mobile phone app	65 (32.5)	26 (39)
Ask a question of their health care provider	36 (18.0)	13 (20)
Monitor disease symptoms	34 (17.0)	10 (15)
Share personal medical information with others	24 (12.0)	13 (19)
Log on to their own electronic medical record	14 (7.0)	5 (8)
Post a health care review	11 (5.5)	5 (8)
Take a Web-based self-management course	10 (5)	5 (8)
Post a message on a peer support forum or social media website	9 (4.5)	2 (3)

[a]Respondents could mark more than 1 answer on this item.

Distributional Properties and Reliability of the Digital Health Literacy Instrument

Table 3 shows the scores and internal consistency of the self-report part of the DHLI. The Cronbach alpha is satisfactory, at .87. The Cronbach alpha of the items on each separate skill are satisfactory as well, indicating that these scales can be used as a subscale in the DHLI (alpha range .70-.89). Only the skill protecting privacy had an unsatisfactory Cronbach alpha score (.57). The item-total correlations (not shown in Table 3) were moderate to large for all items (range .51-.73, P<.001), except for the items on the skill protecting privacy, which showed no significant item-total correlation. Respondents had a total mean score of 3.11 (SD 0.87). Total scores were slightly skewed (–1.004) and showed kurtosis (2.251) due to frequent scores between 2.75 and 3.5. However, the Kolmogorov-Smirnov test was not significant (D_{200}=.06, P=.06), indicating that the scores are approximately normally distributed. The highest scores on the subscales were reported on operational skills (mean 3.67, SD 0.59), navigation skills (mean 3.30, SD 0.52), and protecting privacy (mean 3.52, 0.52). Operational skills were strongly skewed (–2,388), with a ceiling effect of 60.0% (120/200) scoring the highest possible score, and showed kurtosis (6.220). Privacy protecting skills were slightly skewed (–1.059), with

16.0% (32/200) scoring the highest possible score and no one scoring the lowest possible score. Since the items of the protecting privacy scale were not obligatory to fill in, the response rate on this scale was lower (n=86). The scores of respondents who completed the DHLI at both T1 and T2 did not differ from the total sample at T1 (test statistics not shown in Table 3). Cronbach alphas of the subscales at T2 were satisfactory, ranging from .68 to .88. The test-retest reliability was satisfactory, with ICC=.77 (P<.001) between T1 and T2 on the total scores and levels of agreement of .49-.81 on the subscales.

The Cronbach alpha of the performance-based items was .47, which means that these items did not together form a single construct and should be interpreted as separate items that measure individual skills. Table 4 shows the number of respondents who answered each performance-based item correctly. Most respondents answered the items correctly. Among the more complex skills, the number of respondents with an incorrect answer increased. The only exception was evaluation reliability, which was answered correctly by 94.5% of the respondents (n=188).

Table 3. Total scores, subscale scores, and internal consistencies on the Digital Health Literacy Instrument at baseline (T1; N=200) and at 2 weeks (T2; n=67).

Digital health literacy skill	T1 (N=200) mean (SD)	Alpha T1	T1 (n=67)[a]	T2 (n=67) mean (SD)	Alpha T2	ICC[b] between T1 and T2 (n=67)	*P* value
Total digital health literacy	3.11 (0.45)	.87	3.12 (0.39)	3.16 (0.41)	.88	.77	<.001
Operational skills[c]	3.67 (0.59)	.77	3.76 (0.43)	3.68 (0.51)	.86	.81	<.001
Navigation skills[c]	3.30 (0.52)	.70	3.38 (0.42)	3.28 (0.52)	.82	.60	<.001
Information searching[c]	3.04 (0.64)	.89	3.00 (0.62)	3.00 (0.50)	.82	.63	<.001
Evaluating reliability[c]	2.70 (0.63)	.78	2.74 (0.61)	2.84 (0.53)	.79	.67	<.001
Determining relevance[c]	2.81 (0.60)	.81	2.82 (0.56)	2.85 (0.58)	.85	.49	<.001
Adding content[c]	3.00 (0.67)	.89	2.98 (0.72)	3.14 (0.61)	.91	.58	<.001
Protecting privacy (T1 n=86; T2 n=38)	3.52 (0.52)	.57	3.38 (0.46)	3.61 (0.50)	.68	.49	<.02

[a]Scores at T1 of those who also completed the survey at T2.

[b]ICC: intraclass correlation coefficient.

[c]Answer score range 1-4.

[d]Answer score range 2-4.

Table 4. Number and percentages of respondents who answered the performance-based items correctly (n=199).

Subscale	Respondents with correct answer, n (%)
Operational skills	191 (96.0)
Navigation skills	167 (83.9)
Information searching	156 (78.4)
Evaluating reliability	188 (94.5)
Determining relevance	139 (69.8)
Adding content	135 (67.8)
Protecting privacy	111 (55.8)

Content Validity of the Digital Health Literacy Instrument

Since the performance-based items did not form a scale together, we further determined the content validity of only the self-report scale. Principal component analysis showed a Bartlett test of sphericity of χ^2_{210}=2278.360, P<.001, indicating that correlations between items were sufficiently large for this analysis. The correlation matrix showed no correlations higher than .9, indicating an absence of multicollinearity. The Kaiser-Meyer-Olkin measure of sampling adequacy was good (.859), which indicates that the sample size was adequate for factor analysis. Two eigenvalues were lower than 1: navigation skills (0.949) and protecting privacy (0.816). The others exceeded 1, ranging from 1.124 to 7.580. In combination, the scales explained 76% of the variance, varying between 8% and 14% among the subscales. Table 5 shows the factor loadings after rotation. The items clustered among the factors as intended, with satisfactory factor loadings. Only item 9 scored below .55.

Table 5. Principal component analysis on the Digital Health Literacy Instrument at baseline (T1; N=200).

Item		Component[a]						
		1	2	3	4	5	6	7
How easy or difficult is it for you to…								
1.	Use the keyboard of a computer (eg, to type words)?	.838						
2.	Use the mouse (eg, to put the cursor in the right field or to click)?	.879						
3.	Use the buttons or links and hyperlinks on websites?	.817						
When you search the Internet for information on health, how easy or difficult is it for you to…								
4.	Make a choice from all the information you find?		.777					
5.	Use the proper words or search query to find the information you are looking for?		.755					
6.	Find the exact information you are looking for?		.818					
7.	Decide whether the information is reliable or not?			.621				
8.	Decide whether the information is written with commercial interests (eg, by people trying to sell a product)?			.848				
9.	Check different websites to see whether they provide the same information?			.547				
10.	Decide if the information you found is applicable to you?				.557			
11.	Apply the information you found in your daily life?				.777			
12.	Use the information you found to make decisions about your health (eg, on nutrition, medication or to decide whether to ask a doctor's opinion)?				.824			
When you search the Internet for health information, how often does it happen that…								
13.	You lose track of where you are on a website or the Internet?					.705		
14.	You do not know how to return to a previous page?					.584		
15.	You click on something and get to see something different than you expected?					.805		
When typing a message (eg, to your doctor, on a forum, or on social media such as Facebook or Twitter) how easy or difficult is it for you to…								
16.	Clearly formulate your question or health-related worry?						.825	
17.	Express your opinion, thoughts, or feelings in writing?						.880	
18.	Write your message as such, for people to understand exactly what you mean?						.891	
When you post a message on a public forum or social media, how often…								
19.	Do you find it difficult to judge who can read along?							.797
20	Do you (intentionally or unintentionally) share your own private information (eg, name or address)?							.791
21.	Do you (intentionally or unintentionally) share some else's private information?							.888
Eigenvalue		7.58	2.16	1.59	0.95	1.12	1.91	0.82
% of variance		14.3	12.5	9.9	9.2	9.6	12.3	8.0

[a]The items were as follows: 1: operational skills; 2: information searching; 3: evaluating reliability; 4: determining relevance; 5: navigation skills; 6: adding self-generated content; 7: protecting privacy.

Construct Validity of the Self-Report Scale of the Digital Health Literacy Instrument

Table 6 shows the Spearman rho correlations between the total score on the DHLI and the other assessed variables. Overall, age showed a moderate negative correlation, indicating that older age is related to lower digital health literacy. The other variables showed low to high positive correlations, indicating that a higher educational level, Internet use, health-related Internet use, better health status (as measured with the RAND-36), health literacy (as measured with the NVS), and eHealth literacy (as measured with the eHEALS) are related to higher digital health literacy skills.

Table 6. Spearman rho correlations between the Digital Health Literacy Instrument, sociodemographics, Internet use, health perception, the NVS[a] and the eHEALS[b].

Variable assessed	ρ	*P* value
Age	–.41	<.001
Education	.14	.047
Internet use	.39	<.001
Health-related Internet use	.27	<.001
Health perception (RAND-36[c])	.23	<.001
Physical functioning (RAND-36)	.27	<.001
Mental well-being (RAND-36)	.17	.047
Health literacy (NVS)	.31	<.001
eHealth literacy (eHEALS)	.51	<.001

[a]NVS: Newest Vital Sign.

[b]eHEALS: eHealth Literacy Scale.

[c]RAND-36: RAND 36-Item Health Survey.

Discussion

Up until now, measurement instruments on digital health literacy skills have measured only competencies related to searching and using online health information (Health 1.0). No instrument has yet been available that also measures the broader range of skills that are essential to using eHealth applications, including more interactive Health 2.0 skills [17,41]. Moreover, the available instruments are self-report assessments, which provide no information on people's actual competence level [18]. This paper introduces the newly developed DHLI to assess both Health 1.0 and Health 2.0 skills, using self-reportage and performance-based items.

Our results on the nature and scope of our respondents' health-related Internet use underscore the need for a broad measurement instrument. Whereas searching for health-related information on the Web was still most common (conducted by >90%), more than half of the respondents also reported using health-related social media or consumer review sites. Looking at the measurement properties of the DHLI, it can be concluded that the instrument indeed measures a wide range of digital health literacy skills. The overall reliability of the self-report scale of the instrument can be concluded to be sufficient, with satisfying Cronbach alpha scores and a proper overall test-retest reliability. Only the results on the skill protecting privacy are less convincing, which indicates that this subscale should be further improved. Furthermore, the content validity is good, with the 7 theoretical subscales represented in 7 separate factors, which together explain the largest part of variance. The distribution of the self-report scale can be assumed to be approximately normal, despite some skewness and kurtosis in the total scale and 2 subscales. People in our sample tended to score mostly in the third and fourth quartile of the answer range, meaning that they perceived their skills to be good to very good.

Among the subscales, operational skills showed a high ceiling effect; the largest proportion of our samples (at T1 and T2) scored the highest possible score on this scale. This indicates that the general population does not experience problems in this area, which is not very surprising because this can be seen as the most basic skill in using the Internet. Nevertheless, from previous studies, it is known that a smaller subgroup in the population does struggle with these skills [14,16], which makes it nonetheless relevant to assess these competencies. Further research needs to consider the instrument's application to other subgroups for which these skills might be less obvious (such as the elderly and less-educated people) due to less computer experience [7,42]. What is remarkable in relation to the operational skills subscale as well is that the majority of our sample accessed the Internet with a mobile phone, and not with a laptop or personal computer. Operational skills require different competencies, since these devices operate in very diverse ways in terms of knowledge of the function of various buttons, using a cursor, and clicking on items. Therefore, a future developmental step should take this into account and add mobile health skills (mHealth) as well.

In order to measure more than people's perceived digital health literacy skills, we added a performance-based item to each self-report subscale. Together, the performance-based items showed a low internal consistency, which means that the items should be interpreted individually. The low internal consistency could be explained by the diverse nature of the items. As single items they might be usable to detect specific problems in individuals' competencies. To test this, further research should determine how applicable these items are among subgroups with low digital health literacy skills and what the discriminant value is among these groups. Possibly, the items should be altered to compose more difficult tasks. In our sample most respondents answered the questions correctly, but the more complex the skill, the larger the proportion of the sample with an incorrect answer. The only exception to this trend was the item on evaluating reliability. We measure this skill by asking the respondent where to check the source of the information on a website. Possibly, this question is too easy and does not represent this skill sufficiently. All in all, these items propose

a new method to measure actual digital health literacy skills; from here on their applicability should be improved.

Concerning the validity of the DHLI, the correlations between the self-report scale and related variables were as we expected. The relationship between digital skills and both age and education is still present, possibly due to less computer and Internet use [4,43]. This is confirmed by the positive correlations found between digital skills and both Internet and eHealth use. However, the correlation with education is only low, showing a catch-up in skills by the less educated, narrowing this existing gap. This low correlation might be explained by the high availability of the Internet in general in the Netherlands (Internet access is 92% for less-educated people vs 99% for more highly educated people [44]).

The low, but significant, correlations between health status and digital health literacy indicate a relation between people's skills in using Web-based health care and their actual health. This is interesting, since it indicates the impact that using eHealth can have on people's lives. However, no conclusions can be drawn on the causality of this relationship from our data, and the associations found with age and education should be taken into account in this context as well, since these variables are also related to health. Previous studies did find a mediating role of digital health literacy on health behavior [3] and a relationship with self-management of health and interaction with physicians [4]. Future research should reveal more on the impact that digital health literacy has on (physical, mental, and social) health and health behavior, and on how these competencies can be influenced or deployed to improve one's health.

The correlation between the DHLI and health literacy was moderate, which corresponds with a previous study in which a correlation of r=.36 was found between health literacy and digital health literacy [20]. Since digital health literacy comprises both general health literacy and digital skills, a moderate correlation seems appropriate. The correlation with the eHEALS was moderate to high, which shows there is overlap between the 2 instruments, as expected. Still, it also shows that this new instrument partly measures different skills. To further explore the construct validity of the DHLI, we aim to perform follow-up research on the relationship between scores on this instrument and other health-related factors, such as knowledge on health and disease, health behavior, and self-efficacy in health care [3,4,20].

A limitation of this study that should be taken into account is the overrepresentation of more highly educated respondents, which hinders the translation of these results to the general population. Moreover, as stated before, it is particularly interesting to determine the applicability of this instrument among groups at risk for low digital health literacy. This is, therefore, a large implication for further research. A second limitation, related to the performance-based items, concerns the use of 1 format in the formulation of the items. We used print screens from the Web browser Google Chrome; however, naturally many people use other Web browsers and other operating systems (eg, OS X instead of Windows), which intervene with the validity of the items. When the instrument is assessed digitally, an adaptive test could overcome this problem, so participants can first supply information on their browser use, to which the items can be adjusted. With a paper-and-pencil assessment this could also be done when the instrument is used individually (then the suitable version would be handed to the person), but in a (anonymous) research setting, this will be a persistent problem.

All in all, it can be concluded that the DHLI is acceptable as a new measurement tool to assess digital health literacy, measuring 6 diverse skills. Its self-report scale shows proper reliability and validity. The included performance-based items should be studied and adapted further, to determine their value and their discriminant validity. Future research should examine the acceptability of this instrument in other languages and among different (risk) populations and should explore ways to measure mobile health literacy skills as well.

The Digital Health Literacy Instrument, in both Dutch and English, is available and may be used on request via the corresponding author.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

English version of the Digital Health Literacy Scale's 7 performance-based items.

[PDF File (Adobe PDF File), 799KB - jmir_v19i1e27_app1.pdf]

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Abbreviations

DHLI: Digital Health Literacy Instrument
eHEALS: eHealth Literacy Scale
ICC: intraclass correlation coefficient
NVS: Newest Vital Sign
RAND-36: RAND 36-Item Health Survey

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Original Paper

Preventing Depression in Adults With Subthreshold Depression: Health-Economic Evaluation Alongside a Pragmatic Randomized Controlled Trial of a Web-Based Intervention

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Abstract

Background: Psychological interventions for the prevention of depression might be a cost-effective way to reduce the burden associated with depressive disorders.

Objective: To evaluate the cost-effectiveness of a Web-based guided self-help intervention to prevent major depressive disorder (MDD) in people with subthreshold depression (sD).

Methods: A pragmatic randomized controlled trial was conducted with follow-up at 12 months. Participants were recruited from the general population via a large statutory health insurance company and an open access website. Participants were randomized to a Web-based guided self-help intervention (ie, cognitive-behavioral therapy and problem-solving therapy assisted by supervised graduate students or health care professionals) in addition to usual care or to usual care supplemented with Web-based psycho-education (enhanced usual care). Depression-free years (DFYs) were assessed by blinded diagnostic raters using the telephone-administered Structured Clinical Interview for DSM-IV Axis Disorders at 6- and 12-month follow-up, covering the period to the previous assessment. Costs were self-assessed through a questionnaire. Costs measured from a societal and health care perspective were related to DFYs and quality-adjusted life years (QALYs).

Results: In total, 406 participants were enrolled in the trial. The mean treatment duration was 5.84 (SD 4.37) weeks. On average, participants completed 4.93 of 6 sessions. Significantly more DFYs were gained in the intervention group (0.82 vs 0.70). Likewise, QALY health gains were in favor of the intervention, but only statistically significant when measured with the more sensitive SF-6D. The incremental per-participant costs were €136 (£116). Taking the health care perspective and assuming a willingness-to-pay of €20,000 (£17,000), the intervention's likelihood of being cost-effective was 99% for gaining a DFY and 64% or 99% for gaining an EQ-5D or a SF-6D QALY.

Conclusions: Our study supports guidelines recommending Web-based treatment for sD and adds that this not only restores health in people with sD, but additionally reduces the risk of developing a MDD. Offering the intervention has an acceptable

likelihood of being more cost-effective than enhanced usual care and could therefore reach community members on a wider scale.

Trial registration: German Clinical Trials Register: DRKS00004709; http://www.drks.de/DRKS00004709 (Archived by WebCite at http://www.webcitation.org/6kAZVUxy9)

(J Med Internet Res 2017;19(1):e5) doi:10.2196/jmir.6587

KEYWORDS

prevention; major depressive disorders; Internet; early intervention; cost effectiveness

Introduction

Currently, major depressive disorder (MDD) is one of the leading causes of years lived with disability [1] and is further associated with substantial economic costs for society [2]. In high-income countries, the 12-month prevalence of MDD is estimated at 5.1% [3] with an annual incidence rate of 3% [4]. This implies that close to 60% of the depressed cases are new cases, which underscores the importance of both treatment and prevention of depression to reduce its disease burden. In fact, even when assuming full coverage of evidence-based treatments, approximately only one third of the disease burden could be averted [5,6]. In this context, attention has shifted to the prevention of MDD as an additional option to foster further reductions of depression's disease burden by reducing the development of new cases.

Meta-analyses provide evidence for the effectiveness of psychological interventions to prevent first onsets and recurrences in depression [7-9]. Especially indicated prevention, targeting subthreshold symptoms of an emerging depression, appears to be particularly effective [8]. People are then screened for subthreshold depression (sD) not meeting the diagnostic criteria for a full-blown depressive disorder and are subsequently offered a preventive intervention. However, research on the cost-effectiveness of depression prevention is still limited. Economic evaluations conducted alongside randomized trials and economic evaluation studies using decision analytic modeling techniques suggest that preventive interventions for depression can be very cost-effective [10-13]. Research on how to deliver such interventions on a large scale to the community is scant. Using the Internet to provide community members with effective preventive interventions is currently viewed as a potentially cost-effective way of scaling up preventive interventions [14,15]. Web-based interventions are scalable. Scalability refers to the ability of the intervention shown to be effective in a research setting to be expanded under real world conditions. To reach a greater proportion of the eligible population while retaining effectiveness, only a small increase in therapeutic resources is required. Thus, the marginal cost per additional user get lower via an economies of scale effect. Economies of scale might also reduce variable costs (ie, therapist's support per participant) because therapists become more efficient through better organization and experience.

To the best of our knowledge, no randomized controlled trial has investigated the cost-effectiveness of a Web-based guided self-help intervention to prevent the onset of diagnosed MDD. Elsewhere we reported the primary outcomes with respect to progression to MDD at 12 months [16]. Here we will evaluate the cost-effectiveness and cost-utility of the Web-based intervention among self-selected members from the community suffering from sD.

Methods

Study Design

We conducted and reported the health-economic evaluation in agreement with the Consolidated Health Economic Evaluation Reporting Standards statement [17] and the guidelines from the International Society for Pharmacoeconomics and Outcomes Research [18]. We conducted the economic evaluation with a 12-month time horizon from both a societal and a public health care perspective alongside a 2-armed pragmatic randomized controlled trial in Germany to establish the cost-effectiveness and cost-utility of an indicated Web-based guided self-help intervention in conjunction to usual care for people with sD as compared with enhanced usual care (ie, Web-based psycho-education in addition to treatment as usual). Whereas the societal perspective included all costs and consequences regardless by whom they were incurred, the health care system perspective only considers direct medical costs. Full details of the trial design can be found elsewhere [19]. The study was approved by the medical ethics committee of the University of Marburg (reference number AZ 2012-35K) and registered under DRKS00004709 in the German clinical trial registry.

Participants

In total, 406 participants were included in the study. Participants were recruited from March 2013 to March 2014 from the general population via a large German health insurance company and through newspaper articles, on-air media, and related websites. We chose this open recruitment strategy as it reflects the clinical practice for this type of intervention, thus enhancing the trial's ecological validity. As we conducted a pragmatic trial, the use of antidepressant medication was allowed as part of care-as-usual. However, participants needed to be on a stable dose for at least four weeks to be able to enter the study. Textboxes 1 and 2 present participant eligibility for inclusion and exclusion in the study.

Textbox 1. Inclusion criteria for the study.

- Age 18 years and above
- Subthreshold depression (sD) (Centre for Epidemiological Studies Depression Scale (CES-D)≥16) as having some depressive symptoms not meeting the diagnostic criteria for a full-blown DSM-IV major depressive disorder (MDD) as assessed by the telephone-administered Structured Clinical Interview for DSM-IV (SCID)
- Internet access
- Informed consent

Textbox 2. Exclusion criteria for the study.

- Meeting DSM-IV criteria for bipolar disorder or psychotic disorder
- Having a history of a major depressive disorder (MDD) in the past 6 months based on Kupfer's model [20]
- Currently receiving psychotherapy for any kind of mental health problem
- Being on a waiting list for psychotherapy
- Having received psychotherapeutic treatment in the past 6 months
- Showing a significant suicidal risk (item 9 of the Beck Depression Inventory >1)

Randomization and Masking

Randomization took place at an individual level and was conducted centrally by an independent statistician not otherwise involved in the study using an automated computer-generated random numbers table. Block randomisation, of size 2, was used to ensure equal sample sizes across both conditions. Details about the randomization procedure can be found elsewhere [16]. Study participants were not masked to their treatment allocation because of the nature of the intervention. SCID interviewers were, however, unaware of participants' randomization status. Steps taken to maintain blinding are described in detail elsewhere [16]. In case of evidence for blinding breakdown, the interviewer was changed to the second outcome interview. The research staff conducting SCID interviews were not otherwise involved in the study.

Procedures

All study participants had unrestricted access to care-as-usual (CAU). CAU for sD entails visits to the general practitioner (GP), but no treatment provided by mental health specialists. If depressive symptoms deteriorate, the German S3-Guideline/National Disease Management Guideline Unipolar Depression recommends psychotherapy and the prescription of antidepressant medication [21]. In our pragmatic study, we did not interfere in CAU. Instead, we maintained a naturalistic CAU condition to represent current clinical practice as far as possible. It should also be noted that health care use was measured in detail (see Measures), implying that we now can describe CAU in great detail (see Table 1).

Table 1. Mean annual per-participant costs (in €) by condition cumulative over the 12-month follow-up period (based on intention-to-treat sample, N= 406).

Cost categories		Intervention group, (n=202)	Control group, (n=204)	Incremental costs
		Mean (SD), €	Mean (SD), €	Difference, €
Intervention		299 (–)	10 (–)	289
Health care costs				
	General practitioner or internist	142 (142)	117 (154)	25
	Mental health care	117 (308)	175 (447)	−58
	Other medical specialist[a]	243 (428)	236 (363)	7
	In-patient care	48 (679)	123 (1302)	−75
	Day care	0 (-)	35 (499)	−35
	Antidepressants	12 (41)	20 (57)	−8
Patient and family costs				
	Private therapist[b]	137 (354)	117 (246)	20
	Copayments[c]	27 (73)	30 (65)	−3
	Over-the-counter drugs	17 (34)	22 (42)	−5
	Informal care	323 (943)	384 (857)	−61
	Domestic help	143 (455)	120 (511)	−23
	Travel	29 (77)	28 (72)	1
Productivity losses				
	Absenteeism	1475 (2498)	1172 (2209)	303
	Presenteeism	1696 (1622)	2021 (2781)	−325
Total health care costs		904 (989)	768 (1777)	136
Total societal costs		4655 (4674)	4513 (5160)	143

[a]physiotherapist, occupational therapist.

[b]physiotherapist without prescription.

[c]patient's contribution to prescribed medication.

Web-Based Guided Self-Help Intervention

The Web-based intervention, called GET.ON Mood Enhancer, is an online multimedia interactive intervention consisting of 6 sessions. Each session takes about 30 minutes to complete, but the amount of time spent on a session varies among users. Participants were advised to carry out at least one, preferably 2 lessons per week. Intervention usage was monitored by logfile analysis. On average, participants completed 4.93 of 6 sessions (Multimedia Appendix 1). The mean treatment duration was 5.84 (SD 4.37) weeks [16]. The intervention was developed by trained psychologists and therapists at the Leuphana University. Participants created their own password to access the intervention. Trial participants used the intervention free of charge. The intervention was based on behavioral activation and problem-solving therapy. The content of the intervention was frozen during the trial. An emphasis was placed on homework assignments to integrate newly acquired skills into daily life. Therefore, participants had the option to receive a set of about 42 standardized text-messages supporting them to integrate the learned techniques into their lives. Participants were also supported by an online-trainer, who provided written feedback after each session and monitored adherence to the intervention. In case of nonadherence, eCoach sent up to 3 reminders. The total time a trainer spent per participant was approximately 3 hours. Trained and supervised graduate students and health care professionals provided guidance. The guidance focused on supporting participants to work through the exercises. Trainers available on the Web did not provide therapeutic support. Further details about the intervention can be found in the study protocol [19].

Enhanced Usual Care

Participants in the control condition got access to an Web-based psychoeducational intervention, which was based on the German S3-Guideline/National Disease Management Guideline Unipolar Depression [21]. It informed participants about evidence-based treatments of depression should symptoms deteriorate. We thus mimicked and enhanced usual care because we provided patients with information that they may not always be offered thoroughly

by their GP. Similar psycho-educational interventions have been shown to be effective in reducing depressive symptoms and is therefore suggested as a first-line intervention for early manifestations of depression in the primary care setting [22]. Participants could go through the materials as often as they want. However, we did not monitor its uptake and no additional support was provided to participants in the CAU condition.

Outcome Measures

Self-reported measures (ie, EuroQol and SF-12) were collected at baseline, posttreatment (6 weeks after randomization), and 6- and 12-month follow-up using a secured Web-based assessment system (AES, 256-bit encrypted). The SCID interviews at baseline and 6- and 12-month follow-up were conducted by telephone.

Depression-Free Years (DFYs)

The main outcome in the cost-effectiveness analysis comprised DFYs. DFYs were based on the number of depression-free weeks up to the onset of a major depressive episode within the 12-month follow-up period. MDD was assessed according to DSM-IV criteria as assessed by the telephone-administered SCID [23,24] at 6- and 12-month follow-up covering the period to the previous assessment. Time to onset of MDD was assessed as accurately as possible using the Life Chart method as developed by Lyketsos [25]. In this method, life events were recalled using a calendar method where personal landmarks were used to determine the presence of depressive symptoms at each month during the follow-up period. During the interview, the first day of a depressive episode was established. If the exact day could not be established, the closest week (month) was defined and the mid-point of that week (month) was used. The interrater agreement in this study was substantial (Cohen kappa=0.77).

Quality-Adjusted Life Years (QALYs)

QALYs were used as the outcome in the cost-utility analysis. QALYs were based on the EQ-5D-3L (EuroQol) [26] and SF-6D (a subset of items of the SF-12v1) [27]. The EuroQoL and the SF-12 were assessed at baseline, posttreatment (6 weeks), and 6- and 12-month follow-up. The EQ-5D-3L comprises 5 items covering 5 domains (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression), each of which is rated as causing "no problems," "some problems," or "extreme problems." Theoretically, the EQ-5D-3L generates 243 different health states. Preference-based utilities for each of these health states are available for various countries with "full health" and "death" being anchored at 1 and 0, respectively. The SF-6D contains 6 dimensions (each with between 2 and 5 levels) and includes 6 items of the SF-12. The SF-6D generates 7500 different health states. Utility values were derived using Brazier's algorithm [28,29]. QALY health gains were estimated by calculating the area under the curve (AUC) of linearly interpolated EQ-5D-3L and the SF-6D utilities to cover the whole follow-up period of 12 months. This method weighs the 12-month period by the respective utilities of each time period. A QALY gain of 1 would thus indicate full health throughout the 12-month trial period. For the main analysis, we used the EQ-5D-3L QALY based on the UK tariffs [30]. For the sensitivity analyses, we used the SF-6D QALYs because these are known to be more sensitive to changes in mild conditions [31].

Resource Use and Costing

We used the Trimbos and iMTA questionnaire for costs associated with psychiatric illness (TiC-P) [32,33] for collecting data on health care utilization and productivity losses in patients with mental health conditions. We adapted the TiC-P for use in Germany and used it at baseline and at 6- and 12-month follow-ups. We computed health care costs, the patient's out-of-pocket costs, the costs for informal care provided by the patient's family and friends, and costs stemming from productivity losses due to absenteeism and lesser productivity while at work (presenteeism). Costs were expressed in Euro and indexed for the year 2013 (index factor 1.04) based on the German consumer price index [34]. Costs were converted to pound sterling (£) using the purchasing power parities reported by the Organization for Economic Cooperation and Development. For the reference year 2013, €1 was equated to £0.85.

Health Care Costs

We used 2 German guidelines for calculating health care costs [35,36]. A list of unit cost prices (ie, outpatient care) was used to compute the total health care costs on a per-participant basis [36]. Unit cost prices were as follows: (1) €20.92 for a visit to the GP, (2) €68.06 for an internal medicine consult, (3) €46.55 for a session with a psychiatrist, and (4) €81.44 for a session with a psychotherapist. Hospital stays were computed at €335.52 for an in-patient day in a mental hospital and €306.41 for an in-patient day in a hospital for psychosomatic medicine and psychotherapy. Costs were estimated by multiplying the units of resource use with corresponding unit cost prices.

Medication

The costs of prescribed medication were based on the German drug registry (Rote Liste) [37]. The basis for calculating costs of prescribed medication is the pharmacy retail price taking into account a specific pharmacy and manufacture's discount. The rates of discount vary between private and statutory health insurances [36]. Therefore, we weighted the mean costs of the 3 largest packages with the same agent based on the daily defined dose by the statutory population share (89% of the German population are statutorily insured).

Intervention Costs

The total costs for the Web-based cognitive-behavioral intervention were estimated at €299 (£254) per participant by the provider (GET.ON Institute) including €180 for providing feedback by an eCoach. The total cost of the intervention was based on the actual market price of this intervention that has been determined by the provider. The GET.ON Institute aims to transfer scientific knowledge related to the present research into routine health care. This institute licenses the intervention under study from the Leuphana University, Lueneburg, to provide the intervention within routine preventive services of health insurance companies in Germany. We assumed that the cost of IT servers and infrastructure will increase if the intervention is scaled up because more servers are needed.

However, these fixed costs are subject to an economies of scale effect (ie, marginal costs drop per additional user). The per-participant costs for the psycho-educational intervention were estimated at €10 (£9).

Patient and Family Costs

Out-of-pocket costs were directly obtained from participants. Costs for traveling were valued at €0.30 per kilometre. Opportunity cost (ie, time spent on the intervention) were valued at €23.10 per hour. Costs of informal care were valued using a shadow price of €18.33 per hour [36].

Costs of Productivity Losses

We followed the human capital approach to value productivity losses [38]. Productivity losses can be caused by days not worked (absenteeism) and by reduced efficiency while at work (presenteeism). Lost workdays due to absenteeism were valued at the corresponding gross average of participants' income per day. Lost workdays due to presenteeism were computed by taking into account the number of work days for which the participant reported reduced functioning weighted by an inefficiency score for those days. Productivity losses from unpaid work (ie, domestic tasks) were valued using a shadow price of €18.33 per hour needed to pay for domestic help [36].

Analysis

The study was powered to demonstrate a risk reduction of 10% between study conditions as statistically significant in a survival analyses with alpha<.05 (2-tailed), a power of (1−beta)=.80 using survival analysis, and accounting for a 20% dropout (calculated using PASS 12). However, the study was not powered to statistically test differences in health economic outcomes. Therefore, we took a probabilistic decision-making approach for our health economic inferences [39]. We did not discount costs and effects because the analysis was restricted to a 12-month follow-up period.

While evaluating the clinical outcomes, we reported all analyses in accordance to the CONSORT statement [40] (Multimedia Appendix 2). Data were analyzed on an intention-to-treat basis meaning that all participants were included in the analyses as randomized. To this end, we used Cox proportional hazard regression analyses to test differences in time to onset of MDD (in weeks) between intervention and control group. Concurrent use of antidepressants was included as covariate into the Cox proportional hazard model (post hoc). As the use of antidepressants was not a predictor of the outcome, it was excluded from the final model.

To account for missing data in cost and utility data, we used the regression imputation procedure in Stata version 13 (StataCorp) to obtain required predicted values. Predictors of outcome and dropout were identified by (logistic) regression analysis. Identifying predictors of outcome helped us to obtain the most likely values of the outcome whereas identifying predictors of dropout allowed us to correct for bias that might arise by differential loss-to-follow-up. We did not impute hospitalization costs because only 3 participants (0.7%) were hospitalized during the 12-month follow-up period leading to instable imputations. Therefore, we reassessed the impact of hospitalization costs on outcomes in a sensitivity analysis. At baseline, mean EQ-5D utility values were the same in intervention and control group (both groups: 0.74, SD=0.15). Therefore, no baseline adjustments were made when calculating QALYs. Differences in QALYs and DFYs between the intervention and control groups were assessed using independent samples *t*-tests.

In the cost-effectiveness analysis, the incremental cost-effectiveness ratio (ICER) was based on the incremental costs per unit of effect (DFY or QALY) gained. The corresponding equation is $ICER=(Costs_{INT}-Costs_{CTR})/(Effects_{INT}-Effects_{CTR})$, where *Costs* are the annual per-participant costs and *Effects* are the DFYs (QALYs) in intervention and control group (subscripted with INT and CTR, respectively). Sampling uncertainty in the ICER was handled using nonparametric bootstrapping by resampling patient-level data to generate 2500 simulations of the ICER. We bootstrapped the SURE model (seemingly unrelated regression equations; sureg command in Stata) to allow for correlated residuals of the cost and effect equations. Bootstrapping was used to obtain confidence intervals for cost-effectiveness ratios based on the percentile method, since parametric techniques are inappropriate for use on skewed variables and ratios. The bootstrapped ICERs were plotted on a cost-effectiveness plane with effects along the horizontal axis and costs along the vertical axis. A cost-effectiveness acceptability curve (CEAC) was graphed to assess the probability of the intervention being cost-effective at varying willingness-to-pay (WTP) ceilings. All analyses including uncertainty analyses were performed using Stata version 13.

Sensitivity Analyses

We tested the robustness of the outcomes of the main analysis in sensitivity analyses. First, the EQ-5D-3L might suffer from ceiling effects when measuring QALY changes in people with mild conditions. Therefore, we measured SF-6D QALYs, which have been reported to be more sensitive to QALY changes in milder conditions such as sD [31]. Second, we assessed the impact of in-patient care on the ICER because in-patient care is one of the main cost drivers and was surrounded by much uncertainty since only 3 hospital admissions occurred in the whole sample (0.7%, 3/406). Such outliers (driving costs in the control condition) could lead to misleading results, and these costs were removed in a sensitivity analysis.

Results

Sample Characteristics

In total, 406 participants were enrolled in the study (N_{INT}=202; N_{CTR}=204). At the posttreatment stage, 366 participants (90.1%, 366/406) were still participating. At 6- and 12-month follow-up, 325 (80.1%, 325/406) and 286 (70.4%, 286/406) participants completed the questionnaires, respectively. The CONSORT flowchart (of the participants through the trial) can be found elsewhere [16]. Dropout rates did not differ between experimental and control conditions except for the 12-month follow-up. Here, dropout was higher in the intervention group (χ^2_1 = 8.4, *P*=.004). Study dropout was not associated with

baseline depressive symptom severity or any sociodemographic factor. Participants' characteristics at baseline are presented in detail elsewhere [16]. In brief, the average participant was female aged 45 years with an above average level of education and employed.

Effects

The mean depression-free survival time within the 12-month trial period was 43 weeks (95% CI 41-46) in the intervention group and 37 weeks (95% CI 36-40) in the control group [16], corresponding to 0.82 DFYs and 0.70 DFYs, respectively. The incremental effectiveness of 0.82−0.70=0.12 DFYs was statistically significant (95% CI 0.05-0.18; t_{404}=3.37, P<.001). Between-group differences in EQ-5D, QALY gains were not statistically significant (intervention group: 0.78, SD=0.14 vs control group: 0.77, SD=0.13; t_{404}=−0.99, P=.32), but incremental SF-6D QALY gains differed significantly between study groups (intervention group: 0.71, SD=0.08 vs control group: 0.67, SD=0.07; t_{404}=−4.40, P<.001).

Costs

At baseline, mean total costs were €483 (£411) in the intervention group and €528 (£449) in the control group, which is only a small difference of €45 (£38), indicating that randomization had been well balanced. Table 1 presents the 12-month accumulated per-participant costs for various cost categories by study condition. The mean health care costs were higher in the intervention group as compared with the control condition. This difference can largely be explained by differences in the costs of the intervention as compared with the control condition with Web-based psycho-education (€299 vs €10). Patient and family's out-of-pocket costs and the costs stemming from changes in productivity losses remained quite similar between study groups. Mean total costs, as seen from both the health care and societal perspective, were hence slightly higher in the intervention group as compared with the control group (societal perspective: €143 (£121); health care perspective: €136 (£116).

Societal Perspective

Table 2 shows the incremental cost, effects, and cost-effectiveness ratios (based on 2500 bootstrap simulations) for the main analysis and the sensitivity analyses and from both the societal and health systems perspective. From a societal perspective, the intervention resulted in a greater mean health benefit (0.12 DFY gained) achieved at higher mean total costs (€134; £114) as compared with enhanced CAU.

The cost-effectiveness plane, representing the 2500 bootstrap replications, is shown in Figure 1. Most (62%) of the bootstrapped ICERs fell in the north-east quadrant, indicating a 62% probability that the intervention produces greater health, but at greater costs than enhanced CAU. The remaining 38% of ICERs fell in the south-east quadrant, indicating a 38% probability that the intervention dominates enhanced CAU because additional health gains are obtained for lesser costs. In other words, at a willingness-to-pay (WTP) of €0, the probability that the intervention must be regarded as more cost-effective than CAU is 38%.

However, at a WTP of €7350 (£6248), €9680 (£8228), and €20,000 (£17,000) for gaining a depression-free life-year, the intervention's probability of being more cost-effective than CAU rises to 90%, 95%, and 99% (Figure 2).

The ICER based on QALY gains showed a small health benefit (0.01 QALYs gained) for higher mean costs (€134; £114). As seen in Figure 3, most of the simulated ICERs fell in the north-east quadrant (49%; see also Table 2).

The intervention's probability of dominating enhanced CAU was 35% when taking the societal perspective. Assuming a willingness-to-pay of €20,000 (£17,000) for gaining a QALY, this probability rose to 60% (Figure 4).

Table 2. Results of the main and sensitivity analyses (based on 2500 bootstrap simulations).

Analysis and perspective	Incremental costs, € (95% CI)	Incremental effects (95% CI)	Mean ICER[a] (95% CI)	Distribution over the ICER plane			
				North-east quadrant	North-west quadrant	South-east quadrant	South-west quadrant
Cost-effectiveness, DFYs[b]							
Societal	134 (−827 to 1055)	0.12 (0.05 to 0.18)	1117 (−7546 to 11,737)	62%	-	38%	-
Health care	135 (−146 to 418)	0.12 (0.05 to 0.18)	1125 (−1428 to 4715)	83%	-	17%	-
Cost-utility, EQ-5D QALYs[c]							
Societal	134 (−827 to 1055)	0.01 (−0.01 to 0.04)	13,400[d]	49%	11%	35%	5%
Health care	135 (−146 to 418)	0.01 (−0.01 to 0.04)	13,500[d]	68%	14%	16%	2%
Sensitivity analyses							
SF-6D QALYs[e], societal	134 (−827 to 1055)	0.03 (0.02 to 0.05)	4467 (−23,846 to 42,891)	60%	-	40%	-
SF-6D QALYs, health care	135 (−146 to 418)	0.03 (0.02 to 0.05)	4500 (−5000 to 15,088)	83%	-	17%	-
Without hospitalization costs							
Societal, DFY	233 (−649 to 1155)	0.12 (0.05 to 0.18)	1942 (−5169 to 14,705)	70%	-	30%	-
Health care, DFY	245 (119 to 374)	0.12 (0.05 to 0.18)	2042 (865 to 5562)	100%	-	-	-
Societal, EQ-5D QALY	233 (−649 to 1155)	0.01 (−0.01 to 0.04)	23,300[d]	13%	58%	3%	26%
Health care, EQ-5D QALY	245 (119 to 374)	0.01 (−0.01 to 0.04)	24,500 (44220 to −22,333)	16%	84%	-	-

[a]ICER: Incremental cost-effectiveness ratio.

[b]DFYs: Depression-free years.

[c]EQ-5D QALYs: Quality-adjusted life years based on EuroQol.

[d]A dependably accurate 95% confidence interval for this distribution cannot be defined because there is no line through the origin that excludes alpha/2 of the distribution.

[e]SF-6D QALYs: Quality-adjusted life years based on SF-12.

Figure 1. Scatterplot of 2500 replicates of the incremental cost-effectiveness ratio (mean differences in costs from a societal perspective and in depression-free years) on the cost-effectiveness plane: Web-based guided self-help intervention vs enhanced usual care.

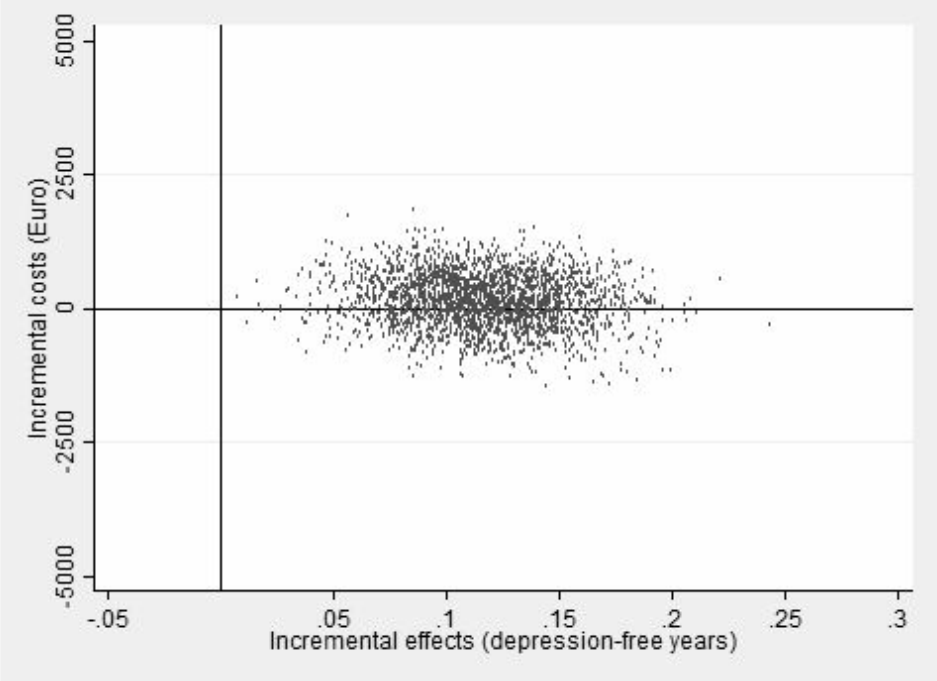


Figure 2. Cost-effectiveness acceptability curve showing the probability of the Web-based guided self-help intervention being cost-effective at varying willingness-to-pay ceilings (based on 2500 replicates of the incremental cost-effectiveness ratio using mean differences in costs from a societal perspective and depression-free years).

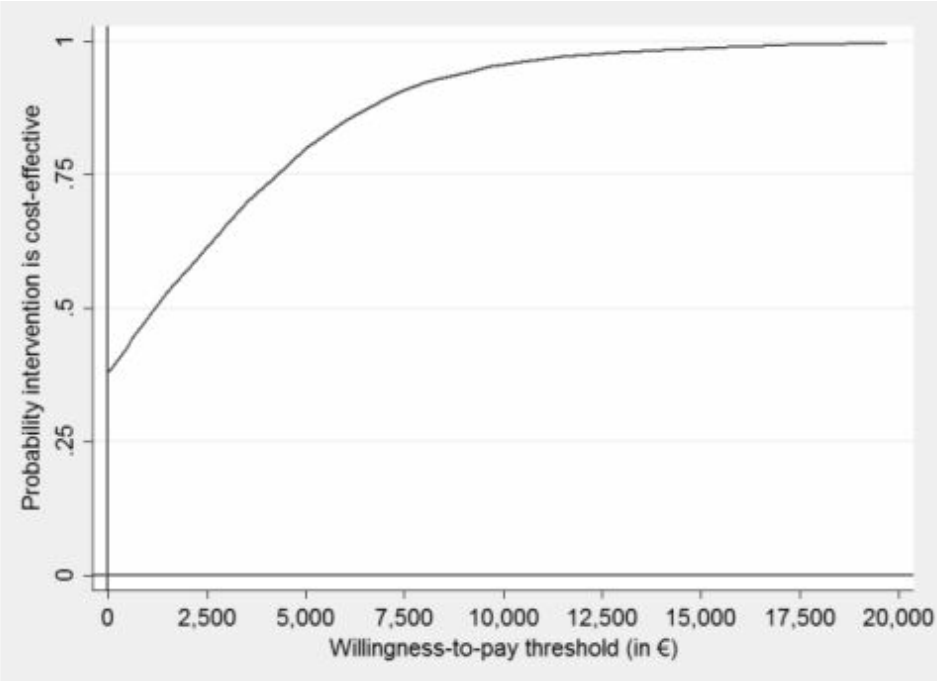


Figure 3. Scatterplot of 2500 replicates of the incremental cost-effectiveness ratio (mean differences in costs from a societal perspective and in quality-adjusted life years [QALYs]) on the cost-effectiveness plane: Web-based guided self-help intervention vs enhanced usual care.

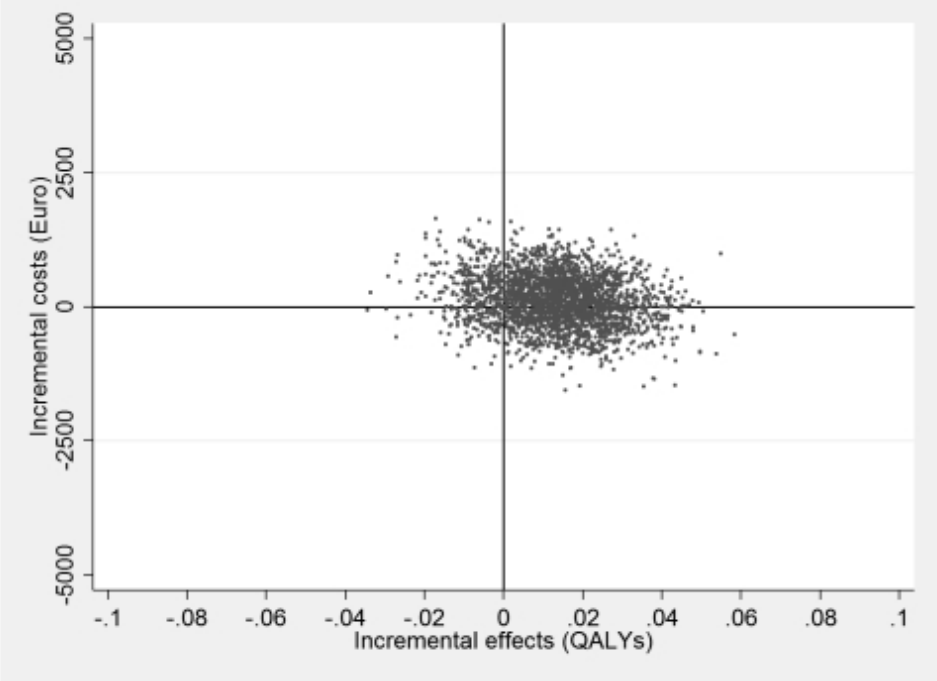
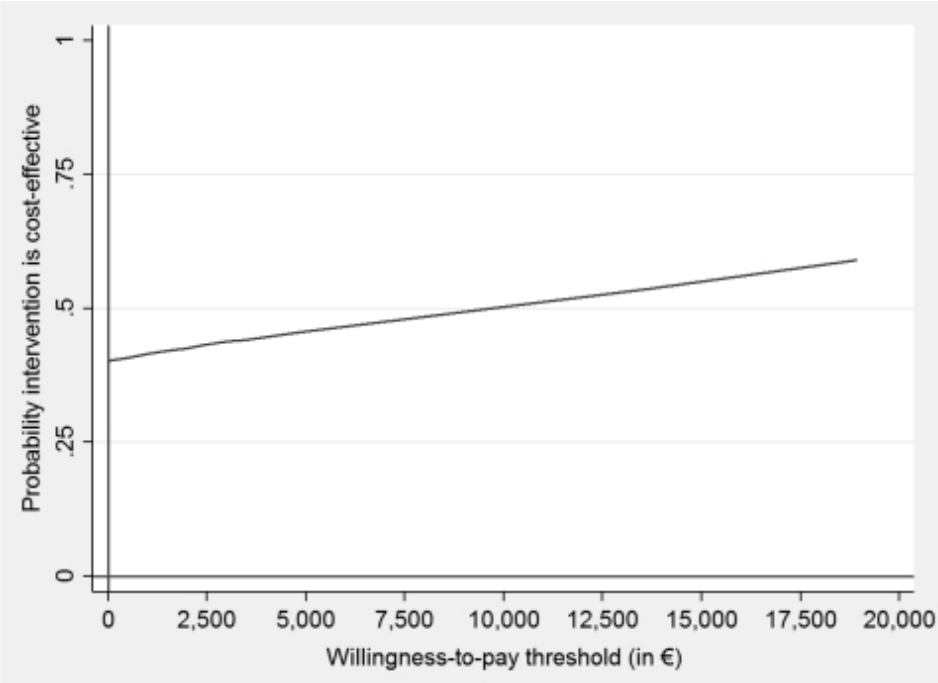


Figure 4. Cost-effectiveness acceptability curve showing the probability of the Web-based guided self-help intervention being cost-effective at varying willingness-to-pay ceilings (based on 2500 replicates of the incremental cost-effectiveness ratio using mean differences in costs from a societal perspective and quality-adjusted life years [QALYs]).



Public Health Care Perspective

From a public health care perspective, the health benefit (0.12 DFY gained) was also achieved at higher costs (€135; £115). In the cost-effectiveness plane, 83% of simulated ICERs fell in the north-east quadrant with the remaining 17% in the south-east quadrant (Table 2). The intervention's probability to be more cost-effective than enhanced CAU increased to 51% at a WTP of €1250 (£1063) and became 90%, 95%, and 99% at a WTP of €3140 (£2669), €3,920 (£3332), and €6000 (£5100), respectively. From the societal perspective, the ICER from the public health care perspective based on QALY gains showed a small health benefit (0.01 QALYs gained) for higher mean costs (€135). In the cost-effectiveness plane, 68% of the simulated ICERs fell in the north-east quadrant (Table 2). The intervention's probability of dominating enhanced CAU was 16% when considering health care costs. Assuming a willingness-to-pay of €20,000 (£17,000) for gaining a QALY, this probability was 64%.

Sensitivity Analyses

Using the SF-6D resulted in a greater incremental QALY gain in favor of the intervention group (0.70 QALY, SD 0.08) as compared with the control group (0.67 QALY, SD 0.07), which was statistically significant (t_{404}=4.40, P<.001). This agrees with available evidence that the EQ-5D suffers from a ceiling effect in less severe diseases [41]. At a WTP of €20,000 for gaining one QALY the probability of being cost-effective was 84% (societal perspective) and 99% (health care perspective). Hospital costs were higher in the control group so excluding these costs resulted in higher ICERs (Table 2). From a societal perspective and at a WTP of €20,000, the intervention's probability of being cost-effective then became 53%.

Discussion

Principal Findings

Our study was set out to evaluate the cost-effectiveness and cost-utility of a Web-based guided self-help intervention to prevent the onset of MDD in adults suffering from sD in comparison with usual care enhanced with Web-based psycho-education. Main outcomes were DFYs and QALYs.

Significantly more DFYs were gained in the intervention group as compared with the control group. The probability that the intervention is deemed to be cost-effective depends on the willingness-to-pay (WTP) for a depression-free year. Assuming that the intervention is considered to be cost-effective if its likelihood of being cost-effective is greater than 90%, a WTP of €7350 and above for gaining a DFY would make the intervention cost-effective. While these DFY health gains were not mirrored in EQ-5D QALY gains, they were observed in SF-6D QALY gains with the latter being more sensitive to change in milder conditions such as sD and therefore not suffering as much from a ceiling effect as the EQ-5D does [31]. If society would be willing to pay €20,000 (£17000) for gaining a QALY, the probability of being cost-effective will be 64% for gaining an EQ-5D QALY and 84% for gaining a SF-6D QALY.

Wider Context

Both burden of disease studies and cost of illness studies [1,2] attest to the importance of cost-effective interventions that can reduce the burden of depressive disorders on a wider scale. Recent meta-analytic evidence suggests that it is possible to prevent the onset of major depression using psychological interventions [8]. Results of our study showed that a guided eHealth intervention can successfully reduce the incidence of diagnosed major depression [16]. In addition, some evidence indicates that bibliotherapeutic self-help interventions for the prevention of depression represent good value-for-money [15]. However, economic evaluations in the field of depression prevention mainly relied on health-economic modelling [12,13,42] with direct evidence stemming only from 2 randomized controlled trials [10,11]. Although some trial-based economic evaluations of computerized cognitive-behavioral interventions for treating depressive symptoms exist (ie,) [43,44], to our knowledge, this is the first trial-based economic evaluation of a Web-based intervention to prevent the onset of major depression in an adult population with sD. Results from our trial adds to the converging evidence pointing to the effectiveness and cost-effectiveness (sometimes even costs-savings) of depression prevention across a range of outcomes.

Limitations

This study has some limitations. First, the time horizon of this study was limited to 12 months. A recent meta-analysis showed a small positive association between effects of preventive interventions during the first months of follow-up, indicating that with passing months, the intervention effects get somewhat larger. However, meta-regression analyses suggested that the effects of interventions are lower at longer follow-up periods of 1 to 2 years [8]. Assuming diminishing long-term effects, the cost-effectiveness of this particular intervention will also decline. However, only few studies had longer follow-up periods than 2 years. Thus, more research with longer follow-up periods are needed to assess the long-term effectiveness and cost-effectiveness of preventive (Web-based) interventions. Second, we did not assess lifetime history of MDD at baseline, and therefore we cannot be sure if we prevented first-ever onsets of MDD or MDD recurrences. Future studies should thus clarify whether Web-based guided self-help interventions are cost-effective both for the prevention of first depression onset and the prevention of recurrence. Third, costs were assessed with the help of self-reports and may suffer from under-reporting. However, the structured questionnaire used in this study can be considered as valid instrument for recall periods up to 3 months [45]. Finally, the trial has been conducted in a highly-educated sample. Evidence suggests that better adherence is predicted by higher education [46]. In our trial, only 2% of participants were low educated. Hence, we cannot predict the uptake of such an intervention in less educated people or among people with a lower socioeconomic status. However, we used an open recruitment strategy in our trial mimicking the way how people will be recruited for eHealth interventions in the future, thus providing ecological validity to the sample on which this study is based. In other words, the trial sample reflects the population segments that are interested in engaging in a Web-based intervention. However, one conclusion drawn from this trial is that not all people who are in need of psychological interventions could be reached via the Internet. The applicability of Web-based interventions is related to (1) the acceptance of such interventions by the target population (ie, preferences for different treatment modalities, such as face-to-face interventions) and (2) the availability of technical requirements (ie, reliable access to the Internet).

Clinical Implications and Future Research

Current guidelines on depression treatment (such as the NICE guideline and the Dutch Multidisciplinary Guideline for Depressive Disorder) recommend low-intensity psychosocial interventions (ie, computerized cognitive behavioral therapy) to manage (persistent) sD symptoms and mild-to-moderate depression [22]. Our study supports this recommendation by showing that an eHealth intervention may not only restore health in people with sD, but in addition reduces the risk of developing a major depressive disorder. Findings from our study also add

that delivering cognitive-behavioral therapy over the Internet has a high probability of being cost-effective to prevent the onset of new depressive episodes. Given low participation rates in face-to-face preventive services and the potential to scale up Web-based interventions to efficiently alleviate the disease burden caused by MDD, it would be worthwhile to integrate such a Web-based intervention into routine practice. However, there are some opportunities and risks that need to be taken into account when scaling up this intervention. First, the feedback provided by an individual trainer on the Web in this Web-based intervention hinders scaling up the intervention. A recent review of randomized controlled trials showed that unguided interventions can also be effective (with lower adherence rates compared to guided interventions) [47]. To be more precise, in our study, out of the 202 participants who were initially assigned to the intervention, 138 (68.3%, 138/202) were intervention completers. This compares favorably with an unguided Internet-based intervention for the treatment of sD that was completed by 48.3% (49/102) of participants [48]. Providing guidance may not only affect the outcome and cost-effectiveness of the intervention but also the target group's willingness to use such an intervention and thereby influencing the effects of such an intervention at population level. It is therefore not possible to predict the effects of this particular Web-based intervention at population level when it is offered without guidance by an eCoach. In addition, there are no guarantees that adherence and (by proxy) effectiveness will be maintained if Web-based preventive interventions are scaled up in the population. For example, Christensen et al reported that less than 1% of public registrants using a preventive intervention delivered openly on a website completed all modules [49]. Second, an unanswered question refers to how Web-based interventions could be rolled out to the population. For example, in the UK and the Netherlands, Internet-delivered cognitive behavioral therapy (CBT) is already prescribed by GPs [22]. In addition, Web-based interventions could be promoted independently at the GP's (ie, promotion videos in the GP's waiting rooms). However, a challenge in preventing depression is that most individuals at risk of developing a major depression do not show up in primary care. Therefore, innovative approaches are needed to reach these groups, for example through a systematic mental health screening of all people in specific settings (ie, occupational setting or universities) and to motivate those at risk to engage in preventive interventions (ie, acceptance facilitating interventions) [50]. However, such strategies do not guarantee uptake either. Third, the costs of the Web-based intervention were calculated without considering economies of scale effect. Economies of scale refer to the reduction in the cost per treatment of an intervention as a result of increasing the number of clients. Economies of scale arise because many of the costs associated with the Web-based intervention are fixed and not dependent on the number of clients (ie, hosting the intervention on a server) and thus increasing the intervention output reduces the fixed cost per treatment. Hence, we assume that the cost of IT infrastructure (ie, the per-client cost of servers to host the intervention) will be cheaper per additional client if the intervention is offered on a larger scale. Economies of scale might also reduce variable costs (ie, therapist's support per participant) because therapists become more efficient through better organization and experience. However, the same technical resources available in the research setting (ie, reasonable Internet connections) may not be available when the intervention is scaled up. Finally, for some individuals a self-help approach might not be sufficient [51]. Some individuals may feel unable to apply psychotherapeutic self-help strategies. Some techniques could be inappropriately implemented by participants without guidance by an eCoach. One could argue that it is easier to observe and react to early signs of deterioration in face-to-face interventions as compared with Web-based interventions. Another potential negative effect of self-help interventions could be a delay in help-seeking leading to a further deterioration of symptoms, if the initial low-intensity self-help intervention should not be sufficient. Hence, multiple approaches to reach the target population are needed in successful depression prevention programs. Thus, future studies should evaluate the preventive effects of unguided Web-based interventions on the onset of MDD and compare the cost-effectiveness of unguided and guided interventions. In addition, implementation studies should be conducted to obtain real world effects of such interventions and to gather knowledge about the willingness to use these interventions in specific population segments (ie, in low-educated people, in a rural setting, or among people with lower socioeconomic status).

Conclusions

Given the evidence for the efficacy of psychological interventions to prevent depression and the potential scalability and cost-effectiveness of Web-based interventions, large-scale dissemination of these interventions might be a promising strategy to alleviate depression's disease burden in an affordable way and on a wide scale. However, before a nationwide dissemination could be considered, future studies need to evaluate the preventive effects of unguided Web-based interventions on the onset of MDD and compare the cost-effectiveness of unguided and guided interventions. Moreover, implementation studies are needed to obtain real world effects of such interventions and to gather knowledge about the willingness to use these interventions in specific population segments (ie, in low-educated people, in a rural setting, or among people with lower socioeconomic status).

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Authors' Contributions

MB and DE obtained funding for this study. All authors contributed to the conception and design of the overall study, which was led by CB and DE. CB, DE, and FS developed the analytic plan for the economic evaluation. CB and DE analyzed the clinical data. CB and SN calculated the costs of services. CB and FS analysed the economic data. CB drafted the manuscript. All authors revised the article critically for important intellectual content and gave final approval of the version to be published.

Conflicts of Interest

The Leuphana University, Lueneburg, has the exploitation rights of the intervention. The authors will not have a share in any possible license revenues from the Leuphana University Lueneburg. DE, MB, SN, and DL are stakeholders of the “Institute for Online Health Trainings,” a company aiming to transfer scientific knowledge related to the present research into routine health care. This institute licenses the intervention under study from the Leuphana University, Lueneburg, to provide the intervention within routine preventive services of health insurance companies in Germany. The foundation of such an institute to disseminate findings and products from the research project was the primary aim of the European Union for funding the presented research. At the time of planning, conducting, and evaluating the study, the institute did not exist. CB, FS, HR, and PC report no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years; no other relationships or activities that could appear to have influenced the submitted work.

Multimedia Appendix 1

Frequencies of the number of sessions completed.

[PDF File (Adobe PDF File), 29KB - jmir_v19i1e5_app1.pdf]

Multimedia Appendix 2

CONSORT-EHEALTH checklist V1.6.2 [40].

[PDF File (Adobe PDF File), 821KB - jmir_v19i1e5_app2.pdf]

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Abbreviations

CAU: care-as-usual
CES-D: Centre for Epidemiological Studies Depression Scale
DFY: depression-free year
DSM: Diagnostic and Statistical Manual of Mental Disorders
GP: general practitioner
ICER: incremental cost-effectiveness ratio
MDD: major depressive disorder
QALY: quality-adjusted life year
SCID: Structured Clinical Interview for DSM Disorders
sD: subthreshold depression
TiC-P: Trimbos and iMTA questionnaire for costs associated with psychiatric illness
WTP: willingness-to-pay

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Original Paper

Digital Pills to Measure Opioid Ingestion Patterns in Emergency Department Patients With Acute Fracture Pain: A Pilot Study

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Abstract

Background: Nonadherence to prescribed regimens for opioid analgesic agents contributes to increasing opioid abuse and overdose death. Opioids are frequently prescribed on an as-needed basis, placing the responsibility to determine opioid dose and frequency with the patient. There is wide variability in physician prescribing patterns because of the lack of data describing how patients actually use as-needed opioid analgesics. Digital pill systems have a radiofrequency emitter that directly measures medication ingestion events, and they provide an opportunity to discover the dose, timing, and duration of opioid therapy.

Objective: The purpose of this study was to determine the feasibility of a novel digital pill system to measure as-needed opioid ingestion patterns in patients discharged from the emergency department (ED) after an acute bony fracture.

Methods: We used a digital pill with individuals who presented to a teaching hospital ED with an acute extremity fracture. The digital pill consisted of a digital radiofrequency emitter within a standard gelatin capsule that encapsulated an oxycodone tablet. When ingested, the gastric chloride ion gradient activated the digital pill, transmitting a radiofrequency signal that was received by a hip-worn receiver, which then transmitted the ingestion data to a cloud-based server. After a brief, hands-on training session in the ED, study participants were discharged home and used the digital pill system to ingest oxycodone prescribed as needed for pain for one week. We conducted pill counts to verify digital pill data and open-ended interviews with participants at their follow-up appointment with orthopedics or at one week after enrollment in the study to determine the knowledge, attitudes, beliefs, and practices regarding digital pills. We analyzed open-ended interviews using applied thematic analysis.

Results: We recruited 10 study participants and recorded 96 ingestion events (87.3%, 96/110 accuracy). Study participants reported being able to operate all aspects of the digital pill system after their training. Two participants stopped using the digital pill, reporting they were in too much pain to focus on the novel technology. The digital pill system detected multiple simultaneous ingestion events by the digital pill system. Participants ingested a mean 8 (SD 5) digital pills during the study period and four participants continued on opioids at the end of the study period. After interacting with the digital pill system in the real world, participants found the system highly acceptable (80%, 8/10) and reported a willingness to continue to use a digital pill to improve medication adherence monitoring (90%, 9/10).

Conclusions: The digital pill is a feasible method to measure real-time opioid ingestion patterns in individuals with acute pain and to develop real-time interventions if opioid abuse is detected. Deploying digital pills is possible through the ED with a short instructional course. Patients who used the digital pill accepted the technology.

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KEYWORDS

medication adherence; opioid; digital pills; digital health; emergency medicine; pain management

Introduction

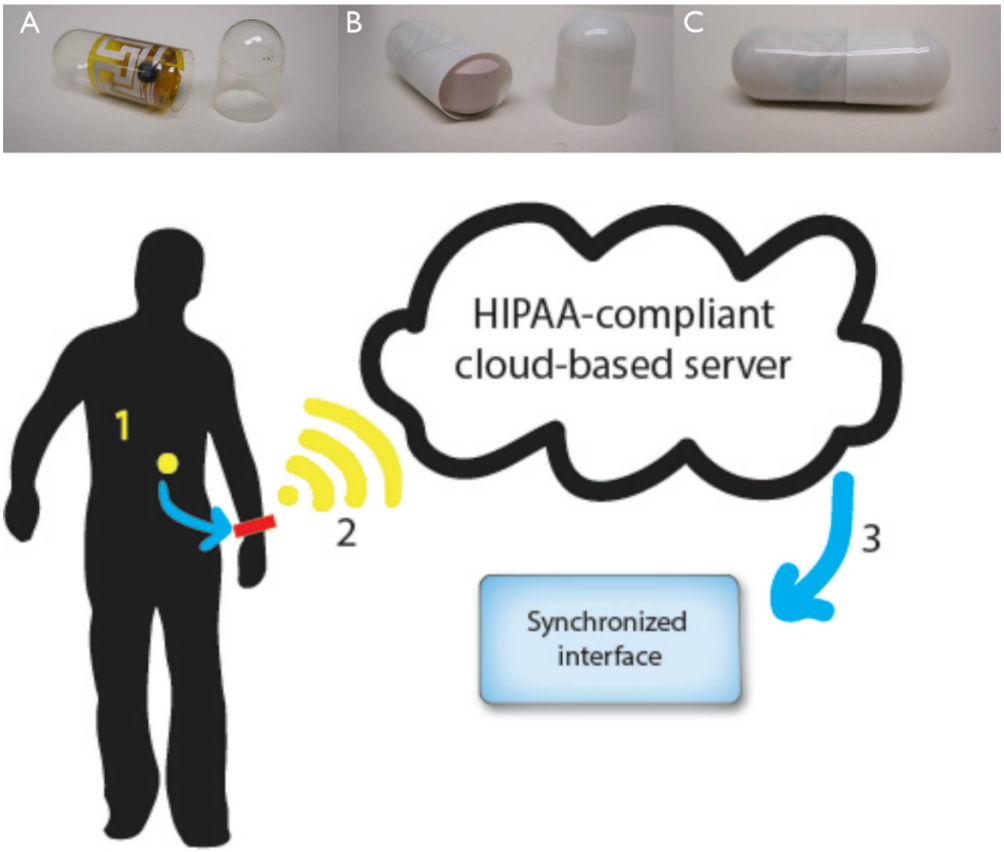
Deaths from opioid overdose in the United States have paralleled a rise in the number of opioid analgesic medications being prescribed [1]. In 2014, more than 259 million prescriptions for opioids were dispensed to the American public [1-3]. Opioids are commonly prescribed on an as-needed basis, meaning that decisions regarding opioid dose and frequency are left up to patients. Unfortunately, the ways in which patients use as-needed opioids outside of hospital settings are unknown, as is the optimal duration of opioid therapy needed for acutely painful conditions. This uncertainty has contributed to wide variability in opioid-prescribing patterns, often for an excessive number of opioid pills than what are actually needed [2,4-6].

Determining adherence to a prescribed opioid medication regimen after discharge and measuring the ways in which patients ingest as-needed medications pose methodological challenges. Because patients determine opioid ingestion dose and frequency based on temporal perception of pain, common measures of adherence (eg, smart pill bottles, pharmacy refill histories, or patient diaries) are impractical or provide aggregate measures that cannot delineate temporal patterns of opioid ingestion [7]. These traditional models measure adherence indirectly and are fraught with recall bias, measure ingestions in aggregate, and are easy to subvert (eg, opening the bottle once, but taking out several pills) [7,8]. Precise measures of opioid ingestion patterns are important because they can suggest incomplete treatment of pain, the development of tolerance, or the transition into problematic use [9].

A Novel Digital Pill System to Measure Medication Ingestion Patterns

Digital pills that activate upon contact with the stomach provide a reliable method to directly measure, rather than infer, opioid ingestion patterns in real time [10,11]. Digital pills consist of a gelatin capsule containing a digital radiofrequency emitter compounded with the desired medication (Figure 1) [10,12]. When ingested, the radiofrequency emitter is activated by the chloride ion gradient in the stomach to transmit a unique signal. A hip-worn receiver detects this signal before relaying data regarding the identity of the ingested medication and time of ingestion through third-generation (3G) cellular signaling to a cloud-based server compliant with Health Information Technology for Economic and Clinical Health (HITECH) and the Health Insurance Portability and Accountability Act (HIPAA). A locus for communication, the server can notify clinicians about the ingestion, send messages that can include behavioral interventions to the patient, and facilitate communication between clinician and patient. Digital pills are energized by the specific chloride ion gradient in the stomach and, therefore, cannot be activated outside of the body. Because each digital pill emits a unique frequency, the system can record multiple simultaneous ingestion events. This technological advantage, which allows the direct observation of the number of opioid pills a patient ingests as well as the time period between opioid ingestion, can personalize the number of opioid pills and the duration of as-needed opioid therapy [12]. Digital pills are simple to operate and passively measure adherence, decreasing the need for an individual to interact with technology to transmit adherence data. Unfortunately, the usability and acceptability of digital pills among “real-world” patient populations remains unknown. Accordingly, we sought to determine the acceptability of digital pills to emergency department (ED) patients with acute extremity fractures instructed to ingest oxycodone prescribed on an as-needed basis.

Figure 1. An ingestible radiofrequency sensor is incorporated into a gelatin capsule (A), which is compounded with the desired medication (B) to create a digital pill (C). Once the digital pill is ingested (1), it is activated and transmits a radiofrequency signal to a hip worn device (2) that collects and transmits ingestion data to a cloud-based server driving an interface (3) that displays ingestion data to clinicians and patients.



Methods

Our study was based at a large tertiary care academic ED, and approved by its institutional review board (University of Massachusetts Medical School, Worcester, MA, USA). We used a digital pill (eTectRx, Newbury, FL, USA) compounded with oxycodone tablets in patients who presented to the ED after suffering an acute extremity fracture to measure real-world ingestion patterns in these patients. Digital pills were purchased directly from the manufacturer (eTectRx) and compounded with 5 mg oxycodone tablets using a standard capsule-filling machine by our hospital investigational drug services pharmacy. Compounded digital pills were dispensed in blister packages. We considered alternative digital pill systems that used radiofrequency signaling to detect ingestion events. Other digital pills required the radiofrequency emitter to be adhered onto a placebo pill, thus requiring ingestion of the study medication and placebo pill to record an ingestion event. We elected to utilize the eTectRx system because it offered the opportunity to directly measure, rather than infer, medication ingestion.

Recruitment

A convenience sample of ED patients was recruited during daytime hours when research staff was available. Patients were eligible for the study if they were consenting adults (>18 years); presenting to the ED after an isolated acute fracture; had no history of psychiatric illness, substance abuse disorder, or chronic opioid use (prescribed opioids for more than one week in duration); and were planned to be discharged with opioid analgesics. Patients who met the eligibility criteria were approached by study staff. A chart review was conducted to ensure potential study participants did not meet exclusion criteria. Basic demographic information including age, gender, and ED pain scale were collected. Study staff then briefed potential participants on the purpose of the study and potential study participants were shown components of the digital pill. Participants who agreed to participate in the study provided written informed consent. Participants were compensated US $100 for participation in the study.

Training to Use the Digital Pill

Study staff provided participants with hands-on training lasting approximately 20 minutes on the operation of the digital pill. Training included a demonstration of digital pill operations, explanation of all the hardware components, and registration of the study participant on the cloud interface. Participants were counseled by the study staff to use nonopioid analgesics (nonsteroidal anti-inflammatory agents or acetaminophen) to manage their pain, and use oxycodone-containing digital pills as needed for episodes of pain not controlled with other medications. Participants then ingested an oxycodone-containing digital pill under observation by study staff to demonstrate their understanding of the system and to verify that all components of the system were operational. If a patient reported their pain levels were managed during the time of system training,

participants demonstrated their understanding of the system without ingesting an oxycodone pill. On discharge, participants received a prescription for one-to-two digital pills containing 5 mg oxycodone every 8 hours as needed for pain (total of 21 digital pills) in addition to a hip-worn device to capture ingestion data. Study participants enrolled in the study did not receive additional opioid analgesics from the primary team.

Qualitative Analysis and Verification of Ingestion

Participants returned to the hospital's clinical research center at the time of their orthopedic follow-up appointment or at one week after ED discharge to return the digital pill system and any uningested oxycodone digital pills. Equipment return and appointments were arranged with the study participants by study staff. We validated ingestion data from the digital pill using pill counts; we resolved discrepancies, if present, with the participant.

Investigators (PRC, EWB, BI) conducted brief (approximately 15 minutes), open-ended interviews with each study participant. We used an interview guide to ensure that each participant was asked the same questions; questions centered on acceptance of the digital pill, barriers to use, adequacy of pain control, and potential improvements in the system. We adapted the technique of applied thematic analysis to code interviews in the context of this pilot study [13]. Participant responses were transcribed by BI and reviewed by the three qualitative analysts (PRC, BI, and EWB), who then met to review topics. Deductive codes were created based on the key interview questions (acceptance of digital pills, willingness to use digital pills, and data privacy); additional inductive codes were derived from emergent participant comments (ie, willingness to use during chronic care, text message reminders, data security, and privacy). After coding, two of the investigators (PRC and BI) met and compared codes to ensure interrater reliability. Summaries of key codes were written and reviewed among the investigators. In this limited and exploratory sample, a key concern was to capture both the common and uncommon experiences participants reported with the pill and sensor.

Results

Eighteen individuals met the inclusion criteria for the study and were approached by the study team (Figure 2). Ten individuals ultimately consented and enrolled in the study (Table 1). They were evenly split between men and women and ranged in age from 21 to 63 years, with a mean age of 43 (SD 15) years. All participants successfully completed training in the ED and used the digital pill system at home. All individuals reported severe pain (pain scale ≥7) on initial presentation to the ED. Five participants required delayed surgical management of their fracture and five participants were managed nonoperatively.

Participants ingested a mean 48 (SD 24) mg oxycodone during the course of the study (Table 2). Oxycodone was ingested in greater frequency during the first 24 hours after discharge, with declining use by 72 hours. Seven participants de-escalated their oxycodone use over two days, changing dosing frequency (from every 4-6 hours to every 8-12 hours) in conjunction with dosing amount (from 10 mg oxycodone per ingestion to 5 mg oxycodone per ingestion). One participant experienced pain from associated injuries and increased the oxycodone dose over the study period. Four participants reported requiring continued opioid analgesia at the end of the study period (40%, 4/10); these participants all required operative repair of their fracture. No participants with nonoperative fractures reported persistent opioid use at the end of the study period.

Table 1. Demographics, fracture pattern, and final treatment of study participants (N=10)

Partici-pant	Age (years)	Sex	Injury	Definitive therapy	Time until orthopedic follow-up (days)
1	32	M	Lisfranc fracture	Surgical fixation	3
2	48	F	Distal radius ulna fracture	Surgical fixation	3
3	55	M	Trimalleolar fracture	Surgical fixation	4
4	55	M	Bimalleolar fracture	Surgical fixation	3
5	63	F	Tibial plateau, proximal fibula fracture	Knee immobilizer	8
6	21	M	C6 right pedicle fracture, L2+L3 transverse process fracture	Cervical collar	20
7	44	F	Distal fibula fracture	Controlled ankle motion boot	7
8	27	F	Distal fibula fracture	Short leg cast	8
9	21	F	Distal radius fracture, ulnar-styloid fracture	Surgical fixation	4
10	50	M	L3 superior endplate fracture	Thoracolumbosacral orthosis	14

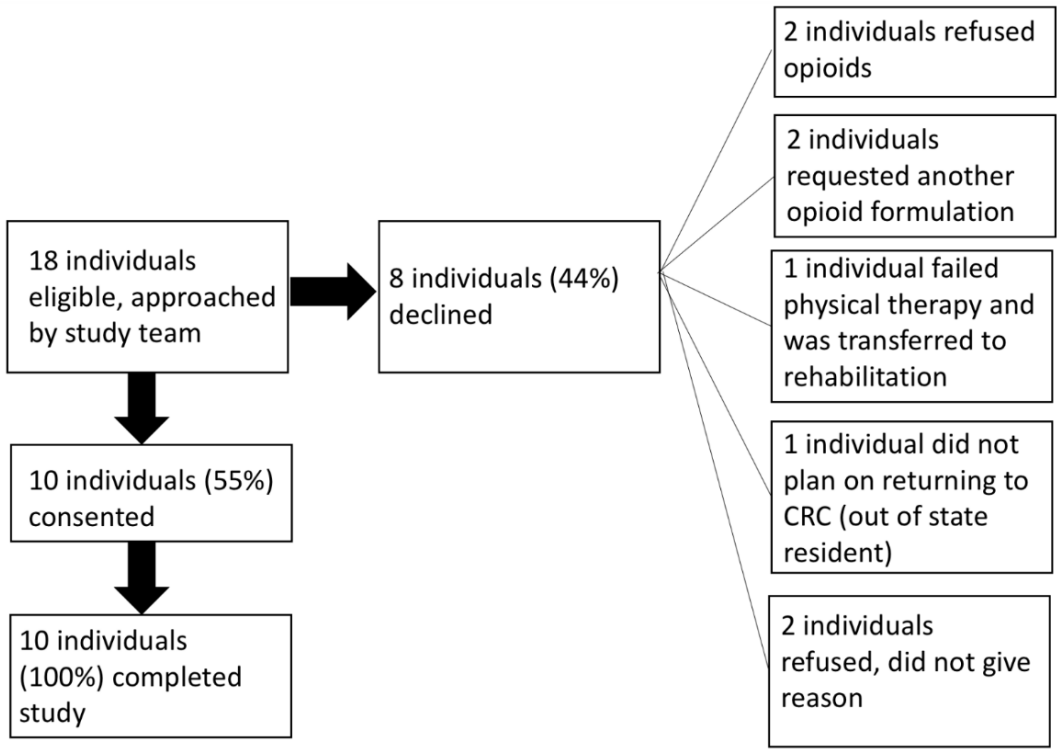
Table 2. Participant oxycodone ingestion patterns from digital pills.

Participant	Pain scale		Number of doses ingested per day (pills/day)							Oxycodone dose ingested in 7 days (mg)	Continued oxycodone for pain after 7 days
	ED[a] arrival	ED discharge	1	2	3	4	5	6	7		
1	7	7	1	2	1	1	2	4	4	75	Yes
2	9	Not recorded	2	2	3	2	2	1	0	60	Yes
3	10	Not recorded	3	7	4	0	0	0	0	70	Yes[b]
4	10	3	3	3	3	0	0	0	0	45	Yes
5	7	6	2	2	4	4	2	0	2	80	No
6	8	5	2	0	2	2	0	2	2	50	No
7	10	4	2	1	1	2	0	0	0	30	No
8	3	Not recorded	0	0	1	1	0	0	0	10	No
9	8	5	5	2	1	0	0	0	0	40	No
10	6	Not recorded	1	1	1	1	0	0	0	20	No

[a]ED: emergency department.

[b]Individual did not record continued ingestions (days 4-7) because he stopped interacting with the digital pill.

Figure 2. Study enrollment schema.



Fidelity of the Digital Pill System

The digital pill system was able to accurately measure oxycodone ingestion events (Table 3). Participants returned the remaining digital pills at the conclusion of the study and a pill count was used to verify the fidelity of the digital pill system. A total of 96 cumulative ingestion events were recorded during the study (87.3% accuracy). A total of 14 ingestion events were not recorded by the digital pill system; all these ingestion events occurred in two participants who were unwilling to interact with the technology, stating that severe pain prevented them from using the receiver or charging the digital pill system's batteries. Some ingestion events were initially not recorded on the cloud-based server due to lack of cellular reception at the study participant's home. Once the receiver entered cellular service, ingestion events automatically uploaded onto the server. In these instances, the receiver was mailed to our industry partner (eTectRx) to confirm all ingestion events had been uploaded.

Table 3. Accuracy of the digital pill.

Participant	Ingestion events recorded	Pills taken (based on pill count)	System accuracy (%)
1	15	15	100%
2	12	12	100%
3	14	20	70%
4	9	9	100%
5	16	16	100%
6	10	18	56%
7	6	6	100%
8	2	2	100%
9	8	8	100%
10	4	4	100%
Total	96	110	87%

Patient Response to Digital Pills

We completed open-ended interviews with all participants at the end of the study period (Textbox 1). Participants reported being able to easily operate the digital pill. Nine participants responded positively to the digital pill; one patient reported it was initially difficult for him to use the hub during the first 24 hours during episodes because of severe pain (Table 3). Attitudes toward the digital pill were positive; 80% (8/10) of participants reported that they would be willing to use the digital pill for adherence monitoring in chronic disease and would be willing to share ingestion data with physicians. Also, 90% (9/10) of participants reported they found the digital pill palatable and easy to swallow, considered the technology valuable, and had no problems operating the digital pill at home. One participant reported difficulty tolerating the size of the digital pill (a standard size 00 capsule; 8.5 mm in diameter, 23.3 mm in length; approximately the size of an 800 mg ibuprofen tablet), but reported willingness to use the digital pill.

Participants did not report any concerns regarding issues of privacy when utilizing the digital pill. Participants preferred real-time transfer of ingestion data to their physician, especially if their physician could use their ingestion data to intervene at potential times of escalating use. Interestingly, participants reported that they preferred text message-based confirmation of ingestion events and, in the context of chronic disease, would have liked mobile phone-based text messages reminding them to take medications.

Textbox 1. Feasibility of a digital pill.

Acceptance of system (9/10, 90%)

- 90% of participants reported a positive experience integrating digital pill into medication regimen
- System became part of medication routine and participants developed different techniques for system use based on individual habits
- Digital pills were easy to swallow
- Appreciated receiving text messages after taking medication when an ingestion event was recorded
- Sample of participant response:

"I thought it was easy. It helped me, because I had a routine of just take the reader off of the charger and go get the medicine"

"I like getting the (text) message, it showed me that the device was working."

Willingness to use in chronic disease (8/10, 80%)

- Participants willing to use in coordination with health care provider for observation of medication taking behavior
- Sample of participant response:

"A prompt would be nice if it was a medication I had to take daily, because people, like myself, forget to take their medication"

"Using the system actually really helped me to realize how much (oxycodone) I was taking"

2 participants reported they would not be willing to use the system in chronic disease (see barriers to use)

Equipment failure and barriers to use (2/10, 20%)

Problem: participant 2 lost reception due to poor cell coverage, so ingestion events were not transmitted via SMS to study server

Solution: ingestion events are stored on reader automatically for manual upload to server as backup

Problem: participant 5 reported that system was hard to remember to use when in severe pain; stopped using system on day 3

Solution: focus on patient-centered improvements for ease of use in next-generation digital pill (eg, integrating reader with receiver sticker into one easy-to-wear reader as a lanyard); use digital pill for conditions not involving severe pain

Problem: participant 5 reported improved battery life would have made system easier to use when in severe pain; participant 6 did not plug in reader when not in use causing the reader to lose power and ingestion events were not recorded on day 1 and day 2; participant 10 reported that they would not be willing to use system in chronic disease because of having to charge reader consistently

Solution: next-generation reader will have improved battery life and not need to be charged consistently when not in use

Discussion

We demonstrated the acceptability and usability conditions of digital pills as a medication monitoring method among patients with acute painful conditions. Importantly, we successfully deployed the digital pill among ED patients; ED-based research is unique in that it oversamples poor, indigent, homeless, and immigrant populations [14]. Notably, acceptance of the digital pill allowed us to measure ingestion patterns in nontraditional research participants (ie, individuals with whom we did not have an ongoing therapeutic relationship). Therefore, digital pills may be a potential method to reinforce adherence to short regimens of high-risk medications such as opioids prescribed in the ED. Furthermore, we successfully recruited and retained participants of low socioeconomic status (including homeless individuals); we feel that our confidence in deploying digital pills in "real-world" environments is justified.

Our data show that digital pills can detect not only real-time oxycodone ingestion in real-world patients, but also the patterns by which they take these medications. Our ability to reliably measure medication ingestion events using the digital pill arises from the technology's capacity to detect simultaneous ingestion of two separate digital pills. When two simultaneous digital pills were ingested, the digital pill recognized two distinct ingestion events 100% of the time. These pilot data demonstrate that digital pills can mirror an individual's medication ingestion pattern in the real world and that these data can be delivered to physicians in real time.

Failure of the digital pill to record ingestion events resulted from technical difficulties of the emerging technology (eg, reader was not charged or lack of cellular signal at the reader location), not operator error. Notably, in cases when the reader could not link to a cellular network, the reader recorded ingestion events in its on-board memory, which we downloaded at participant follow-up. The 20 minutes of hands-on instruction—a time period expected to drop as technology improves—ensured fidelity to tasks needed to operate the digital pill. This short training period and 90% acceptance of the system implies that it is simple and intuitive for the user. We believe technical improvements in the reader—improved battery life, the ability to switch between wireless networks, low energy Bluetooth and cellular transmission, and improved capture of the radiofrequency signal—will only improve detection accuracy and decrease the steps required to operate the reader.

We identified conflicting responses regarding the impact of a medication monitoring system on participant behavior. For example, participants did not perceive that physician notification of real-time ingestion events altered their decisions surrounding

medication use or altered the dose or frequency with which they ingested digital pills. Conversely, in the theoretical case of medication monitoring for chronic disease, participants reported that the technology would be an adherence-improving measure in itself.

Importantly, our formative interviews of study participants demonstrate their perception that the digital pill maintains patient privacy. This finding contrasts with multiple reports in the lay media hypothesizing that real-time detection of medication ingestion events could violate privacy [15,16]. Our study participants reported that our security measures—encryption of data streams, deidentification of ingestion data prior to transmission, and access of data that was limited to clinicians—were acceptable. This suggests that individuals with other stigmatized conditions that require strict medication adherence, such as substance abuse disorders or human immunodeficiency virus (HIV), may also similarly accept the data security offered through the digital pill. Continued data security and protection of patient privacy can be accomplished through excluding protected health information from ingestion data (eg, transmitting only ingestion time and pill number instead of transmitting a patient identifier) and improvements in radiofrequency encryption.

Discovering the ways in which patients take opioids in natural environments is of particular interest given the increasing rate of opioid overdose deaths. Ingestion data from our study shows that patients may require only brief periods of opioid analgesia following an acute extremity fracture. Most study participants ingested opioids for only 72 hours after their injury while self-tapering their dose. Study participants experienced greatest pain in the first 48 hours following injury. Participants successfully controlled subsequent episodes of pain with nonopioid analgesics such as acetaminophen or ibuprofen. Study participants who ingested opioids after 72 hours reported doing so for specific reasons, such as treating a second painful condition (eg, a soft tissue laceration in one case) or to maximize analgesia before bedtime. This formative data, although drawn from a small cohort of patients, may provide guidance for physicians hoping to provide effective yet safe duration of opioid therapy.

This study represents the first time digital pills have been deployed from the ED. We demonstrate that digital pills feasibly monitor medication ingestion events in the real world, require minimal training, and are acceptable by users, even those of low socioeconomic status. Our approach may be adapted to the deployment of digital pills to monitor chronic medication adherence in chronic conditions such as antiretroviral agents to prevent or treat HIV infection, or the use of anticoagulants in atrial fibrillation. Continued advances in radiofrequency signaling and energy harvesting will boost signal strength for future digital pills while continued miniaturization, improved battery life, and advanced detection techniques will allow future receivers to blend into the background of daily life, increasing acceptance and fidelity of digital pills. Automated interpretation of adherence data and integration with electronic medical records will improve data visualization by physicians and patients and may serve as a novel method to boost adherence. Digital pills may be an effective method to detect real-time medication ingestion events for many chronic, expensive, and intractable conditions.

This study had several limitations. First, our data demonstrate the feasibility of a digital pill to monitor medication ingestion, but the small sample size makes it difficult to determine whether decreased opioid usage was statistically significant. Second, we studied patients with acute extremity fracture—a painful condition for which opioids are commonly prescribed. Therefore, our data should not be generalized to all painful conditions. Future studies should focus on various painful conditions to guide the creation of a more comprehensive set of opioid-prescribing guidelines. Third, patients in this study had stringent enrollment criteria, including the lack of psychiatric illness or a history of substance abuse. Fourth, we did not follow patients after their operative repair because our main goal was to understand the feasibility and acceptability of the digital pill. Therefore, we do not know the patterns of chronic opioid use.

This pilot study demonstrates the feasibility of digital pills to detect medication ingestion events and discern patterns of opioid analgesic use in patients discharged from the ED. Patients readily accept and interact with digital pills in the real world. Our study adds to the growing data regarding natural environment interactions with digital pills. When formulated with oxycodone, digital pills can help clinicians discover natural ingestion patterns of opioids.

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Conflicts of Interest

None declared.

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Abbreviations

ED: emergency department
HIV: human immunodeficiency virus

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Original Paper

“Happiness Inventors”: Informing Positive Computing Technologies Through Participatory Design With Children

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Abstract

Background: Positive psychological interventions for children have typically focused on direct adaptations of interventions developed for adults. As the community moves toward designing positive computing technologies to support child well-being, it is important to use a more participatory process that directly engages children’s voices.

Objective: Our objectives were, through a participatory design study, to understand children’s interpretations of positive psychology concepts, as well as their perspectives on technologies that are best suited to enhance their engagement with practice of well-being skills.

Methods: We addressed these questions through a content analysis of 434 design ideas, 51 sketches, and 8 prototype and videos, which emerged from a 14-session cooperative inquiry study with 12 child “happiness inventors.” The study was part of a summer learning camp held at the children’s middle school, which focused on teaching the invention process, teaching well-being skills drawn from positive psychology and related areas (gratitude, mindfulness, and problem solving), and iterating design ideas for technologies to support these skills.

Results: The children’s ideas and prototypes revealed specific facets of how they interpreted gratitude (as thanking, being positive, and doing good things), mindfulness (as externally representing thought and emotions, controlling those thoughts and emotions, getting through unpleasant things, and avoiding forgetting something), and problem solving (as preventing bad decisions, seeking alternative solutions, and not dwelling on unproductive thoughts). This process also revealed that children emphasized particular technologies in their solutions. While desktop or laptop solutions were notably lacking, other ideas were roughly evenly distributed between mobile apps and embodied computing technologies (toys, wearables, etc). We also report on desired functionalities and approaches to engagement in the children’s ideas, such as a notable emphasis on representing and responding to internal states.

Conclusions: Our findings point to promising directions for the design of positive computing technologies targeted at children, with particular emphases on the perspectives, technologies, engagement approaches, and functionalities that appealed to the children in our study. The dual focus of the study on teaching skills while designing technologies is a novel methodology in the design of positive computing technologies intended to increase child well-being.

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KEYWORDS

positive computing; positive psychology; participatory design; cooperative inquiry; children

Introduction

Two parallel, yet often disconnected, tracks are advancing in the science of technology and well-being. One, stemming from the positive psychology movement, has focused on Web-based positive psychological interventions [1]. This track has mainly translated positive psychological interventions developed offline into Web and mobile versions that could be made widely accessible, able to reach people around the world at the times and places they might most benefit from these interventions. The second track—positive computing technology [2,3]—originates from human-computer interaction and human factors. Positive computing focuses on the design and implementation of technologies that have a beneficial psychological and behavioral impact on the user. Positive computing has often leaned on research in positive psychology to help define what constitutes a beneficial psychological and behavioral impact, borrowing constructs such as subjective well-being [4], or models such as self-determination theory [5] or flourishing [6] to identify and operationalize important targets such as happiness, positive affect, meaning, autonomy, competence, and relatedness. However, with few exceptions, positive computing has rarely focused on translating the principles underlying effective positive psychological interventions into novel technologies developed to promote well-being. As such, interdisciplinary perspectives bringing together positive psychology, human-computer interaction, and human factors are mostly lacking.

This is unfortunate because the pervasiveness of technology affords the potential to reach many more people than can be reached through traditional dissemination of psychological resources. Technology might be especially relevant for children whose time on electronic screens exceeds their time spent either with their parents or in school [7]. However, to successfully design technologies to promote children's well-being, two types of tailoring are necessary. First, these technologies need to employ design principles that are developed for children to ensure that interaction styles are tailored to children's interests and capacities (eg, [8]). Second, positive psychological interventions need to align with children's understanding of the underlying conceptual principles rather than simply adapting language and examples to be age appropriate. In many instances, positive psychological interventions with established efficacy in adults (eg, counting blessings [9]) are simply given to children to evaluate the interventions' efficacy in new populations (eg, [10]). The alternative approach is to explore what specific positive psychology concepts (eg, gratitude) mean to children and how to promote these concepts within child populations. This approach places children at the center of the process of intervention development rather than viewing them as simply another group for which adaptations need to be made.

In this study, we took a participatory design approach to understanding children's perspectives on positive psychology concepts such as gratitude, mindfulness, and problem solving and worked from these perspectives to iterate ideas for positive computing technologies. Through a 14-session participatory design study with 12 children, we elicited children's interpretations of these concepts and positive computing technology designs to answer the following research questions (RQs). RQ1: What do children's "happiness inventions" reveal about their perspectives on happiness and positive psychology concepts? RQ2: What kinds of positive computing technologies and approaches are emphasized in children's designs? RQ3: How can positive computing technology designs targeted at children better match their mental models and priorities?

To position our work, we begin this paper by contextualizing both our methodological approach of participatory design and the specific positive psychology skills and concepts emphasized in our 14-session study. Next, we describe the specific operationalization of participatory design we enacted in this investigation. We discuss the design ideas generated and developed by the children in this study to address RQ1 and RQ2. Finally, we return to RQ3 with implications for design in this context.

Participatory Design

The basic principle of the participatory design approach is that people who are affected by the introduction of a new technology have the right to participate in the creation of this technology. Participatory design has become an important approach in human-computer interaction as a set of theories, practices, and studies related to end users as full participants in activities leading to the creation of technologies [11]. In the late 1990s, this approach was adapted to support intergenerational design partnerships with children, terming this adaptation the cooperative inquiry method [12]. The method has been used in many projects—for example, designing a children's digital library [13]. It provides benefits in terms of both leading to more creative and better-situated final outcomes [14] and increasing the agency of and empowering the child partners involved in the design process [15]. Our goal reflected the priorities of cooperative inquiry and participatory design—to create well-contextualized digital artifacts to support teaching well-being skills to children. As in other cooperative inquiries, we were also interested in providing benefits to study participants in terms of both fostering agency [15] and teaching specific, actionable, and useful skills (in this case, design thinking; science, technology, engineering, and mathematics education; and positive psychological skills to promote well-being) to participants.

Technology Design for Well-Being and Resilience

Positive computing technology is a well-explored and growing priority in both positive psychology and human-computer interaction. Some particularly noteworthy examples of projects are a mobile intervention to help capture and reflect on positive occurrences and thoughts [16]; a context-sensitive mobile app designed to promote gratitude [17]; a sensor-based interface for supporting meditation practices [18]; and conceptual physical computing designs to help promote mindfulness [19]. Although these projects are generally viewed as effective, sustained engagement with such programs is a considerable barrier (eg, [20]). These barriers may be amplified when technologies or interventions that are designed for adults are adapted and deployed with children. As we seek to include children in well-established positive psychology practices such as gratitude, mindfulness, and problem solving, we must review and engage

with previous work to understand the goals, potential benefits, and potential challenges of such interventions. We briefly review each of the three practices below.

Gratitude

Promoting gratitude in children is a key interest of researchers and educators. Gratitude refers to the disposition to recognize good things and an appreciation for receiving these things [9]. Gratitude is a social emotion that serves several functions, including facilitating and strengthening relationships [21] and promoting subsequent prosocial behavior [22]. Mounting evidence suggests that interventions can effectively increase gratitude and subsequently improve well-being in adults and children [23-25]. Child-targeted modifications of common gratitude interventions (eg, counting one's blessing [9], gratitude visits [26,27]) include conducting the intervention in a relational context [28] and providing it to children in sixth- and seventh-grade classrooms [10,23]. From this and other previous work, gratitude appears to be a beneficial and teachable skill for children; thus, we chose it as one of the concepts we fostered in this study.

Mindfulness

Mindfulness refers to a skill to attend to one's present environment in a receptive and nonjudgmental fashion [29]. Mindfulness skills have been linked with improvement in stress management, mood, and behavior [30-32], and consistent mindfulness practice has been linked to beneficial structural changes in the brain [33]. Mindfulness interventions are becoming increasingly popular in school-based settings, with research reports demonstrating their effectiveness and detailing their implementation [34-38]. Despite the benefits of these interventions, their successful implementation in school-based settings faces several barriers. These issues include communication among facilitators, acceptance by school administrators, the necessary space, time, and resources to conduct instruction, and perceptions of mindfulness and related practices as "primarily an activity of white privileged females" [38] (pg 281). These barriers emphasize the importance of working alongside stakeholders to build relationships and the need to frame mindfulness practices appropriately for those for whom the intervention is intended. Although operationalizing mindfulness for specific populations remains an open question, mindfulness principles have been successfully taught to children and have broad benefits that contribute to their well-being. As such, mindfulness was the second concept we selected as a focus in this study.

Problem-Solving and Cognitive Skills Training

Problem-solving skills training is both a standalone treatment [39,40] and a major component of cognitive behavioral therapy (which is one of the most widely researched and validated treatments for a host of social and emotional issues for children [41,42]). Increasingly, schools have recognized the value of teaching these problem-solving skills to boost well-being and resilience before social and behavioral issues occur (eg, [43,44]). One of the most widely researched resilience programs for children is the Penn Resiliency Program, which was originally designed as a school-based program but has been evaluated in other settings, including primary care clinics [45] and juvenile detention centers [46]. Several studies have evaluated its effectiveness to reduce depressive symptoms and have found reliable but small benefits [47]. These skills are relevant and teachable to children even at young ages, and supporting these skills can contribute to personal, interpersonal, and academic success, leading us to select problem solving as the third and final emphasized concept in this investigation.

Positive Psychology in the Classroom

Ours was not the first project to attempt to bring positive psychology skills into the classroom. Previous efforts have been based on the notion that well-being skills are fundamental (yet often overlooked) goals of education [48]. Furthermore, well-being is teachable through specific skills that can complement rather than constitute academic learning objectives. Lastly, increasing well-being can benefit education through promoting learning. Positive moods have been found to broaden attention [49], increase creativity [50], and promote more holistic [51] and analytic thinking [52]. As such, positive psychological skills have been taught in educational settings either as adjunctive programs or integrated more tightly with traditional educational lessons. A complete review of all such programs is beyond the scope of this paper, as teaching well-being skills was only one aspect of our larger program, serving as the context for our participatory design process. Nevertheless, we discuss a few programs that inspired our selection of well-being strategies and offer potential paradigms in which positive psychological interventions or positive computing technologies inspired by our program could be integrated.

As previously mentioned, the Penn Resiliency Program was designed for school-based administration and has been successfully disseminated to different populations by tailoring several aspects of its delivery. A meta-analysis of 17 controlled evaluations of Penn Resiliency Program found reliable but small benefits in terms of reduction of depressive symptoms [47]. The review also found that programs led by members of the initial Penn Resiliency Program research team experienced greater benefits than those led by community providers. This suggests that, although such programs can be beneficial, issues of successful dissemination and training might affect their effectiveness when scaling. Positive computing technologies serving as supports to the intervention could potentially increase the scalability of such efforts. Other efforts have attempted to intertwine positive psychology principles directly into education. As an early example, the Positive Psychology Program evaluated providing language arts education that aimed to help students identify their character strengths and increase their use of these character strengths in their lives [48]. These programs were foundational for the Geelong Grammar School model for positive education, which integrates well-being skills deeply into classroom education through a "live it, teach it, embed it" philosophy [53]. These efforts demonstrated that teaching well-being can be beneficial and relevant to the educational context, if scaled effectively. Positive computing technologies could go a long way in making these efforts more scalable and sustainable.

Methods

We conducted 14 cooperative inquiry sessions lasting 90 minutes each with 12 sixth and seventh graders. During these sessions, we contextualized the participatory design process by practicing specific positive psychology skills, we conducted ideation sessions, and we prototyped and documented selected ideas that emerged through this process. Multimedia Appendix 1 includes a more thorough description of these skills organized by topic areas (gratitude, mindfulness, and problem solving).

Setting

Participants were recruited from a summer learning program offered by a local youth development agency (Youth & Opportunity United [Y.O.U.] Program [54]) in a suburban middle school outside of Chicago, Illinois, USA. The summer learning program's theme was "Technology and its Impact on Society," which was an 8-week, 4.5-hours-per-day program enrolling approximately 40 middle-school students. Students enrolled in this program were allowed to choose between one of three elective projects, one of which was the Happiness Inventors study we led. The students were informed that the Happiness Inventors elective was a research project and that informed consent would be required to participate in this elective. Participants in elective projects met twice a week (Mondays and Wednesdays) for 1.5 hours after lunch and free recreation, and before debriefing and snack. No elective session was held on the first day of the summer learning program and one Monday was a national holiday. Thus, our study consisted of 14 total sessions. As attendance in the summer learning program was not mandatory, the number of participants at each session differed considerably from day to day. We did not formally take attendance during each session but constructed attendance data based on evidence of participants' activities (eg, writing in their invention notebooks). Table 1 documents individual attendance by session.

Table 1. Demographics and attendance of the 12 children taking part in the Happiness Inventors elective.

Participant number	Age (years)	Sex	Race/ethnicity	Session number													
				1	2	3	4	5	6	7	8	9	10	11	12	13	14
1	12	Male	White	X		X	X	X		X		X	X	X	X		
2	11	Female	African American	X	X	X	X	X	X	X	X	X	X	X	X	X	X
3	12	Male	White	X	X		X	X	X	X		X	X	X	X		
4	11	Male	White	X	X		X	X	X	X		X		X		X	X
5	N/A[a]	Male	Hispanic or Latino	X	X			X	X			X	X	X		X	
6	11	Male	African American		X	X						X	X	X	X	X	X
7	N/A	Female	African American	X	X	X	X	X			X	X	X	X	X		
8	N/A	Male	African American		X	X		X	X	X		X	X	X		X	
9	12	Female	White	X	X		X	X	X	X	X	X	X	X	X	X	X
10	N/A	Female	Hispanic or Latino		X			X	X	X	X	X	X	X	X	X	
11	N/A	Male	Hispanic or Latino	X	X	X		X		X		X			X	X	
12	12	Female	White	X	X	X	X	X	X	X	X	X	X	X	X	X	X

[a]N/A: not available.

Participants and Recruitment

A total of 12 children participated in our study, along with 2 researchers (SY and SMS) and 1 behavioral aid provided by the summer learning program. Complete demographic data were available from 8 children (the other 4 missed classes where data were collected and contributed only partial data). Table 1 displays demographic data for each participant. The children were predominantly seventh graders (5/7, 71%), with a mean age of 11.57 (SD 0.54) years. The group consisted of more boys (7/12, 58%) than girls (5/12, 42%) and was ethnically diverse, with 42% (5/12) non-Hispanic or Latino white, 33% (4/12) African American, and 25% (3/12) Hispanic or Latino.

All Y.O.U. summer program participants were provided with the opportunity to choose to take part in this Happiness Inventors study. Those who expressed interest after an introductory session filled out assent forms and were given parental consent forms to take home and return. Any child could choose to stop participating in the study at any time (by switching to one of the other elective sessions). Additionally, parents could elect to pull their child from any given session (eg, if the family was going on vacation that week). The institutional review boards at both the University of Minnesota, Minneapolis, MN, USA, and Northwestern University, Chicago, IL, USA, approved this project.

Procedure

In this study, we worked with children to understand and design positive computing technologies. As in previous work with children, we adapted a cooperative inquiry approach to participatory design [55], enlisting the children in the study both as inventors and as fellow investigators. This cooperative inquiry took place over the course of an 8-week summer program, with two 90-minute sessions each week. The goals and structure of each week were as follows.

Orientation and Introduction

All camp children were introduced to the investigators and given the opportunity to join the study. As the group first came together, we jointly created and signed a charter to guide our collaboration on the project (including rules such as "respect ideas in how you give feedback").

How to Be an Inventor

A computer scientist (first author, SY) with years of experience being an inventor introduced the children to the process of inventing (including the importance of formative work, ideation, and prototyping). We also introduced invention notebooks as a common industry practice for documenting patentable ideas. The goal of these workshops was to position the ideation, documentation, and low-fidelity prototyping processes as authentic practices of real inventors.

Happiness and Gratitude

A clinical psychologist (second author, SMS) with expertise in positive psychology introduced the children to the idea of happiness as a practice. Gratitude was the first happiness skill introduced to children through age-appropriate exercises (see Multimedia Appendix 1 for more details about these exercises). This session provided them with the opportunity to reflect on the fairly abstract concepts of happiness and gratitude and become investigators of their own experience as they practiced the taught skills.

Mindfulness and Problem Solving

The clinical psychologist continued teaching positive psychology skills, focusing on mindfulness and problem solving through age-appropriate exercises (see Multimedia Appendix 1 for more details about these exercises). This session provided the children with the opportunity to reflect on these fairly abstract concepts and become investigators of their own experience as they practiced these skills.

Technical Possibilities Workshop

Two experts in mobile app development and embodied computing (eg, wearable technologies) each led 1 session with the children, describing common approaches to prototyping technology in their respective fields. Technologies covered included low-fidelity prototyping, the *Prototyping on Paper* app (Woomoo Inc, Taipei, Taiwan), littleBits electrical circuit kits (littleBits Electronics Inc, New York, NY, USA), and the Oculus Rift virtual reality head-mounted display (Oculus VR, LLC, Menlo Park, CA, USA). The goal of these workshops was to broaden the children's perspectives on what constitutes technology, in order to inform the ideation stage.

Gratitude Ideation

The children used the IDEO ideation approach [56] in small groups (approximately 4 children depending on attendance and 1 adult per group) to generate 180 ideas for technology that could help other children practice gratitude. They reflected on the best ideas in their invention notebooks, voted on clusters of ideas, regrouped by favorite cluster, and created detailed sketches and videos of their final ideas. (Multimedia Appendix 2 documents all ideas.)

Mindfulness Ideation

The children used the same approach to generate 152 ideas for technology that could help other children practice mindfulness. They reflected on the best ideas in their invention notebooks, voted on clusters of ideas, regrouped by favorite cluster, and created detailed sketches, prototypes, and videos of their final ideas. (Multimedia Appendix 2 documents all ideas.)

Problem-Solving Ideation

The children used the same approach to generate 102 ideas for technology that could help other children practice problem solving. They reflected on the best ideas in their invention notebooks, voted on clusters of ideas, regrouped by favorite cluster, and created detailed sketches, prototypes, and videos of their final ideas. On the last day of the study, we also reserved time for final reflection and to view the videos created by the children throughout the summer. (Multimedia Appendix 2 documents all ideas.)

We took an action research approach (eg, [57]) to iteratively structure the workshops, keeping in mind the overarching goals of equalizing power between the children and the researchers, increasing the children's acceptance of the project, and adjusting specific plans based on the attendance and participation on any given day. For example, our original plan was to structure each ideation workshop in two parts, where children first focused on designing apps and then on designing other technologies. But, during the first workshop (focused on gratitude), we found that this artificial division was frustrating for the children, and they were generally less excited about focusing on app ideas. In subsequent workshops, we did not prompt this separation. As another example, the action research approach led us to change our video data collection process. During the first ideation workshop, we set up webcams to record each group's progress. We found these to be distracting for the children and that these amplified the power differential between them (as data sources) and us (as data collectors). In subsequent sessions, we instead asked the children to document their own ideas and process using the cameras. Enlisting the children as the directors of their own self-documentaries increased their agency and willingness to participate (although at the expense of objective data quality).

We collected data from many sources throughout this process. The primary sources used in these analyses were the transcripts of the ideas generated by the children, the reflections and sketches in the children's invention notebooks, and the transcripts of the video documentation collected by them during their invention process.

Qualitative Content Analysis

To support qualitative analysis, we converted all data from the study into a textual format as follows: (1) transcribing all (434 total) ideas from the ideation sessions, (2) transcribing all written notes and describing all (51 total) drawings from the children's invention notebooks, (3) transcribing and describing in words all (8 total) video-documented ideas and prototypes from the ideation workshops.

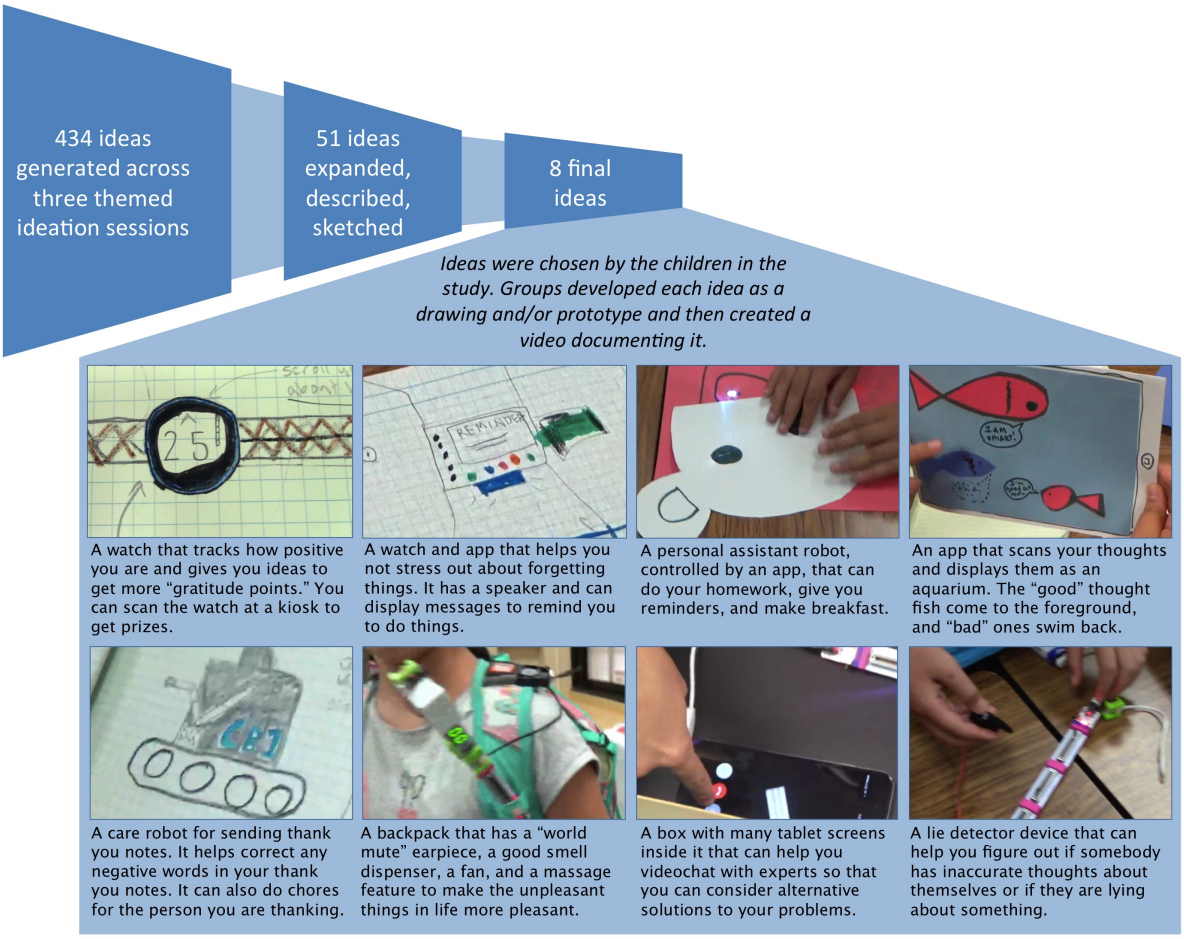
We conducted a data-driven inductive thematic analysis, characterized by the generation and constant comparison of

open codes [58]. The first author (SY) conducted the open coding by reading through all of the transcribed data and adding one or more short descriptive phrases to label each idea. No clustering was attempted at this stage. SY then read through the open codes, added memos, and initiated discussions with the second author (SMS) to begin noting and articulating interesting themes. Based on the open codes, memos, and discussions, the first author (SY) and a student apprentice applied affinity mapping to cluster the resulting set of open codes and memos to identify patterns and overarching themes in the data. The first author described the resulting set of 47 clustered codes as a codebook, specifying concrete inclusion and exclusion criteria for applying a particular code. To ensure that this codebook was clear and the codes could be consistently applied, the 2 coders (authors SY and SMS) independently applied the codebook to categorize a randomly selected set of ideas (43/434, 9.9% of the full set of ideas, where 1 or more of the 47 codes could be applied to each idea). The 2 coders achieved strong agreement (Cohen kappa=.80) as calculated using the Cohen kappa test of nominal data agreement by 2 coders [59]. The coders discussed all cases of disagreement until reaching consensus, and the specific points of that discussion were encoded as modifications of the codebook (eg, the "robot" code should be applied to any idea that includes a "drone"). The first author (SY) then applied the modified codebook to coding the remaining 391 ideas, 51 notebook entries, and 8 videos. We present the major results of this process and provide specific examples of each code in the Results section.

Results

In this section, we provide empirical data to address the first 2 research questions: how children interpret positive psychology concepts and which technological approaches are emphasized in their designs. In the Discussion, we return to the third research question of how to best design and target positive computing technologies for children. Figure 1 describes the quantitative characteristics of the ideation, selection, and documental process, along with images and short descriptions of the final design ideas that the children chose to document as low-fidelity prototypes and videos.

Figure 1. Summary of the ideation and idea selection process showing a brief description and a still image captured from each video of each of the final 8 ideas chosen by the children for their prototyping and video documentation.



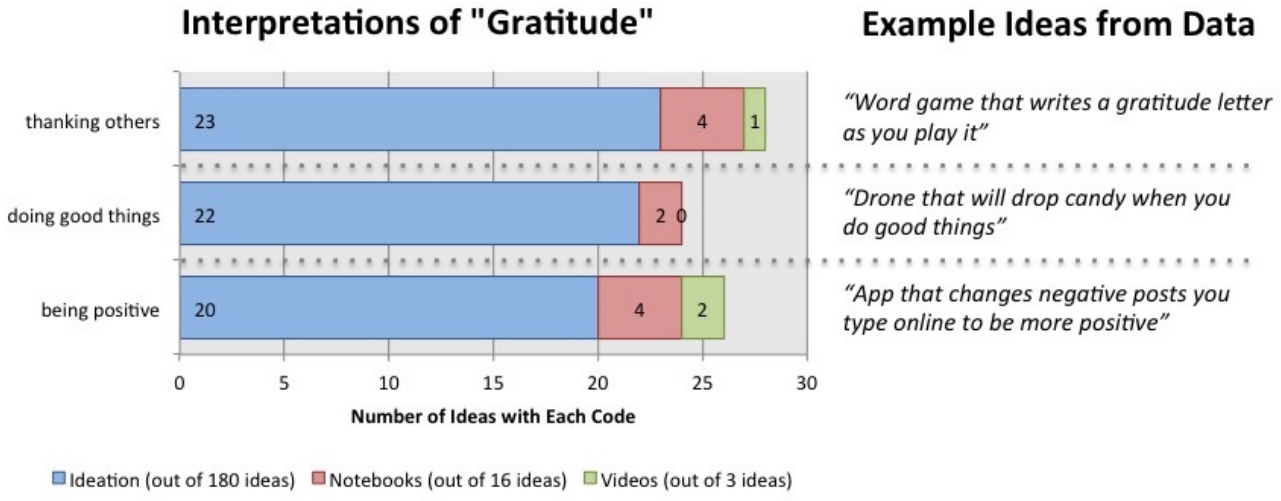
RQ1: What Do Children's Happiness Inventions Reveal About Their Perspectives on Happiness and Positive Psychology?

We coded the ideas that the children generated (434 ideas total), documented in notebooks (51 designs), and developed as prototypes and videos (8 total) (Figure 1) for specific interpretations of each of the positive psychology skills covered in the cooperative inquiry sessions. Multimedia Appendix 2 provides the complete list of ideas.

Interpretations of Gratitude

During the weeks focused on the concept of gratitude, the children generated 180 ideas, 16 notebook sketches, and 3 videos describing ideas for technologies that would help children practice gratitude skills as they interpreted them. Not all of the ideas expressed a specific interpretation, as the IDEO process specifies deferring judgment at the ideation stage (ie, many of the ideas were irrelevant to gratitude). We coded relevant ideas for implicitly or explicitly expressed interpretations of gratitude, finding a relatively equal split between three concepts (Figure 2). The most common interpretation was that practicing gratitude is about thanking others. Many of the ideas in this category focused on writing thank-you notes, making gifts, etc, for others. The next most common interpretation focused on generally remaining positive in life. Ideas included devices or apps that enforced or rewarded positive thinking (or punished negativity). Finally, another interpretation focused on gratitude as enacted by "doing good things" (typically for others), and many ideas in this section focused on encouraging people to "do good things" and engaging with people who need help (eg, donating to charity, helping a friend who is not feeling well).

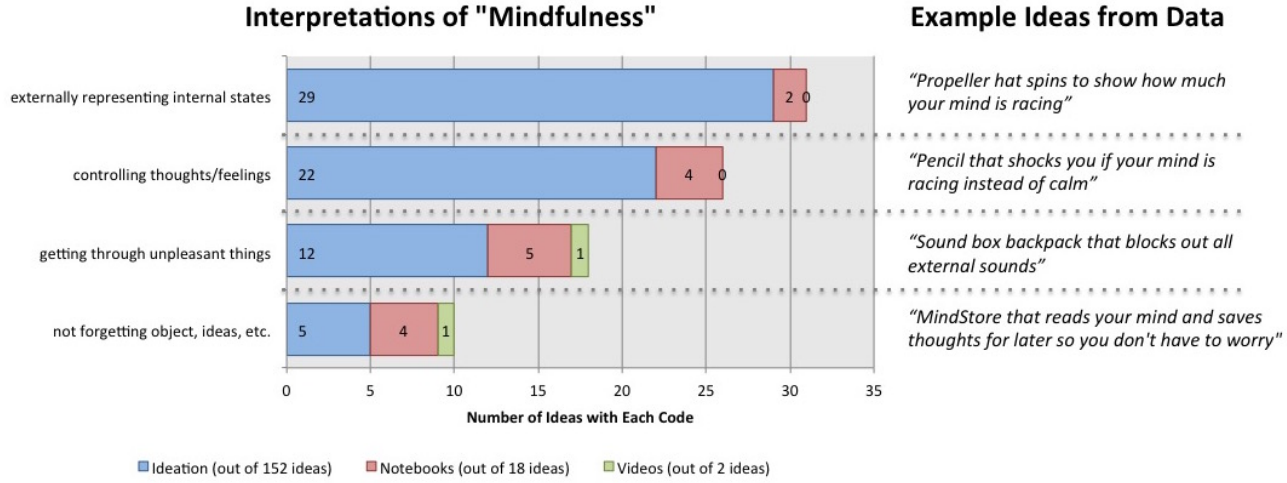
Figure 2. Prevalence of each of the 3 codes for interpretation of "gratitude" observed in the children's ideas, documentation, and videos.



Interpretations of Mindfulness

During the weeks focused on the concept of mindfulness, the children in the study generated 152 ideas, 18 notebook sketches, and 2 videos describing ideas for technologies that would help children practice mindfulness skills as they interpreted them. Not all of the ideas were relevant to the prompt or expressed a specific interpretation. However, it is worth noting that the relative prevalence of relevant ideas increased from 36.1% (65/180) in gratitude sessions to 44.7% (68/152) in mindfulness sessions. We coded relevant ideas for implicitly or explicitly expressed interpretations of mindfulness as a concept, identifying four major themes (Figure 3). The most common interpretation was that the best way to practice mindfulness is by externally representing internal states. Many of the ideas in this category focused on creating physical and visible manifestations or representations of emotions and thoughts. The next most common interpretation focused on controlling thoughts and feelings. Ideas included erasing unwanted thoughts or transitioning from a "bad" emotional state (mind racing, feeling sad) to a "good" emotional state (calm, feeling happy). The next class of ideas focused on mindfulness as a way of getting through unpleasant external situations. Many of the ideas in this class focused on avoiding or removing oneself from unpleasant situations and controlling the sensory aspects of one's environment (eg, sound, smell). The final interpretation saw "being mindful" as the opposite of being "absentminded" and operationalized this idea as preventing a person from forgetting an object or idea. Many of the ideas in this category focused on saving ideas and reminding one to take specific actions. While the last two interpretations were not as strongly represented in the ideation process as the first two, they seemed to get more vetting from the children by being documented as sketches, prototypes, and videos.

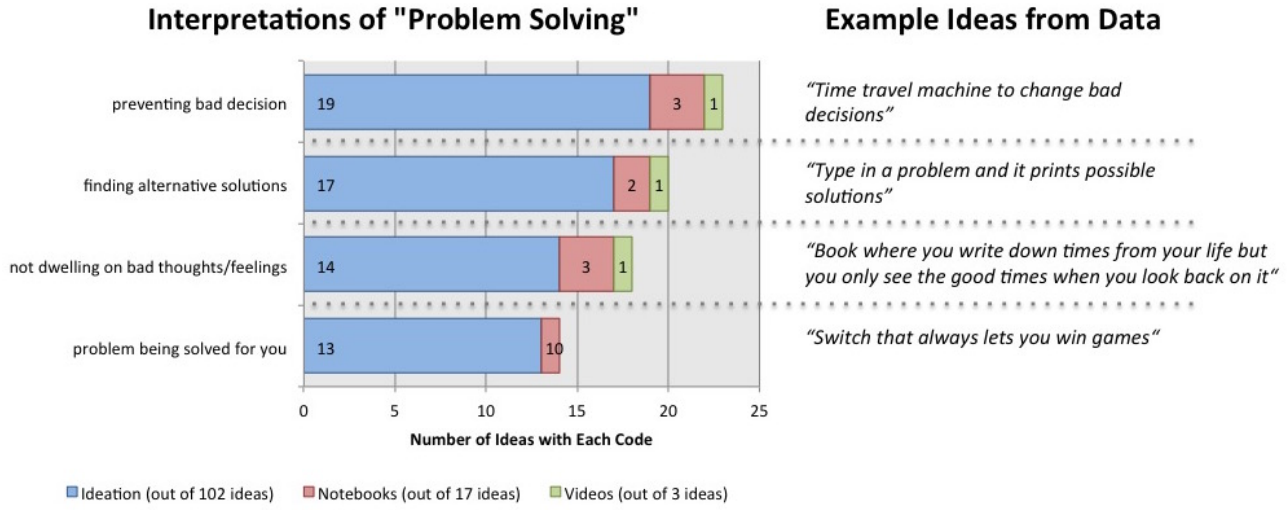
Figure 3. Prevalence of each of the 4 codes for interpretation of "mindfulness" observed in the children's ideas, documentation, and videos.



Interpretations of Problem Solving

During the weeks focused on the concept of problem solving, the children generated 102 ideas, 17 notebook sketches, and 3 videos describing ideas for technologies that would help children practice problem-solving skills as they interpreted them. We saw a relative increase in the number of relevant ideas that emerged from the ideation, from 36.1% (65/180) in gratitude sessions and 44.7% (68/152) in mindfulness sessions to 61.7% (63/102) in problem-solving sessions. We coded relevant ideas for implicitly or explicitly expressed interpretations of problem solving as a concept, identifying four major themes (Figure 4). The most common interpretation was that the best way to practice problem solving is by preventing a person from making a bad decision. Many of the ideas in this category focused on providing additional information about the issue at hand, getting more time to think about a decision, and finding ways to control the damage when bad decisions were made. The next most common interpretation focused on finding alternative solutions. Ideas included generating lists of possible solutions and turning to others to identify new ways of looking at a problem. The third category focused on problem solving as preventing dwelling on ideas or feelings that may be unproductive. Many of the ideas in this class focused on erasing specific thoughts or feeling or getting others to help correct inaccurate thoughts. The final interpretation of problem solving focused simply on the solution itself, typically generated automatically for the user by a device or person. These ideas focused on devices that solved specific situations in the children's lives that they saw as problems, such as doing homework, completing chores, losing at games, and getting bullied. This is a somewhat naïve interpretation of problem solving, but it is important to note that the vetting process of documenting the best ideas as sketches, prototypes, and videos largely removed this interpretation from the set. Children were able to see this interpretation of problem solving as naïve and gravitated toward more productive ideas.

Figure 4. Prevalence of each of the 4 codes for interpretation of "problem solving" observed in the children's ideas, documentation, and videos.



RQ2: What Kinds of Positive Computing Technologies and Approaches Are Emphasized in Children's Designs?

We also took note of the specific aspects of the technology solutions generated by the children. We divide this discussion into three major aspects of solutions: technology employed, functionalities described, and approach used to engage the user. These reflect a post hoc clustering of the codes observed in the data, rather than any specific prompts given to the children during the design process.

Featured Technologies

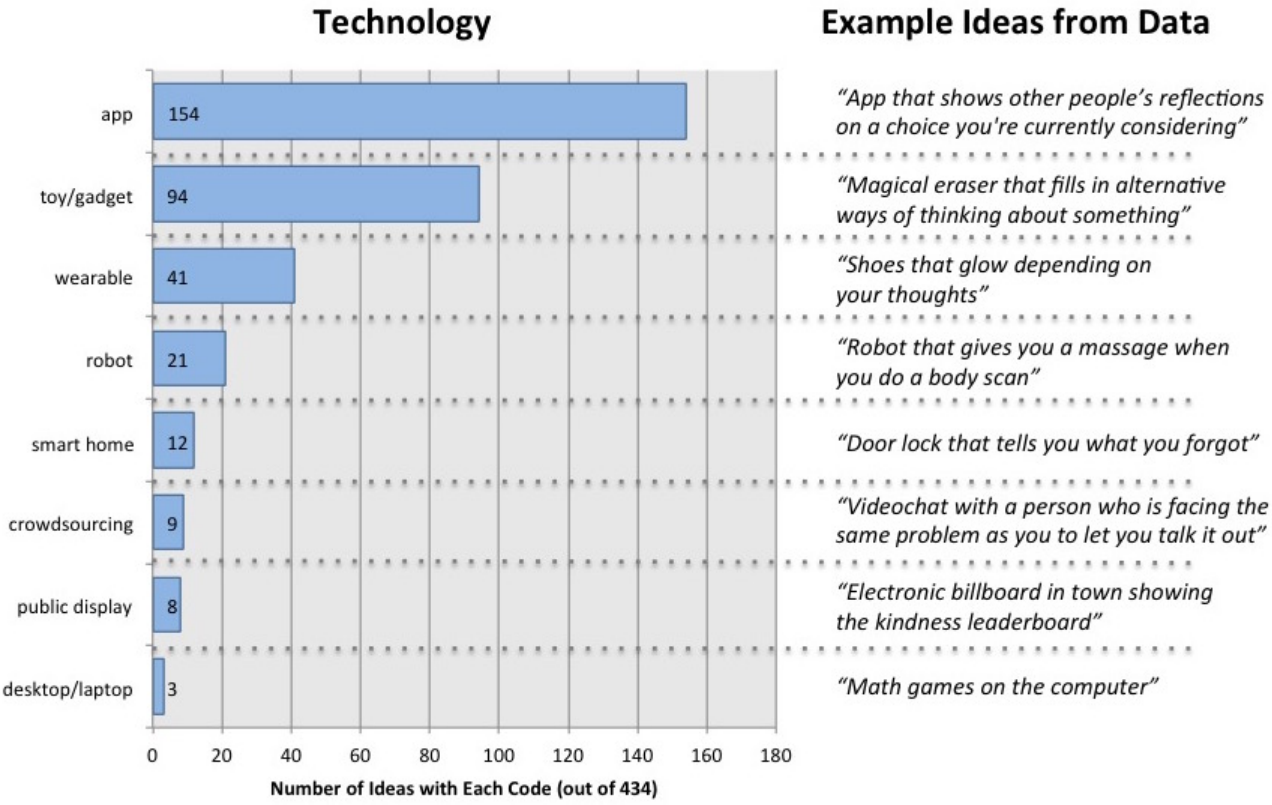
We categorized ideas generated throughout the 3 ideation sessions based on the technological solution featured (Figure 5). While the reader should be familiar with technologies such as apps (154 ideas), toys (94), and robots (21), a few of the other terms may need to be defined (none of these words were used explicitly by the children, but they are the industry terms for the ideas described):

- Wearable (41 ideas): an on-the-body technology worn as an accessory (eg, watch, jewelry, glasses) or as apparel (eg, shirt, shoes).
- Smart home (12 ideas): digital intelligence embedded in home infrastructure, appliances, or furniture.
- Crowdsourcing (9 ideas): leveraging technology to structure an interaction with strangers who provide a service or information.
- Public display (8 ideas): a public device for distributing content, such as a billboard, kiosk, or information panel.

The most common category of technology included in the children's ideas was a phone or tablet app, although it is important to note that roughly half of these (71) came from the first workshop, where we specifically asked them to come up with a total of 90 app ideas (and then 90 physical ideas). In subsequent sessions, where we did not enforce any technology-specific breakdown of ideas, children gravitated to embodied technologies (toy/gadget, smart home, wearable, robot, public display) to a greater extent. In the mindfulness ideation workshop, these 5 categories jointly accounted for 65 ideas, while apps were mentioned in 47. In the problem-solving workshop, these 5 categories accounted for 45 ideas, while apps were mentioned in 36. An interesting note is that conventional, on-the-desktop technology ideas were almost completely absent from the children's ideation. Only 3 ideas out of the 434 mentioned computers, laptops, or websites. This may highlight the importance of a mobile-first approach in designing Web-based interventions for children.

Additionally, throughout the ideation process, many ideas did not match specific technologies. For example, a total of 34 (out of 434) ideas were coded as "No Technology" (eg, "Play with a pet") and a total of 19 (out of 434) ideas were coded as "Magic" (eg, "Something that grants you 16 wishes"). The frequency of these types of ideas decreased through the duration of the study, and none of these ideas were documented in invention notebooks or videos.

Figure 5. Prevalence and examples of each of the 8 codes for technological solutions observed across 3 ideation workshops.

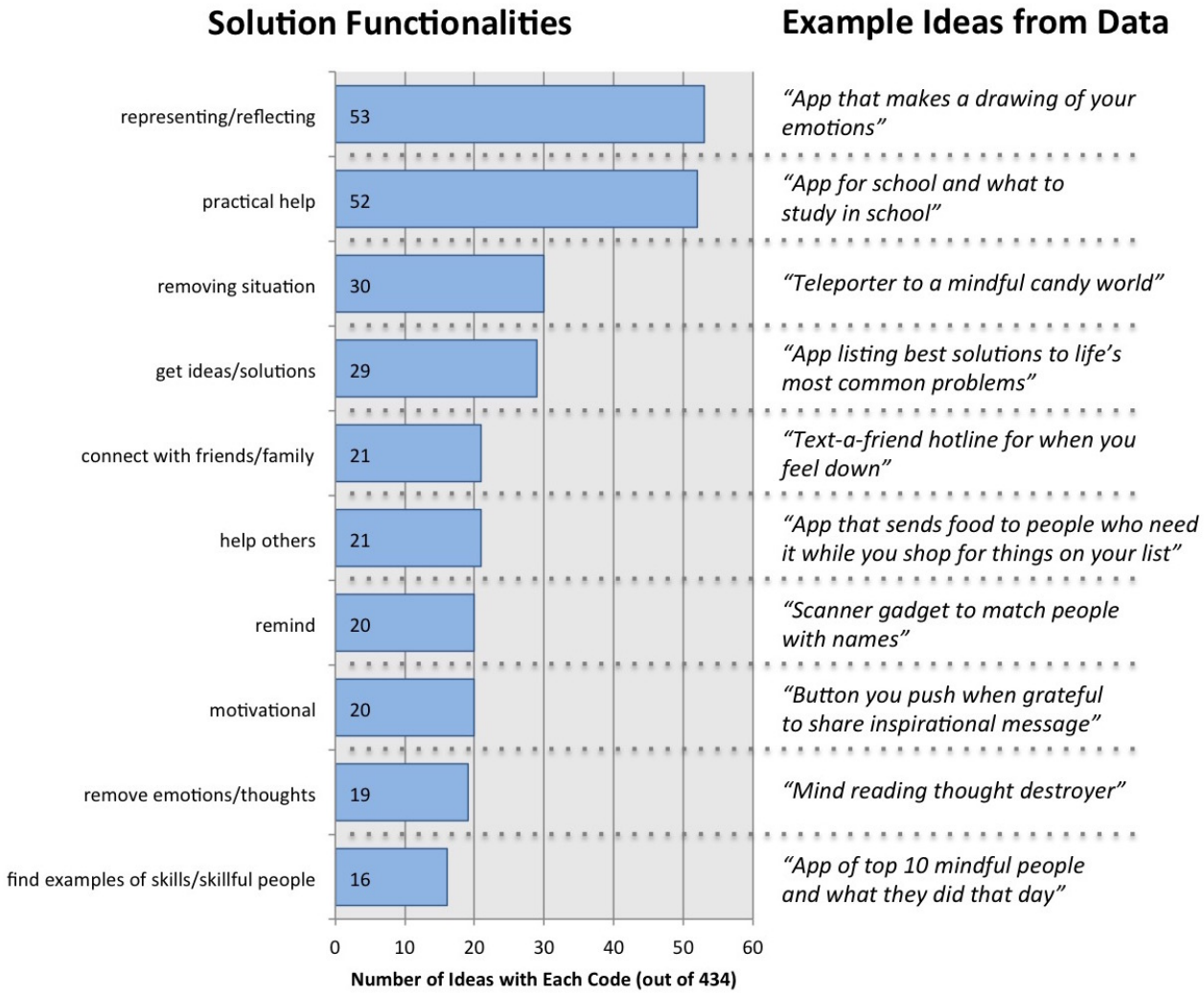


Common Solution Features and Functionalities

Through our coding process, we also noted that certain functionalities kept reappearing in children's ideas across all 3 ideation workshops (Figure 6). A few of these are particularly interesting. The most common functionality presented in the technology solutions was an opportunity to represent and reflect internal states. Particularly, many of the ideas focused on representing ideas, feelings, and thoughts as physical or digital objects to see and manipulate at will. Related to this idea, several of the solutions focused on the ability to remove feelings (eg, sad, tired) or thoughts (eg, feeling insecure, having negative thoughts about someone) at will. It is also telling how frequently solutions included connecting with others. The children designed technologies to connect with friends and family, to help others in their communities, and to find examples of people modeling happiness skills.

However, not all ideas focused on happiness as an internal process. Many of the children manifested the belief that happiness is largely due to the external environment. Many of the ideas addressed the specific *causes* of stress in their lives, such as the need for practical help (eg, homework, chores) and frustrations with forgetting something important (eg, object, activity, idea). Many of the other solutions focused on removing yourself or others from a problematic situation rather than dealing with the situation itself. These ideas included teleporters, "disappearing machines," "day restarters," invisibility cloaks, and "world pause" buttons.

Figure 6. Prevalence and examples of each of the 10 codes for solution functions observed across 3 ideation workshops.

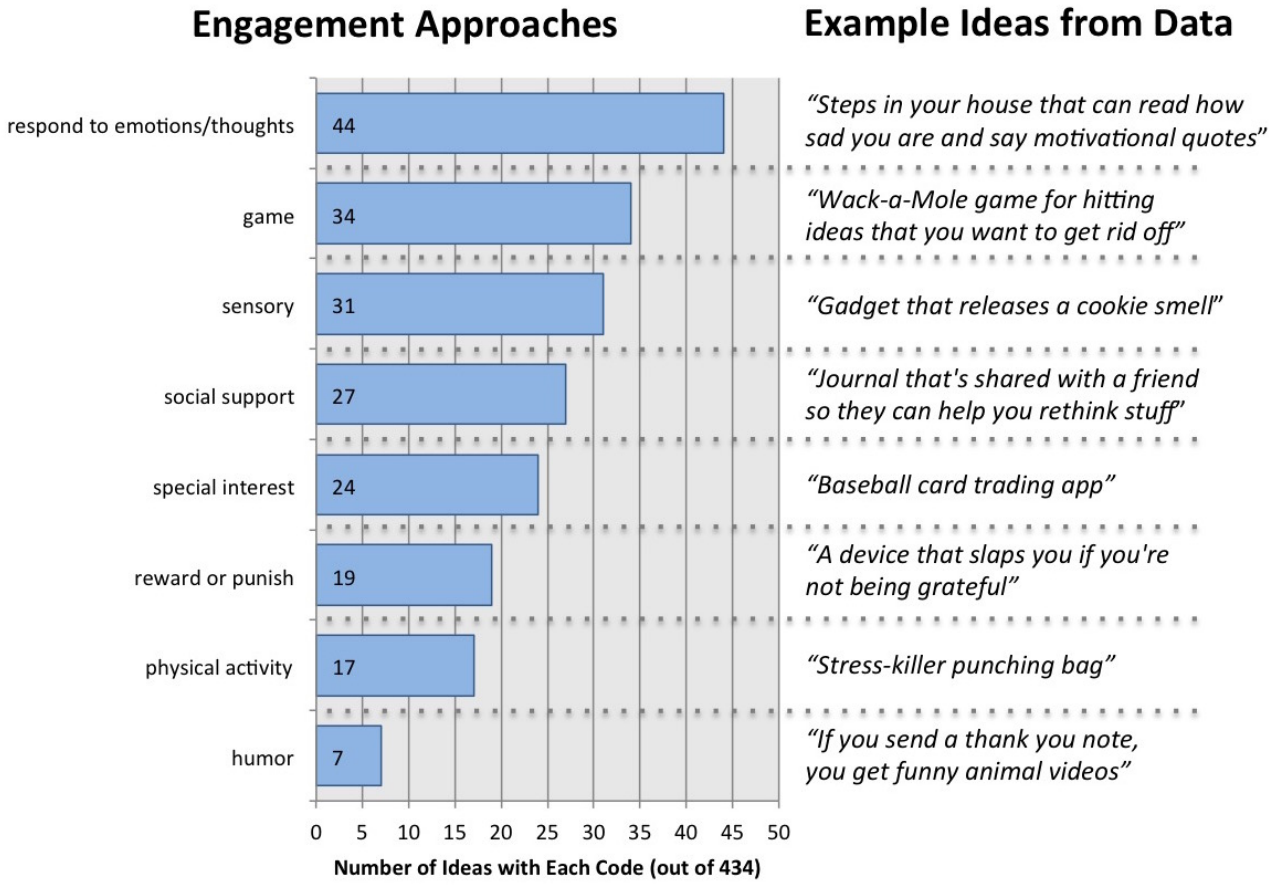


Strategies for Sustained User Engagement

Children in this study seemed to have an intuitive understanding that designing a technology to practice a specific happiness skill requires consideration of *why* somebody would engage and continue engaging with a particular device or app. A total of 8 of the codes highlighted specific approaches for engaging the user (Figure 7). It is not surprising to see games as one of the top strategies on this list. However, it may be more surprising that games were just one of the ideas suggested and not the most prevalent one. Rather than seeking to be entertained with games, the children focused on solutions that could understand and engage directly with their emotions and thoughts. In addition to playfulness and responsiveness, the children emphasized solutions that engaged with all the senses, allowed them to seek out social support, and connected with existing special interests that they had (eg, the Chicago Bulls basketball team). Early in

the design process, they also frequently focused on the idea of engagement through rewarding skill practice or punishing lack of skill practice, but these ideas seemed to garner less favor as the sessions continued (only 8 of the 19 ideas that featured rewards or punishment came from the last 2 ideation sessions). It seemed that children favored more nuanced interpretations of engagement as they had more experience with ideation.

Figure 7. Prevalence and examples of each of the 8 codes for engagement approaches observed across 3 ideation workshops.



Discussion

To our knowledge, this is the first study to employ a participatory design approach to the development of positive computing technologies for children, building on principles of positive psychological interventions. We reflect on this process and provide implications for the design of positive technologies.

Principal Results

We generated 434 ideas, 51 sketches, and 8 videos of potential positive technologies through a 14-session cooperative inquiry process with 12 children. These ideas and prototypes revealed specific facets of how children interpreted gratitude (as thanking, being positive, and doing "good things"), mindfulness (as externally representing internal states, controlling those states, getting through unpleasant things, and avoiding forgetting something), and problem solving (as preventing bad decisions, seeking alternative solutions, and not dwelling on unproductive thoughts). This process also revealed the particular technologies that were emphasized by the children in their solutions. While there was a notable lack of desktop and laptop solutions, other ideas were roughly evenly distributed between apps and embodied computing (toys, wearables, etc) ideas. Finally, we were able to understand both the desired functionalities and approaches to engagement in the children's ideas, with a notable emphasis on representing and responding to internal states. Our work points to new promising directions in the design of positive technologies with and for children.

Methodological Reflections

One of the methodological factors underscored through this participatory design process was the importance of ongoing engagement with and iteration of ideas. As the children in this study practiced ideation, they were able to increase the relative number of relevant ideas generated: from 36.1% (65/180) in the first workshop, to 44.7% (68/152) in the second one, to 61.7% (63/102) in the final ideation session. Additionally, we observed that allowing the children multiple sessions to gain some distance from their ideas, document their favorites, and reflect served as a vetting process that favored more nuanced interpretations of certain concepts. For example, the children largely ruled out the naïve "problem solving is having problems solved for you" interpretation, which appeared in ideation but not in subsequent stages. The opportunity to reflect also focused the design process, weeding out many ideas that were not relevant to positive technology and ideas that focused on "magical" solutions. These benefits from ongoing engagement and iteration would not have been possible had we conducted a single focus group or multiple focus groups with different

children as a way of eliciting ideas. In fact, our 14-session format is unique among work in this field, yet helped build a deep engagement with the children as well as the youth organization. This sustained engagement is not without challenges, such as keeping the children interested over time and managing evolving relationships, but the benefits realized in terms of ideas produced would likely not be possible otherwise.

Comparison With Prior Work

We expanded on past work that applied user-centered practices to the development of positive psychological interventions [60] and positive technologies [61] by engaging in cooperative inquiry with children around positive technologies. Our work is novel in that we engaged in participatory design around positive psychology skills drawn from empirically validated positive psychological interventions (eg, gratitude, mindfulness, and problem solving) and we explicitly taught these skills as part of the cooperative inquiry investigation. While this allowed us to benefit from the previous investigations in positive psychology, our unconstrained ideation process also supported a broader perspective than simply creating digital versions of existing interventions (a common approach in positive technology development [62]). For example, studies in this domain have tended to replicate (eg, [63]) or create new versions of (eg, [64]) Seligman and colleagues' seminal study [27], which evaluated a gratitude visit, three good things, optimism, and two signature strengths exercises disseminated through a website. Our findings have the strongest bearing on and relevance to the design of positive psychological interventions by revealing several technologies (eg, embodied computing), engagement approaches (eg, responding to internal states, sensory engagement, humor), and functionalities (eg, representing internal states, crowdsourcing solutions and examples) that may be promising in designing positive interventions for children (we discuss the implications of this in more detail below).

Some of our findings have relevance not just to positive technology, but also to positive psychological interventions more generally, incorporating children's views on happiness, gratitude, mindfulness, and problem solving. First, it is worth noting that several design ideas (7.8%, 34/434) were not related to technology whatsoever. Children continued to think of happiness and happiness strategies more broadly even with our explicit focus on technology. Of their design ideas, many had some aspect both of enhancing positive aspects of the children's experience and for removing negative or problematic aspects of it. This is quite different from most positive psychological interventions, which tend to promote happiness through didactic instruction in well-being skills (eg, [48,65]). Second, this "removing negative" experiences pathway to happiness is inconsistent with most conceptual thinking in positive psychology about what is unique about positive psychological interventions compared with other clinical approaches [66-68]. However, external supports and contingencies might align more with children's mental models and capacities, as concrete examples are often necessary to help support cognitive and other regulatory processes (eg, [69]). As such, positive psychological interventions that use physical artifacts to embody abstract concepts or provide additional support may be particularly beneficial for children (eg, [60]).

Implications for Design of Positive Computing Technologies for Children

In this section, we propose some directions to address our third research question of how positive technology designs targeted at children can better match their mental models and priorities.

Children's interpretations of positive psychology concepts such as gratitude, mindfulness, and problem solving may not always match adult interpretations and perspectives of these concepts. For example, some of the children interpreted mindfulness as "not forgetting ideas or objects" or problem solving as "having problems solved for you." Additionally, many children's interpretations of happiness across all three concepts revolved around external influences on happiness, such as getting practical help (eg, with homework) or avoiding unpleasant situations. These may not be typical concepts within positive psychology, but these concepts are worth considering when developing interventions for children. If a child's mental model of happiness and how it can be achieved does not match the model forwarded by a particular intervention, the intervention's effect may be limited for that child. Researchers should make the effort to engage with the mental models of the particular child audience and, if necessary, work on changing counterproductive belief structures before deploying a positive technology intervention.

The children's designs pointed to several specific features and engagement approaches that may increase the appeal of positive technologies. One noteworthy aspect of our findings is that participants often imagined technological solutions that could understand and react to various internal states, such as thoughts and emotions. Indeed, a growing number of efforts are attempting to glean psychological and emotional states from various affective computing technologies as diverse as electroencephalograms, galvanic skin response, and automated sentiment analysis on social media. Positive technologies use such features may have particular appeal for children, who are still learning to understand and interpret their affective states and the affective states of others. Another noteworthy aspect is in the number and diversity of approaches that the children posited for encouraging sustained engagement with interventions. While gamification and social interaction were two important approaches that have been considered in previous interventions (eg, [70,71]), there were also a few surprising ideas. One of these surprises was sensory engagement. Many of the children's ideas posited that somebody could be motivated to engage with an intervention simply because it was beautiful and appealing to the senses, whether it be visual, aural, olfactory, or haptic. This is not a well-explored approach in the design of positive technologies, and it would be interesting to know the smells associated with happiness (our children suggested some, which included warm chocolate chip cookies and the smell of one's own bed). Other surprising ideas were physical activity (as an engagement approach, not outcome) and humor.

Another design insight from this investigation emerged from observing the types of technologies that children cited in their inventions. It was clear that children were not drawn to

interventions for laptops or desktops. At the very least, the implication of this is that Web-based interventions for children should be designed using a mobile-first paradigm. However, we should emphasize that this is just a temporary solution, as recent studies highlight that sustained engagement with such interventions is fairly minimal (eg, visits drop from an average of 5.19 per week during the first 2 weeks to 0.85 per week by 6 weeks later [72]). Indeed, there may be an opportunity to increase engagement by thinking outside the box (or the computer, as the case may be here). The children in our study suggested solutions that went beyond apps and websites, to consider several instantiations of embodied computing. These instantiations included wearable accessories and apparel, toys and gadgets that may operate independently or in conjunction with a phone app, smart furniture and home infrastructure, robots and drones, and public kiosks and displays. It may be fruitful for designers to consider their positive technology interventions not as sites that children visit, but rather as tools that live alongside with them in the real physical world.

Limitations and Future Work

Our methodological approach has its limitations. Participatory design is an inherently subjective process that was likely influenced by the specific contexts, lenses, and biases of both the researchers and the children involved in the process. The same process carried out with another group of children or by other researchers may lead to a different perspective or emphasis in the findings. As such, we strongly encourage the replication of this work for greater confidence in the generalizability of these findings. Another limitation of our approach is that we started with three empirically supported happiness-increasing strategies (gratitude, mindfulness, and problem solving) rather than using a more general starting point such as *any* strategies that help make children happy. We believed it was more useful in our case to begin from such a starting point because it would help promote fidelity to the science of positive psychological interventions while still allowing some flexibility for the children to be creative and design new ideas. However, future work could use a different set of happiness-increasing strategies or work with children to generate novel happiness-increasing strategies within this age group. Finally, due to the constraints of the 8-week study, we were not able to develop any ideas into functional prototypes. Future investigations could develop functional interventions based on the underlying concepts expressed in the ideas created and vetted by our participants, could further iterate these prototypes with another group of codesigners, or could test such interventions through controlled in-the-wild deployments with children. We note that a full replication of our complete process could be challenging—not all research teams might be able to find community partners to conduct an 8-week program—but the principles of participatory design and cooperative inquiry can be applied in a shorter study. However, even though our process introduced challenges, we believe it offered insights that would not be possible in a shorter investigation.

Overall, this study is an important step forward in the design of positive technologies for children. It was truly an interdisciplinary undertaking, combining human-computer interaction and participatory design with positive psychology and positive psychological interventions. The dual focus of exploring design ideas while providing tangible benefits to the participants may be a useful approach to conducting research in school-based settings, where the first priority is returning value to the children. The results of this study reveal children's understanding of three major concepts in positive psychological interventions (gratitude, mindfulness, and problem solving) and highlight strategies (such as directly engaging with thoughts and emotions, games, social support, and multisensory experiences) that might be critical in producing engaging interventions and technologies that would capture children's interests. The future of positive psychology and positive technology would be well served by integrating more participatory methods and by listening to the voices of those they intend to support through interventions and technology.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Specific age-appropriate positive psychology topics and exercises used for instruction.

[PDF File (Adobe PDF File), 28KB - jmir_v19i1e14_app1.pdf]

Multimedia Appendix 2

All ideas generated and expanded in the codesign workshops.

[PDF File (Adobe PDF File), 68KB - jmir_v19i1e14_app2.pdf]

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Abbreviations

RQ: research question
Y.O.U.: Youth & Opportunity United

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Corrigenda and Addenda

Acknowledgment Correction of: Impact of Game-Inspired Infographics on User Engagement and Information Processing in an eHealth Program

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The authors of "Impact of Game-Inspired Infographics on User Engagement and Information Processing in an eHealth Program" (J Med Internet Res 2016;18(9):e237) would like to change the acknowledgments section of their paper to the following:

"This research was supported by the University Cancer Research Fund. For graphic design and software development, the authors thank UNC CHAI Core, which is supported in part by a grant from NIH (DK056350) to the University of North Carolina Nutrition Obesity Research Center and from NCI (P30-CA16086) to the Lineberger Comprehensive Cancer Center. The authors are grateful to Barbara Alvarez Martin, MPH, and Anne Cabell, MPH, for their assistance with the study. The first author also thanks Deanna Puglia for assistance preparing the manuscript."

This correction has been made in the online version of the paper on the JMIR website on January 09, 2017, together with publishing this corrigendum.

A correction notice has been sent to PubMed, and the publication was resubmitted to PubMed Central and other full-text repositories.

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